

Consumer-Directed Transformation to a Recovery-Based Mental Health System

**A Consumer/ Survivor Led Transformation of Today's Institutionally-based System to
Tomorrow's Recovery-based System**

Executive Summary

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Executive Summary

Today's mental health system has failed to facilitate recovery of most people labeled with severe mental illness, leading to increasing expressions of dissatisfaction by people using services, their families, and administrators. Only a fundamental change of the very culture of the system will ensure that the changes made in policy, training, services, and research will lead to genuine recovery. In accordance with the President's New Freedom Commission on Mental Health Report, mental health consumers/survivor, representing diverse cultural backgrounds, should play a leading role in designing and implementing the transformation to a recovery-based mental health system. This paper provides an outline of how survivor/consumers can catalyze a transformation of the mental health system from one based on an institutional culture of control and exclusion to one based on a recovery culture of self-determination community participation. At the national policy level, this paper recommends that consumers develop and implement a National Recovery Initiative. At the State and local policy levels, State and local Recovery Initiatives are recommended. On the direct service level, the paper provides a road map for developing services, financing, and supports, which are based on self-determination and recovery.

A recovery-based mental health system would embrace the following values:

- Self-Determination
- Empowering relationships based on trust, understanding and respect
- Meaningful roles in society
- Elimination of stigma and discrimination

Changing the mental health system to one that is based on the principles of recovery will require a concerted effort of consumers and allies working to bring about changes in beliefs and practices at every level of the system. The building of these alliances will require the practice of recovery principles of trust, understanding, and respect by all parties involved.

Goal: Transformation from the Institutionally-based Mental Health System to a Recovery-Based System through consumer/survivor Leadership

Objective 1: Transform the system to one based on a recovery culture through consumer led development of a National Recovery Initiative (NRI) and State Recovery Initiatives (SRI)

Step 1.1: Consumer leaders will set up a National Recovery Initiative Steering Committee, which will establish an NRI Agenda and assist the SRI's to do so

I. Establish a NRI Steering Committee

II. Committee develops National Recovery Initiative Action Agenda:

III. The NRI Steering Committee would play a role in implementation of the New Freedom Commission Report at the Federal and State levels

IV. The NRI Steering Committee will establish subcommittees on recovery education, recovery policy development, and recovery-based evaluation and research, and development of recovery-based services and supports

Step 1.2: The NRI subcommittee on recovery education will launch a nation-wide pro-recovery, anti stigma education campaign

Step 1.3: NRI Subcommittee on Policy will develop and synthesize model recovery policies as well as materials for training consumers in board participation.

Step 1.4: NRI Subcommittee on Recovery-based Evaluation and Research will develop materials and train consumers in carrying out evaluations of the performance of mental health systems

Step 1.5: NRI Subcommittee recovery-based services and supports will supply the

Objective 2: Consumer-driven transformation to a system of self-determined and recovery- based services and supports

Step 2.1: Shift to person-centered planning

Step 2.2: Shift to financing mechanisms, which support increased consumer control

Step 2.3: Expand the range of choices of services and supports available by creating roles for peers in service delivery and support

I. Expand peer-provided services

A. Peer professionals

B. Peer specialists

C. Peers as staff in consumer-run programs

D. Peers involved in mutual support.

II. Expand the use of Personal Assistance Services for people with psychiatric disabilities

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Introduction:

Though many people with mental illness have been moved from state institutions to community settings, most have not recovered. Though the consumer/survivors are living in the community, they are not integrated into the community in a meaningful manner. Though state hospital patients have been transported to community settings, and been renamed consumers, their recovery is being impeded by the persistence of institutional thinking by all stakeholders. This institutional thinking persists in the application of an outdated, classical medical model that describes serious mental illnesses as permanent, biological diseases. Institutional thinking considers recovery unlikely, and “good” outcomes are considered to be lifetimes of maintenance on psychiatric drugs, residence in halfway houses or other supervised settings, and repetitive days of mindless “activities” or dead-end, below minimum wage jobs, or work in sheltered workshops. This system has led to huge costs for maintaining this population, hopelessness for people diagnosed with mental illness, political inertia, and a lack of interest on the part of many professionals for dealing with a population deemed to be incurable. In short, we have taken the people out of institutions but we have not taken institutional thinking out of the people. Institutional thinking persists in all societal thinking about mental illness and severely hampers efforts to facilitate recovery.

Since empowerment, hope, and self-determination are repeatedly cited as the keys to people's recovery (Ahern and Fisher(2001), Anthony et al. (2002), Zinman (2002), Chamberlin(2003)), it appears that the underlying institutional medical culture of the present system, with its over emphasis on the narrowly defined version of the medical approach, is actually interfering with recovery. Recently consumer/survivors, administrators, and families have united in the conviction that the mental health system needs a fundamental transformation at the level of its mission and values to one based on recovery. In this paper we present a roadmap for consumer-driven transformation to a recovery-based system that can act as a unifying action plan for citizens and government alike. No longer can people with mental illness wait for government to lead the way to a new system. The leadership for this transformation

needs to be taken up by consumer/survivors, families, and other advocates, in partnership with government and mental health authorities.

Many voices have been calling for change, including segments of the professional community, families, political leaders, and, perhaps most importantly, diagnosed people themselves, many of whom have refused to accept the limited roles they were expected to fulfill. These voices for change have recently received support from the President's New Freedom Commission on Mental Health, whose Report (Mental Health Commission Final Report, 2003, which will hereafter be referred to as the Commission Report) called for a transformation of the mental health system to one based on the principles of recovery, as stated in its vision: "We envision a future when everyone with mental illness will recover"(Commission Report, pg. 1). The Report also states that "...care must focus on facilitating recovery and building resilience not just on managing symptoms" (Commission Report, pg. 5).

Other government studies have reached similar conclusions. The recently released Veterans' Administration Action Agenda (2003) has called for recovery to be a central principle in the transformation of VA services and supports by recommending that the VA:

- Adopt the Recovery Model in VA Mental Health Programs nationwide
- Develop VA adapted Recovery implementation tools as the basis for a national rollout
- Involve veteran consumers and families in educating staff/veterans/family members on recovery.

