Consumer Involvement With State Mental Health Authorities

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We wish to acknowledge the courage, intellect and perseverance of the many individuals with disabilities who have brought the concept of "recovery" into the main stream.

Executive Summary

This is a joint report of the National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) and the National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council. Developed through a review of materials and extensive discussions at a technical report team meeting held June 21-22, 2010 in Arlington, Virginia, this report articulates a variety of national, state, and local recommendations to strengthen and expand consumer involvement. During the meeting, the participants reviewed and discussed the history of consumer involvement, available evidence and literature as well as the consumer role within treatment, administration and management, oversight of policy and funding and the independent consumer voice. In addition challenges and solutions for optimizing consumer involvement were discussed. The work of the team and the recommendations outlined within this report are based on the premise that neither consumers and the consumer movement nor the SMHA's can optimize the services of a public mental health system unless both work in tandem collaboratively and succeed together.

Since the mid-1850's, the involvement of mental health consumers has expanded significantly as they have taken on greater responsibility in managing their own care and impacting the delivery of services they receive. Consumers are increasingly involved advocating for and designing services that are holistic, and address wellness dimensions beyond only the mental and emotional. Housing, financial services and self-directed care models, peer run employment, and peers as navigators are all ways in which consumers have and are impacting service delivery and innovation. Persons with mental illness have made positive contributions to the three domains of the State Mental Health Authority (SMHA) responsibility: 1) Treatment/Care Service Delivery; 2) Administration and Management of such programs; and 3) Oversight of public policy and funding.

This involvement was furthered by two recent federal documents that recognized the value of consumer and family involvement and self-help. Both the 1999 Surgeon General's Report on Mental Health and the President's New Freedom Commission on Mental Health found that, "nearly every consumer of mental health services… expressed the need to fully participate in his or her plan for recovery. Consumers and families told the Commission that having hope and the opportunity to regain control of their lives was vital…"

Consumer roles and impacts are reviewed on page 25 in the following categories:
- Consumers as providers;
- Consumer directed provider organizations;
- Consumer involvement in the evaluation of treatment services;
- Offices of Consumer Affairs;
- Hospital-level involvement;
- State-wide consumer networks; and
- The therapeutic alliance with mental health and other professionals.

The review of published research on consumer services and involvement in SMHA operations on page 21 finds that consumer provided services are as effective as or more effective than standard services of a similar type.

The involvement of consumers in state-operated behavioral health services has been growing over the years, however across the nation, their involvement and roles in the state mental health authority (SMHA) services and administration has varied greatly. While these roles have merits and create opportunities for the consumer's voice to be heard, there continues to be a lack of national guidelines on consumer involvement in policy making and oversight of the delivery of the provision of public mental health services. Through these roles consumers have improved the delivery of services for themselves and their peers; however there has been little or no systemic activity in the areas of:

- Developing formal mechanisms to incentivize the hiring of consumers in recovery;
- Allowing for consumer involvement in regulatory functions, such as certification and licensing ; and
- Creating metrics to measure consumer involvement and its impact on outcomes

Initiatives are not well-connected or well-coordinated with each other and with the SMHA. Consumers of mental health services must stand at the *center* of the system of care and the system needs to develop ways for them to design, administer, provide, and monitor their services and supports. This report provides evidence and recommendations to improve the national mental health system by further increasing involvement of consumers self-directing their care and participating in oversight of the very programs that are built to provide services.

Key themes presented within this report are:

- Shared responsibility, power, authority, decision-making, and accountability.
- Integration with and impact of Health Care Reform.
- Integration with other systems: The mental and behavioral health care delivery system is not an island, and changes/initiatives need to pay attention to interfacing systems such as medical care, education, social services, housing, spiritual concerns, family involvement, income/benefits, and criminal justice.
- Shared Authority: Systems and providers must acknowledge differences in power and aim to involve and engage recipients meaningfully and equitably.
- Mental health integration into health: Good mental health is necessary for good overall health.
- Focus on a person's strengths: Promoting self-help alternatives that nurture mental health recovery, self-direction, and wellness rather than overreliance on medications and costly institutional services that foster dependence and learned helplessness.
- Consideration of the economic impact: Influencing all issues, including "recovery oriented program financing." It is clear that the model of fees by the day or hour creates a financial disincentive for programs to help people reduce their need for services. Peer Operated Services and self-help, while generally cost-effective, need to have ways to prove their efficacy and derive economic benefit. Self-directed care

models are a key way of maximizing consumer empowerment and they need to be funded and increased.