The Surgeon General's Report on Mental Health (Surgeon General, 1999) and the National Council on Disability Report, *From Privileges to Rights* (NCD, 2000) also highlight the importance of having people who have recovered from mental illness play an active role in the policies and services of the system.

Only a fundamental change of the very culture of the system will ensure that the changes made in policy, training, research, and services will lead to genuine recovery. Consumers/survivors must play a leading role in designing and implementing this transformation. Otherwise, we will see people who have recovered playing a secondary role and their work fit into the existing system, rather than their work leading the transformation to a recovery-based system. An example is provided by a mental health center, which pointed proudly to their use of peer counselors. However, rather than using their personal experiences to serve as role models and guides to clients in earlier stages of recovery, these "peer counselors" had been given the job of monitoring medication. In other words, they had to adapt to the existing institutional culture of dependency instead of leading the transformation to a system

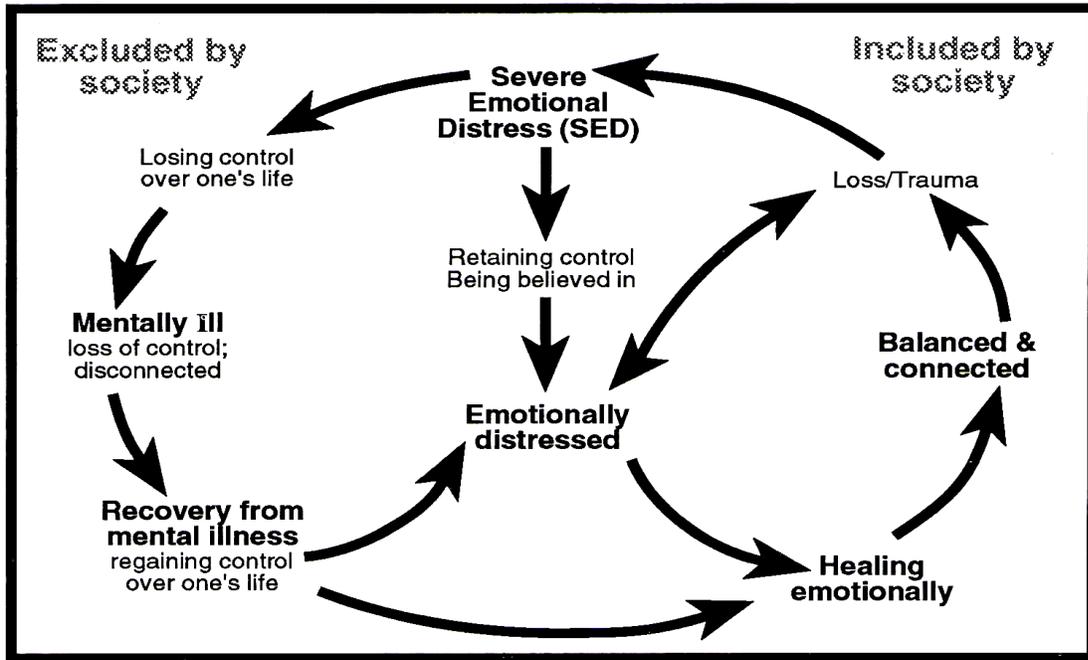
based on recovery. In addition, the recovery culture needs to be culturally competent as recommended in the Surgeon General's Report on Culture, Race and Ethnicity (Surgeon General, 2001). The existing institutionally-based system is narrow in its scope, thereby leaving little room for minority cultures. A recovery-based system would be more accepting and understanding of people from a variety of backgrounds.

The Western New York Care Coordination Program (WNYCC) provides a further illustration of the importance of culture change to influencing lasting transformation of the system. They stated, "Despite the care taken to develop a template for individual service planning that focused on the interests of individual recipients, a review of the first set of individual service plans developed by care coordinators revealed little change from the 'provider knows best' case management system (cite)." Their steering committee recognized "culture change as the critical first step to system transformation." (www.carecoordination.org), Therefore, care must be taken to introduce cultural change training, which emphasizes recovery and person-centered planning, into the initial steps of system transformation. Most important, people who have recovered should lead this training.

In a recovery culture, peer support will be seen as central focus of the services and supports. Peers can transform both the individuals they are helping and those around them. It will be important for survivor/consumers to take the lead because they have the greatest commitment to real change. Although the term "recovery" has come into the lexicon of federal, state, and local reports and plans, there is a concern among survivor/consumers that the meaning of recovery has been subverted. The first example of what we call a limiting version of recovery appeared in the rehabilitation literature of the early 90's (Anthony et al.,2002). These authors contend that mental illness is analogous to a spinal cord injury. According to this limiting version of recovery, people with mental illness can, like people with a spinal cord injury, learn to cope with their illness but they will never fully recover from mental illness. On the other hand, survivor/consumers and researchers have experienced, researched, and written about complete recovery from mental illness(Harding et al., 1987; Karon and Vanden Bos, 1981; Ahern and Fisher, 2001). This we will call genuine recovery. The National Empowerment Center has described the path to genuine recovery: the empowerment model of recovery. According to this model, people with mental illness can completely recover by taking control of the major decisions of their life and thereby assuming or resuming major social roles. We emphasize the importance of this distinction because it lies at the heart of the transformation of the system. If the vision of recovery really means limited recovery, the services will still be designed to control a consumer's major decisions for the rest of their life. A system based on a goal of limited recovery is a system with no exit points. It is a system, which is always run from the top down by administrators, doctors, and other clinicians that perpetually make decisions for the consumer.

It is, however, important to emphasize that, in the NEC definition of full, genuine recovery, people may continue to experience symptoms or may choose to use medication. The hallmark of genuine recovery is the individual regaining control of his or her own life and filling valued social roles.

The empowerment model of genuine recovery has the following features:



Empowerment Model of Recovery from Mental Illness

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Figure 1

The Empowerment Model is based on the research findings that genuine recovery is possible for most people labeled with mental illness (Ahern and Fisher, 2001). Given the right mix of relationships, attitudes, and resources, people with mental illness can fully recover by (re)gaining control of the central decisions of their lives, learning to live with intense emotions, and developing the skills and relationships needed to establish a major social role. According to this model, most people begin life at the right side of the diagram (Figure 1), balanced and whole. However, we all suffer trauma and loss, which lead, to emotional distress and a feelings of fragmentation and not being whole. Through coping strategies and social supports most people are able to heal emotional and indeed develop and stronger sense of self. Sometimes, however, a major trauma or loss, such as a move to college or the loss of a loved one, can lead to severe

emotional distress. At that point (at the top of the diagram) it is crucial that there be sufficient non-institutional supports and coping strategies available to allow the person to heal. During this period it is also vital that the person retain their connections with their community and as much control over their life as possible. In the absence of such supports, such as people who believe in her/him, housing and finances, and coping strategies, the person's life and controls are taken over by institutional mental health systems and programs and they are labeled severely mentally ill. Once a person is labeled with mental illness they must recover not only from the severe emotional distress, but also from the role and identity of a person with mental illness. The label not only relegates people to a low status and diminished rights, but it also eats away at a person's confidence and initiative to pursue dreams and to lead a full life of one's own choosing. Consumer/survivors have unified around the goal of genuine recovery as outlined in this Empowerment Model.

The report of the Subcommittee on Consumer Issues to the New Freedom Commission (www.mentalhealthcommission.gov) described genuine recovery very well:

Mental health research shows that people can and do fully recover, even from the most severe forms of mental illness. Most fundamentally, recovery means having hope for the future, living a self-determined life, maintaining self-esteem, and achieving meaningful roles in society. Most consumers report they want the same things other people want: a sense of belonging, an adequate income, a way to get around, and a decent place to live. They aspire to build an acceptable identity for themselves and in the community at large. These are the essential ingredients of recovery from mental illness.

An emerging literature on the success of the recovery approach comes from the self-help movement, testimony of consumers, the psychiatric rehabilitation community, and research. Public and private sectors of the mental health community are initiating recovery-based programs, services and self-help technologies to overcome the barriers faced by people living with a mental illness in America. Recovery is an organizing principle for mental health services, programs, and supports that is based on consumer values of choice, self-determination, acceptance, and healing.

For recovery to take place, the culture of mental health care must shift to a culture that is based on self-determination, empowering relationships, and full participation of mental health consumers in the work and community life of society. To build a recovery-based system, the mental health community must draw upon the resources of people with mental illness in their communities.

It is widely recognized that changing the mental health system to be more responsive to consumer needs requires the participation of consumers at all levels of policy planning and program development, implementation, and evaluation. Meaningful involvement of consumers in the mental health system can ensure they lead a self-determined life in the community, rather than remaining dependent on the mental health system for a lifetime.

A recovery-oriented mental health system embraces the following values:

- Self-Determination
- Empowering Relationships
- Meaningful Roles in Society
- Eliminating Stigma and Discrimination

We are proposing in this paper a Recovery Initiative Action plan, of which the major goal is:

Goal: A Consumer/ Survivor Led Transformation from an Institutionally-based System to a Recovery-based System

In order to insure that mental health services are truly empowering and recovery-focused, attention must be paid to the underlying values of each service (e.g., hospitalization, crisis intervention, housing, rehabilitation services, employment services, etc.). Services, which are focused on symptom management or maintenance, for example, must give way to those which stress movement, development, and change (in other words, are recovery-based). Services must provide mechanisms for community integration and promote opportunities to live in ways that non-disabled people live.

It is clear that a massive shift in philosophy, accompanied by changes in funding mechanisms, will be necessary to implement successful self-determination approaches that maximize the ability of people with psychiatric disabilities to gain control of their lives. In the next section, we will describe a proposal for making the necessary shifts to a recovery culture so that the kinds of new programs and funding mechanisms described above can flourish.

Objective 1: Transform the system to one based on a recovery culture through a consumer/survivor led National Recovery Initiative (NRI) and State Recovery Initiatives (SRI)

The New Freedom Commission Report recommends that the system “involve consumers and families fully in orienting the system to recovery...local, State, and Federal authorities must

encourage consumers and families to participate in planning and evaluating treatment and support services. The direct participation of consumers and families in the development of a range of community-based, recovery-oriented services is a priority (Commission Report, pg. 37)...Every mental health education and training program in the Nation should voluntarily assess the extent to which it...engages consumers and families as educators of consumers, families, and health care providers...about the concepts of recovery” (Commission Report, pg. 75.)

Over the past two decades, mental health consumers/survivors have started to build such a national presence within the public mental health sector, with growing numbers now participating in research and evaluation (Van Tosh, Ralph & Campbell, 2000) and taking leadership roles in policy and administration of public mental health services (McCabe & Unzicker, 1995). They have led efforts to determine housing preferences (Tanzman, 1993), to define outcome measures (Campbell, 1997; Trochim, Dumont, & Campbell, 1993), and to develop partnerships models with public mental health professionals (Campbell, 1996). Consumers/survivors carved out an expanding role in lecturing, conducting grand rounds, teaching continuing education classes, and offering workshops at national professional conferences. In 1993 consumer-practitioners and psychiatrists engaged in a dialogue in New York regarding coping strategies and recovery from mental illness (Blanch, Fisher, Tucker, Walsh & Chassman, 1993).

To truly transform a system it is necessary to effect changes at all levels. The Commission Recommendations provide the roles for consumers to catalyze such a transformation because they encompass all levels and activities of the system. Consumers are the best agents to foster the needed changes. In March, 2003, the Report of the Consumers’ Issues Subcommittee to the New Freedom Commission proposed the concept of a National Recovery Initiative: “In order to facilitate recovery from mental illness, the Subcommittee urges Federal, state and local governments to together develop a National Recovery Initiative that promotes consumers' self-determination at both the collective and individual levels of recovery” (www.mentalhealthcommission.gov).

The policy options that follow comprise the key components of the proposed National Recovery Initiative. This idea has captured the imagination of many consumer/survivors across the country because it gives substance to a unifying principle. Recovery inspires consumers to be involved in transforming the system and in their own lives in a manner that the present system has failed to do. A National Recovery Initiative also gives consumer/survivors an opportunity to exercise a degree of control in their lives, which was never before apparent. The vision of recovery has unified consumer/survivors as never before. This is a proposal to form temporary

committees, which are centered on shared recovery values and shared implementation rather than the formation of a permanent national organization.