- Collaboration: If we come together, partner, and focus on where an impact can be made in collaboration with wellness concepts, we can truly make significant strides in health care reform implementation. Wellness is something that providers, consumers, and the general populace can all grasp allowing for shared communication, coordination and collaboration with the same language - which can be powerful.

Specific recommendations included in this report on page 34 are divided into the categories of leadership, administration and management, policy and funding, and consumer voice. This report also highlights areas of concern and respective recommendations related to the recently enacted health care reform (HCR) legislation. In addition, the technical report team made a number of other recommendations that were determined to be outside the scope of this paper. These recommendations were reported in Appendix II. Each state should look at the needs and strengths of existing groups and then focus on expanding consumer involvement within each state. Each state should establish as a clear priority for the SMHA to establish a comprehensive and transparent plan for expansion of consumer involvement into all aspects of system planning, decision-making, policy development and service design, delivery, and evaluation of services.

By doing so, consumer involvement will be enhanced, and the responsibilities of the SMHA to oversee and provide quality public mental health services will optimized.

Introduction

Persons with mental health conditions have proven able to positively contribute to the three domains of the State Mental Health Authority (SMHA) responsibility: 1) Treatment/Care Service Delivery; 2) Administration and Management of such programs; and 3) Oversight of public policy and funding. Consumers have been very involved advocating for and designing services that are holistic, and set up to address life and wellness dimensions beyond mental and emotional. Housing, financial services and self-directed care models, peer run employment, and peers as navigators are all ways in which consumers have and are impacting service delivery and innovation.

Two important federal documents have recognized the value of consumer and family involvement and self-help, including the 1999 Surgeon General Report on Mental Health[1] and the Presidents New Freedom Commission on Mental Health. In 2003, the President's New Freedom Commission on Mental Health said, "nearly every consumer of mental health services who testified before or submitted public comments to the Commission expressed the need to fully participate in his or her plan for recovery. Consumers and families told the Commission that having hope and the opportunity to regain control of their lives was vital to their recovery."

The Commission further indicated that, "emerging research has validated that hope and self-determination are important factors contributing to recovery." The Commission advocated that consumers of mental health services must stand at the *center* of the system of care and that consumer's needs must drive the care and services provided. The Commission concluded that while, capable and willing, consumers and families do not control their own care and that the time had come for increasing the opportunities for consumer and family choice in service delivery as well as creating flexible funding mechanisms that pays for services and supports and are directed by the consumer or family. The Commission argued that by, "increasing opportunities for consumers to choose their provider and allowing consumers and families to have greater control over funds spent on their care and supports such actions facilitate personal responsibility, create an economic interest in obtaining and sustaining recovery, and shift the incentives towards a system that promotes learning, self-monitoring, and accountability." In one sentence, "increasing choice protects individuals and encourages quality."

Through public testimony the Commission became convinced of the need to increase opportunities for consumers and family members to share their knowledge, skills, and experiences of recovery. The Commission then advocated for the increased creation and adoption of recovery-oriented services and supports provided by consumers through consumer-run organizations as well as allowing consumers to work as providers in such capacities as peer-support and psychosocial rehabilitation programs. The Commission

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[1]U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General—Executive Summary*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999.

felt that consumers working as providers of mental health services "bring different attitudes, motivations, insights, and behavioral qualities to the treatment encounter.[2]

These concepts are continuing to be fully interwoven into the further development of consumer-lead service development and health care reform. In a 2007 Centers for Medicare and Medicaid Services (CMS) letter marked SMDL#01-011, State Medicaid Directors were provided guidance on developing peer support services. As indicated by the letter, "there is greater emphasis on recovery from even the most serious mental illnesses when persons have access in their community to treatment and supports that are tailored to meet their needs."

The involvement of consumers in state-operated behavioral health services has been growing over the years, however across the nation, the involvement and roles of persons with mental illness in the state mental health authority (SMHA) services and administration has varied greatly. Many states have offices of consumer affairs (OCA) facilitating a variety of opportunities for consumer involvement, while others have focused solely on the creation of state advisory councils to improve consumer involvement. While these efforts have merits and create opportunities for the consumer's voice to be heard, there continues to be a lack of national guidelines on consumer involvement. A recent article on "Developing Statewide Consumer Networks[3]" suggested that these networks of mental health consumers could provide direct services, advocacy and technical assistance to smaller consumer-operated services but did not address SMHA policy making and oversight of the delivery of the provision of public mental health treatment.