Step 1.1: Consumer/survivor leaders will set up a National Recovery Initiative Steering Committee, which will establish an NRI Agenda and assist the SRI's to do so

I. Establish a NRI Steering Committee: The purpose of this steering committee would be to recommend national goals, policies and actions for carrying out the steps outlined below. The committee would also monitor progress towards these goals through an evaluation component. Since the theme of “nothing about us without us” is a key principle throughout the consumer/survivor community, it will be important to have all the significant segments of that community represented from the outset. Consumer/survivors from diverse cultures have rarely had a voice in mental health policies. Therefore, from the outset, it will be important to assure that representatives from diverse cultures are actively engaged at the table and that attention is given to culturally responsive materials. In addition, it would be important to be inclusive of people from sexual and gender identity/expression minority communities. The criteria for inclusion would include:

- **Experience at a state and/national level with development of mental health policies**
- **An ability to work with a variety of people from a variety of backgrounds**
- **An understanding and acceptance of the basic recovery premises outlined in the New Freedom Commission Report**
- **Representation of the various philosophical views, geographic regions, ages, ethnic groups, and sexual and gender identity/expression minority communities**

A congress of 40-50 consumer leaders would be the mechanism through which the steering committee is established. Although ideally such a congress should take place in person, several teleconferences could be used instead. A primary function of this steering committee would be the development of a National Recovery Initiative Action Agenda. This agenda would consist of a section on the process for bringing such an Initiative into being and a section on guidelines for content guidelines.

II. Committee develops National Recovery Initiative Action Agenda:

The process of developing a NRI Action Agenda was started by the Mental Health Commission's Subcommittee on Consumer issues in the 2002-03 period. The feedback from consumer leaders received at Alternatives 2002, the 2002 meeting of National Association of

Rights, Protection and Advocacy (NARPA), and a meeting of the National Association of Consumer/survivor Mental Health Administrators (NAC/SMHA) in 2002 was used to generate the paper on consumer issues. The next step is for the steering committee to develop an action agenda to carry out the goals established to date through the New Freedom Commission Consumer Issues Subcommittee.

Since its appearance a year ago, the idea of a National Recovery Initiative has captured the imagination of numerous consumer leaders. This theme has been capable of unifying factions of the consumer movement and the family movement around a common, positive concern. The proposed contents of the Initiative were outlined in the subcommittee's report, and are divided into two levels of consumer activity. These two levels were collective (systemic) and individual self-determination:

The Subcommittee recommends increasing *collective* consumer self-determination by ensuring consumers' significant participation in the development of a National Recovery Initiative. This initiative would inform policy, evaluation, research, training, and service delivery at local, state and national levels in all systems integral to recovery from mental illness. The Subcommittee urges Federal, state and local governments to employ consumers in leadership roles in the development of a National Recovery Initiative.

The Subcommittee urges the mental health system at the Federal, state and local levels to increase *individual* consumer self-determination by helping people with mental illness to acquire the self-management skills needed to manage their own lives. To accomplish this, we urge a shift from traditional services to recovery planning services, such as peer support services and services provided by independent living centers (www.mentalhealthcommission.gov).

The NRI Steering Committee would have an interactive Website on which it would post its membership and its agenda, and on which it would receive feedback. Additional methods of dissemination and dialogue would be provided as well, in recognition that Web access is not universal, and is probably more limited for consumers, and even more so for consumers who are members of ethnic and racial minority groups.

III. The NRI Steering Committee would play a role in implementation of the New Freedom Commission Report at the Federal and State levels

The commission recommends that the fragmentation in funding and services be reduced by the development of a federal mental health policy across department lines. For instance, though SAMHSA is the lead agency in federal mental health policy, it plays a minor role in

financing relative to CMS, SSA, HUD, RSA, NIMH, and the VA. The NRI Steering Committee could play a valuable role in assisting these agencies in coordinating the changes in their funding and regulations needed to facilitate the shift to a recovery-based system. If the NRI could have representation on the strategic planning bodies of these agencies, it would allow for representation of a broad cross-section of consumers nationally. In addition, The NRI Steering Committee could give support and coordination of transformation at the state levels. The steering committee could facilitate the establishment of a State-wide Recovery Initiative (SRI) in each state.

IV. The NRI Steering Committee will establish subcommittees on recovery education, recovery policy development, and recovery-based evaluation and research, and development of recovery-based services and supports.

These subcommittees would be selected by the NRI Steering Committee and would need to lead this systemic transformation to a recovery culture through their education of decision makers and the public about recovery and their participation in setting policies consistent with a recovery culture, in carrying out system evaluation to ensure that changes are carried out which promote the transformation to recovery, and their development of recovery-based peer-run services and supports, These subcommittees would use an NRI Website to interact with constituents.

Step 1.2: The NRI subcommittee on recovery education will launch a nation-wide pro-recovery, anti stigma education campaign

The present mental health system is a top down hierarchy. The culture of the present system is carried by the top decision-makers: administrators, funders, clinical directors, and mental health professionals. These are the people who need to buy into a shift to a recovery culture. These are the people who need to see that sharing their decision making power will make the system function better and facilitate recovery of the consumers. These are the people who need to give inspiration and guidance to their service providers that a transformation to recovery is a desirable outcome. To answer this need, the steering committee would select a subcommittee on recovery education, consisting of representatives of the steering committee and nationally recognized recovery educators. In addition, a national panel of consumer leaders with experience in providing recovery education will be convened to develop a national recovery curriculum. It would be important to ensure that the curriculum is culturally competent to the needs of diverse ethnic, sexual, and gender communities.

Since personal contact with people with first hand experience with recovery is generally the most effective tool for transforming the hearts and minds of people entrusted with mental health policy direction, and service delivery, it is proposed that a large scale recovery education project be initiated under the guidance of consumers, in consultation with the top level decision makers. Bassman and Penney established a viable model for such an educational initiative in New York (Bassman, 2000) by pairing consumer recovery educators with local consumers. These teams educated hospital staff on the principles of recovery. New York Association of Psychosocial Rehabilitation (Rosenthal, personal communication) has also used a similar model and in addition educates the community. Some states such as California have placed a high priority on recovery education and have relied on national and local educators. It would undoubtedly be necessary to start by having the present recovery educators training and mentoring emerging consumer leaders to build capacity. This could be carried out by regional training conferences. These recovery educators could teach recovery competencies to all persons who provide assistance to consumers. This recovery training could also serve to reduce stigma and discrimination among community residents. A pro-recovery message is usually the best anti-stigma approach.

Another responsibility of this subcommittee would be the development, in conjunction with the Consumer TA Centers, of a Website and library of self-help materials. In addition, this Website could provide information on the four areas which the Commission Report highlighted as needing extra attention: disparities for minorities in mental health, a study of the effects of long-term medication use, an examination of the effects of trauma, and problems of acute care (Commission Report, 2003, pp. 76-77).

Step 1.3: NRI Subcommittee on Policy will develop and synthesize model recovery policies as well as materials for training consumers in board participation.

To play a significant role in policy development, consumers/survivors need to understand recovery principles, have ideas of policies for which they could advocate, and have an understanding of evaluation methodologies, so that the effectiveness of the instituted policies could be determined. Many of these materials already exist in different locales. The job of the committee would be to bring together the best materials and agree on a tool-kit for consumer participation in policy development. Consultants can help, but consumers need to play a lead role to ensure that the materials focus on genuine recovery and are presented in formats and languages, which are accessible to a variety of educational levels and are responsive to cultural differences. In addition to people of various racial and ethnic differences, training materials need to consider the needs of people with disabilities other than mental illness. For example this might

include material and training accommodations (e.g. Braille, large print, sign language interpretation, cassettes, and CD's).

This committee would also prepare ongoing policy analysis and supply the information to the Steering Committee to assist them in participating in national policy formation.

Step 1.4: NRI Subcommittee on Recovery-based Evaluation and Research will develop materials and train consumers in these areas.

This subcommittee will establish a tool-kit for the evaluation of programs to determine the degree to which new programs reflect recovery values and practices. Consumer-run evaluation teams have already shown their ability to evaluate mental health programs in Ohio, Pennsylvania, Georgia, Florida, South Carolina, and Massachusetts (Campbell, 1997). Consumers are much candid when speaking to fellow consumers. Evaluations would supply valuable information to the policy setting committee. In addition, there needs to be much more attention and resources allocated to consumer-driven research in the area of recovery. This need was also highlighted in the Commission report. This activity will require the funding and training of consumer researchers. These researchers should be in a good position to develop baseline data that can be used as the foundation for future collection and evaluation of evidence based data on recovery and recovery-based services.

Step 1.5: NRI Subcommittee on recovery-based services and supports will supply the networking and technical assistance needed to help in the further development of peer-run services

Consumers are uniquely suited to further develop peer-run services. It is very difficult for even the most well intentioned professionals to start peer-run services. The shared experience of being labeled and living on disability benefits, the role modeling afforded by one's own recovery, and the decrease in stigma and discrimination all make consumers much more open to participating in peer-run services than in professionally-run services. The subcommittee would work closely with the National Technical Assistance Centers to survey the statewide consumer organizations, which in turn would assess the extent of peer support groups and determine what they need for further development

The following section will elaborate in more detail the topic of implementing self-determination at the services and supports level.

Objective 2: Consumer-driven transformation to a system of expanded choices of recovery-based services and supports

The existing mental health system is based on an institutional medical model which sees mental illness as a lifelong condition from which it is impossible to fully recover. Therefore, service users have only limited opportunities to fulfill any role other than that of passive recipient of whatever services treating professionals determine they should receive. "Choice," in this context, is limited to, at best, selecting within a pre-determined set of options. Even when service users are allowed such limited choices, they are frequently overruled on the basis of clinical judgment. The implicit message is that service recipients are incapable of assessing or acting on their own best interests, and that disagreement with treating professionals is evidence of symptomatology rather than of self-assertion and self-determination.

A recovery-based mental health system, on the other hand, would start from an entirely different premise. Each person entering the system would be viewed as undergoing a period of *temporary* distress and disorganization, from which he or she is expected to recover, given appropriate supports. Each service user would have the full opportunity to select those services and supports, which, in his/her evaluation, would best meet his or her needs at that time.

For a person entering the system in acute crisis, such needs would most likely center on providing safety and security *as defined by the individual*. This would probably involve a small, home-like setting (or the person's own home), with helpers of his or her choice ensuring that basic needs (such as nutritious food and adequate sleep) were met. As the person emerged from an acute state, the range of options and choices would enlarge, based on assisting the individual to resume former roles or move on to new ones. Peer support options should be offered as early as possible on a one on one basis with the goal of moving the person into mutual support. The peer specialist could help the consumer negotiate the systems involved in recovery by providing insider knowledge, hope, and role modeling. Helpers would include the full array of mental health professionals, as well as peer supporters and natural supports (family and friends).

At present there are only a small number of adequately funded consumer-run program. Even when mental health authorities have funded small projects for peer support, these are seldom well-integrated into the existing mental health system, are usually viewed as adjuncts and "frills," and still leave only very limited avenues for meaningful consumer involvement.

There is currently only a narrow range of clinically based services reimbursable under Medicaid for adults with psychiatric disabilities living in the community. These programs are designed by clinicians and tend to be medically based with little relevance to concepts of independent living, consumer choice, or recovery. Consumers can increase their control by being the author of their own individualized recovery planning which would then form the basis for which supports and services would be covered. Consumers at the individual level need to lead

the transformation of their own lives to becoming self-determining adults, by exerting maximal control in the choice and provision of the services and supports they need to integrate into the community. (cite a quote from the commission report on self-determination, it is under goal 2) Several states have experimented with new financial models called cash and counseling or self-determination projects. There have been successful demonstrations of such new financing arrangements of money following the person in area of developmental disabilities (Foster, L. et al , 2003). Medicaid recipients in Arkansas with developmental disabilities who direct their own supportive services were significantly more satisfied and had a higher quality of life than those receiving services through a home care agency. However, for people labeled with mental illness, only Florida has succeeded in its attempts, though even that demonstration is on a small scale.

Dr. Thomas Nerney (Nerney, 2004) has described the five principles of self-determination as follows:

- Freedom, the opportunity to choose where and with whom one lived as well as how one organized all important aspects of one's life with freely chosen assistance as needed;
- Authority, the ability to control some targeted amount of public dollars;
- Support, the ability to organize that support in ways that were unique to the individual;
- Responsibility, the obligation to use public dollars wisely and to contribute to one's community;
- Confirmation, the recognition that individuals with disabilities themselves must be a major part of the redesign of the human service system.

Nerney noted how these ideas of self-determination are being incorporated into the care of people with a variety of disabilities:

In the last decade public policy for individuals with physical and cognitive or intellectual disabilities has gradually been coalescing around several important themes. These themes all lead toward greater recognition of community participation, income production or work, control over resources and leading meaningful lives that resemble in all-important respects the aspirations and ambitions that all Americans have for them. This is not to say that these goals have been realized or that the impetus to achieve them does not vary from state to state.(Nerney, 2004)

In Michigan in 2003, the Michigan Department of Mental Health issued a directive stating:

Persons who rely on the public mental health system for necessary supports and services must have access to meaningful options from which to make choices, and be supported to control the course of their lives. Arrangements that support self-determination must be sponsored by the public mental health system, assuring methods for the person to exert control over how, by whom, and to what ends they are served and supported (Nerney, 2004)

Despite this policy goal, Nerney has found that such policies fall short in assisting people with mental illness: “As Michigan attempts to valiantly implement self-determination, people with psychiatric disabilities still fall through the cracks, experience homelessness in great numbers and live in abject poverty in greater numbers than any other population” (Nerney 2004).

The experience in Florida has been more successful, though it only has been provided to 100 consumers. The Florida Self-Directed Care program describes itself as:

...an approach to providing publicly funded behavioral health care services wherein the individual has a high degree of self-determination in choosing services and providers necessary for recovery from mental illness. AMHSDC [Adult Mental Health Self Directed Care Program assists in funding] mental health treatment and support services to adults who have serious mental illness allowing the individual to control the public mental health funds allotted for his/her treatment and to directly purchase the services from the vendor of choice. Individuals are offered independent advice and guidance in securing the services they need to begin the recovery process.

The AMHSDC program allows individuals with a severe and persistent mental illness to take more personal control of their recovery. It allows them to become less passive and more pro-active in the treatment and recovery process. Those who have the necessary motivation and ability to do so are able to receive the treatment that, in their own judgment, is best for them. Each participant's recovery progress is being tracked carefully in an effort to determine what potential value lies in this approach.

Participants in the AMHSDC program choose from a variety of community-based providers that may or may not already be a part of the current community mental health system. Residential and crisis stabilization services are delivered by existing community mental health providers through the traditional delivery system. Participants are responsible for determining

exactly which community-based services they want and by whom these services will be provided. An independent community advisory board comprised of service recipients, their significant others, and advocates guides the program. Participant recovery is being measured in a number of ways including productive days in the community (productive as defined by each individual), structured self-reports of satisfaction with the program's delivery approach from participants, and structured self-reports about achievement of personal recovery goals and objectives. Standard objective measures are being used to evaluate individual outcomes that will include input from significant others and recovery coaches. The major difference in measurements between AMHSDC and the traditional system is focused on participant self-reports about personal recovery achievement and satisfaction with the total AMHSDC delivery system. (www.floridasdc.info/Pages/Welcome.html)

Implementing a self-determination approach requires at least three major changes in the system. First, there needs to be a shift away from prescriptive, professionally designed treatment planning to individualized, consumer-authored recovery planning. This has been called person-centered planning in the developmental disabilities field. This person-centered planning maximizes consumer choice (see step 2.1.1). A second element of the change to self-determination is a redesign of financing mechanisms to increase consumer control of their care (see step 2.1.2). The third element is the expansion of the range of available choices (see step 2.1.3).

Step 2.1: Shift to person-centered planning: Existing treatment planning is currently directed by professionals. These plans are based on diagnostic labels and treatment guidelines, which neglect the individualized nature of recovery. The Mental Health Commission recommends “that each adult with serious mental illness...have an individualized plan of care[and] consumer needs and preferences should drive the type and mix of services provided” (Commission Report, pg. 35). When people are allowed to fashion their own recovery goals based on their dreams, they are much more motivated to carry them out. In contrast, when their goals are set for them by professionals, they appear unmotivated.

An example of the person-centered approach is provided by the Western New York Care Coordination Program in which “the person’s dreams, interests, preferences, strengths, and capacities are explicitly acknowledged and drive activities, services, and supports” The Program further states, “services and supports are individualized and don’t rely solely on pre-existing models” (www.carecoordination.org),

Step 2.2: Shift to financing mechanisms which support increased consumer control

I. Financing services and supports to allow money to follow the individual:

Current funding mechanisms are inflexible, medically based, and present many challenges to these fundamental shifts in the system toward one that is person-centered and recovery-based. In contrast the Mental Health Commission Report recommends that “ the funding for the plan should then follow the consumer, based on their individualized care plan, pg. 35)” We will describe two models here; but much more work needs to be done to insure that money follows the person and is used to purchase those services which are desired by the individual and which promote recovery.

In Florida, the Self-Directed Care Program, which covers a four county area and 100 participants, has established individual budgets for program participants, through which they can select and purchase the services they want to fulfill their individual recovery plans. Payment will be made through a fiscal intermediary by means of vouchers. Participants can select from a wide array of traditional and non-traditional services; the criterion is that they must promote the individual’s recovery. The program is utilizing a mix of Medicaid and state funds.

In New Hampshire, some Department of Behavioral Health (DBH) funding is planned to be shifted to a “recovery bundle,” which includes those services and activities that promote recovery directly through education, vocational training, supported employment, recreation, community involvement, additional treatment, and other activities to be defined. This is in addition to a separate “clinical bundle.” Recovery services are non-medical services that do not require supervision by a physician, and are expected to be reimbursable through Medicaid. Participants may use the assistance of a consumer advocate to help develop individual budgets defining the use of available funds, subject to review by the case manager. Through this mechanism, DBH intends to empower consumers to take instrumental action on their own behalf toward their recovery goals. A project oversight group consisting of DBH, participating centers, and consumers will oversee implementation and make reports to all providers and interested parties. (Personal communication from Linda Paquette, New Hampshire Department of Behavioral Health.)

The State of Michigan received a grant in 2003 to begin a consumer cooperative demonstration, which would encourage groups of consumers and their families to pool economic resources to obtain the best set of services for their members. This approach (similar to a food-

buying cooperative) is based on market-based incentives and the increase of consumer economic power, (Barrie, 2003).

II. Financing consumer-run National and State-wide Technical Assistance

Centers: These TA Centers can play a vital role in the shift to services, which are truly self-determining. Just as the NRI and SRI's are important in the development of policies which support self-determination, these TA Centers can provide the training and information to providers and consumers to needed to carry out person centered planning, flexible funding such as through individual accounts, and an expansion of consumer-run services.

Step 2.3: Expand the range of choices of services and supports available

I. Expand peer-provided services

The Report of Consumer Issues Subcommittee to the New Freedom Commission also recommended that peer support services be integrated into the continuum of community care and that public and private funding mechanisms be made sufficiently flexible to allow access to these effective support services. The Subcommittee proposed that a carve-out from the Federal Community Mental Health Block Grant funding be established to support the integration of community-based peer support services within the continuum of community care:

We encourage the inclusion of billable peer services under the Medicaid Rehabilitation Option [as has been carried out in Georgia]. (www.mentalhealthcommission.gov)

In order to expand the range of choices of services in the NRI Action Plan, an increase in the involvement of consumers in the four major peer roles is recommended:

A. Peer professionals. A peer professional is someone who has professional training (for example, as a psychiatrist, psychologist, nurse, or social worker), who has also recovered from a personal experience of mental illness, and who is open about his/her experiences. A peer professional combines both academic and experiential knowledge, and brings both aspects to his or her work. By improving the supports for consumers entering professional schools and by recognizing recovery from mental illness as a positive asset, the field can be greatly enriched. The enthusiasm and knowledge of people who have recovered is a valuable and underutilized asset.

A 26 year old man who has recovered from schizophrenia recently wrote to the NEC, "Since I have made a miraculous recovery, I want to go into the field, get my graduate degree in social work, and share my recovery process with as many schizophrenics as I can and help them recover too."

B. Peer specialists. A peer specialist is someone who has recovered or is in recovery (see above distinction between limited and genuine recovery) and who has received

specialized training to provide peer support services. In a number of states, such as Georgia, programs have been developed in which peer specialists receive training and certification, and their services are reimbursable through Medicaid .

The Georgia Consumer Network proposed an idea for peer-led services, and the state mental health authority formulated a plan for services that would be led by professional consumers, and would meet all the parameters of a Medicaid-financed service. In discussions with the Medicaid authority it was determined that the state should shift its delivery practices from the Medicaid Clinic Option to the Rehabilitation Option in order to better facilitate the promotion of rehabilitation principles. Negotiations through the state plan process with the federal Medicaid agency yielded results, and in July of 1999, service delivery began. New Peer Support Services as well as other more recovery focused day services were made available. Georgia has the distinction of being the first state to gain approval from the Center for Medicaid and Medicare Services (CMS) to offer “Peer Supports” as a billable service in the state plan for Medicaid Mental Health Services. On Feb. 1, 2004, South Carolina became the second state to approve of Peer Support Services as Medicaid billable services.

C. Peers as staff in consumer-run programs. Most states now have at least a few consumer-run programs. Some states, such as Michigan and New Hampshire, have funded large numbers of them. Most consumer-run-programs are drop-in centers, where people can come to spend time meeting with others and participating in activities. Other examples of consumer-run programs include a smaller number of housing programs, job-finding programs, warmlines and a few crisis centers. In all cases, people who participate in the programs have a major role in running them and making decisions about them. People who work in these programs are usually paid, with funding sources including state and local governments, private foundations, and individual donations. Two recent reviews of the literature (Davidson, Chinman et al., 1999; Solomon & Draine, 2001) established that there is preliminary evidence to support the effectiveness of peer-run support services to help people with mental illness. Consumers in the consumer-run support centers had better social functioning than the ones in Community Mental Health Centers (Yanos et al., 2001).

The Ruby Rogers Advocacy and Drop-In Center in Somerville, Massachusetts, provide an example of a peer-run program. The Center was started in 1984 under the auspices of MPLF, Inc., a freestanding consumer-run advocacy program, which applied for funding from the Massachusetts Department of Mental Health. The Center’s budget included funds for a part-time (eventually full-time) director, who was specified to be a person who had recovered from mental illness, as well as a number of part-time staff positions that enabled members to take on leadership roles while still being able to collect benefits. The Center provided informal peer

counseling, and a wide range of member-led activities that engaged the interests of members and went far beyond the typical “busy work” of traditional day treatment.

Funding and bureaucratic limitations created constant obstacles. Because the Center did not fit into any existing Department of Mental Health program descriptions, there were a number of funding crises. Eventually the Center was put under the auspices of a professionally run program, limiting its autonomy. Nonetheless, the Ruby Rogers Center, along with literally hundreds of consumer-run drop-in centers around the country, provide models of how consumer/survivors take on leadership roles in helping their peers toward recovery.

D. Peers involved in mutual support. This is the most informal kind of peer support, which can evolve into ordinary friendship. In addition to peer support that is provided on a one-to-one basis, there are also informal networks of support, involving larger numbers of people. For example, many people participate in support and discussion groups over the Internet. Every year, hundreds of people get together for the annual Alternatives Conference, which provides not only information and knowledge about peer support and other important learning experiences, but also gives people the opportunity to network informally.

II. Expand the use of Personal Assistance Services for People with Psychiatric Disabilities

In addition to services provided by peers, there are other models, which increase consumer choice. A model that should be carefully examined is that of consumer-directed personal assistance services (PAS). PAS are widely available for people with physical and (to a certain extent) developmental disabilities. In 1999, the National Blue Ribbon Panel on Personal Assistance Services (cite) stated:

...people with disabilities should have meaningful and informed choices regarding types of long-term services and supports they receive. This choice should include choice of setting (home vs. institution) in which long-term services are received. After this choice has been made, consumers should have control over the extent to which they will manage and direct those services. This emphasis on consumer choice and control is congruent with core American values that put a priority on personal independence and responsibility.

The Commission recommended that PAS be available for a number of different population groups, including both those with physical disabilities and those diagnosed with mental illness. Nonetheless, the availability of PAS for people with psychiatric disabilities continues to be extremely limited.

In Oregon, the state mental health authority runs the C-PASS program for people with psychiatric disabilities, which funds personal care services (PCS) through the Oregon Home and Community Based Waiver. Eligible individuals (who must be Medicaid recipients who live in independent settings and require assistance with basic life tasks) are eligible for up to twenty hours a month of PCS services. These services are consumer-directed and are received by approximately three hundred individuals statewide. The consumer has the power to hire, train, and fire the personal assistant, and payment is by means of a voucher, which is signed by the service recipient and paid by the state using Medicaid waiver funds. A study is currently underway in Oregon to study the ways in which consumers use these services, and to greatly increase the number of people utilizing these services (currently only about 4.3% of eligible individuals statewide) (cite study).

PAS is only one methodology for making mental health services responsive to individual needs. It is being described in such detail here because it is a method which already has a long and successful track record for serving people with disabilities in a self-determined manner, and for which Medicaid funding is already available (although significantly underutilized for people with psychiatric disabilities).

Conclusion

In conclusion, we see that changing the mental health system from its dependency-oriented institutional thinking to one that is based on the principles of recovery will require a concerted effort of consumers and allies working to bring about changes in beliefs and practices at every level of the system. Without fundamental changes in the overall culture of the system, none of the most clever funding schemes or peer-run services will be significantly different from the traditional, institutional medical model approach. The President's New Freedom Commission

Report is a start in the right direction. However, to make the vision of that report a reality there will need to be a core of national and state level consumer leaders who embrace it and are supplied with the resources to carry it forward. Alliances must be developed with all stakeholders who believe in the recovery approach, to enable the implementation of transforming activities, which will make possible the Commission's vision of a system in which every person can recover .

References

Achieving the Promise: Transforming Mental Health Care in the VA,(2003). Department of Veterans Affairs, Wash., DC.

Ahern,L. and Fisher,D. (2001). Recovery at Your Own PACE. *Journal of Psychosocial Nursing*. 39:22-32.

Anthony,W., et al. (2002). *Psychiatric Rehabilitation* (3rd Edition). Boston U. Center for Psychiatric Rehabilitation, Boston, MA.

Barrie, P. (2003). Talk given on flexible financing at SAMSA/CMS sponsored conference on Self-Determination, College Park.

Bassman, R. (2000). Consumers/Survivors/Ex-Patients as Change Facilitators. In *The Role of Organized Psychology in Treatment of the Seriously Mentally Ill*, Fred Freese, Editor, Jossey-Bass, pp 93-102,.

Blanch, A., Fisher, D., Tucker, W., Walsh, D. and Chassman, J. (1993). Consumer-practitioners and psychiatrists share insights about recovery and coping. *Disability Studies Quarterly* 13(2), 17-20.

Campbell, J. (1996). Towards collaborative mental health outcomes systems. *New Directions for Mental Health Services* 71, San Francisco, CA: Jossey-Bass Publishers, pp.69-68.

Campbell, J. (1997) How consumers/survivors are evaluating the quality of psychiatric care. *Evaluation Review*, 21 (3), 357-363.

Chamberlin, J. (2003). *On Our Own*. National Empowerment Center, Lawrence, MA.

Davidson,L. et al. (1999). Peer support among individuals with severe mental illness: a review of the evidence. *Clinical Psychology: Science and Practice* 9(2): 165-187.

Foster, L. et al. (2003). Improving the Quality of Medicaid Personal Assistance through Consumer Direction, Health Affairs.

Harding, C. et al. (1987). The Vermont longitudinal study of persons with severe mental illness, I. Methodology, study sample, and overall status 32 years later. *American Journal of Psychiatry*, 144:718-728.

Karon, B. and VanDen Boos, G. (1981). *Psychotherapy of Schizophrenia*. Aronson, New York.

McCabe, S. and Unzicker, R. (1995). Changing roles of consumer/survivors in mature mental health systems. *New Directions for Mental Health Services* (66). San Francisco, CA: Jossey Bass Publishers, 61-73.

Nerney, T. (2004). The Promise of Freedom for Persons with Psychiatric Disabilities. In UIC NRTC'S National Self-Determination and Psychiatric Disability Invitational Conference Papers (J. Jonikas and J. Cook, Eds.) pg. 129, Chicago, IL.

Solomon P. and Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services. *Psychiatric Rehabilitation Journal* 25(1), 20-7.

Tanzman, B. (1993). An overview of mental health consumers' preferences for housing and support services. *Hospital and Community Psychiatry* 44(5), 450-455.

Trochim, W., Dumont, J. and Campbell, J. (1993). A report for the state mental health agency profiling system: Mapping mental health outcomes from the perspective of consumers/survivors. Technical report series. Alexandria, VA: NASMHPD Research Institute, Inc.

US PHS Office of the Surgeon General. (1999). *Mental Health: A Report of the Surgeon General*. Rockville, MD, DHHS, PHS.

US PHS Office of the Surgeon General. (2001). *Culture, Race and Ethnicity* a Supplement to: *Mental Health: A Report of the Surgeon General*. Rockville, MD, DHHS, PHS.

Van Tosh, L., Ralph, R. and Campbell, J. (2000). The rise of consumerism. *Psychiatric Rehabilitation Skills* 4(3), 383-409.

Yanos P.T., Primavera, L., and Knight, E. (2001). Consumer-Run Service Participation, Recovery of Social Functioning, and the Mediating Role of Psychological Factors. *Psychiatric Services* 52: 493 - 500.

Zinman, S. (2002). Testimony before the President's New Freedom Commission on Mental Health, Washington, DC.