NAC/SMHA as the organization representing state consumer initiatives does not have staff or funding leaving initiatives involving consumers not well-connected or well-coordinated with each other and with the SMHA. Unfortunately, due to the current economic crisis and continuous changes in leadership some successful initiatives have been eliminated or left unfunded. This report provides evidence and recommendations to improve the national mental health system by further increasing involvement of consumers self-directing their care and managing the very programs that are built to provide care to them.

This Report:
The NASMHPD Medical Directors Council and the NAC/SMHA jointly developed this seventeenth technical report through a review of materials and extensive discussions at a work group meeting held June 21-22, 2010 in Arlington, Virginia. Primary sources of data and information used within this report were gathered from presentations and commentary from work group meeting participants, published literature on the history of consumer roles and involvement, and other information distributed prior to and at the meeting.

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[2]New Freedom Commission on Mental Health: Interim Report to the President. Available at www.mentalhealthcommission.gov/reports/interim_report.htm#p75_10348.
[3] Miller, LaVerne D., Moore, Latrease R. (2009). Developing Statewide Consumer Networks. *Psychiatric Services*, 60(3), 291-293. Found at: http://psychservices.psychiatryonline.org/cgi/reprint/60/3/291.

Participants included State Mental Health Authority (SMHA) medical directors and commissioners as well as leadership from SAMHSA; expert faculty from the Appalachian Consulting Group, the National Association of County Behavioral Health and Developmental Disability Directors, the Los Angeles Department of Mental Health, the University of Illinois at Chicago; consumer representatives from a Statewide Peer Wellness Initiative, the National Alliance for Mental Illness, the National Empowerment Center, the Mental Health Association of Southeastern Pennsylvania, the Federation of Families for Children's Mental Health; and other technical experts. A complete list of participants is included as Attachment A.

The work group reviewed and discussed a variety of data sources prior to and during the meeting. The history of consumer involvement, and available evidence and literature on peer delivered services was presented. The group discussed consumer roles within treatment, administration and management, oversight of policy and funding and the independent consumer voice as well as the challenges and solutions to optimizing consumer involvement. Data and discussion led to recommendations reviewed by the workgroup which appear in this paper.

The goals of the technical report are to: 1) Evaluate the extent to which consumer involvement in state mental health authority operations has been successful in pursuing the goals of both the SMHA and consumers and 2) Identify a specific set of actionable recommendations for consumer involvement in SMHA operations are most likely to be successful in furthering the goals of both. The work of the group and the recommendations of this report are based on the premise that neither consumers and the consumer movement or SMHAs can succeed unless both succeed. This report will also document what is known about the successes of consumer involvement initiatives and advocate for substantive involvement of consumers the design, delivery and evaluation of effective services. The "framework" for such consumer involvement should include: the recovery model, the eight dimensions of wellness; total quality management (communication, collaboration and coordination) and consumer safety. The spectrum of involvement should range from consumer having input into his or her own treatment planning, to a consumer assuming a staff role taking part in transformational leadership of the SMHA.

This report will present strategies that continue to move the state mental health system along where the roles of consumer's are enhanced and recommendations are made at the National and State levels. Seven common themes will emerge, these include:
1. Furthering self-directed care;
2. Improving responsibility, power, authority, and accountability;
3. Integrating such strategies with health care reform;
4. Increased involvement with the behavioral health system and beyond;
5. Improved clarity of roles with various audiences;
6. New strategies for prevention and early intervention; and
7. Implementing the principles and practice supporting mental health recovery, resilience, and wellness.

Besides outlining recommendations for National, State, and local mental health organizations, this report will also highlight areas of concern and respective recommendations related to the health care reform (HCR) legislation that was signed by President Obama in 2010 in Appendix I. In addition a set of recommendations regarding concerns that need to be addressed but are outside of the scope of this paper is included in Appendix II.

NASMHPD:

The National Association of State Mental Health Program Directors (NASMHPD) is a 501(c)(3) organization, operating under a cooperative agreement with the National Governors' Association (NGA), which represents the $29.5 billion public mental health service delivery system serving 6.1 million people annually in all 50 states, 4 territories, and the District of Columbia.

The Commissioners/Directors of state mental health agencies make up the membership of NASMHPD and are those individuals, many of whom are appointed by the Governors of their respective states, responsible for the provision of mental health services to citizens utilizing the public system of care. There are 220 state operated psychiatric hospitals nationwide and they serve approximately 50,000 patients at any given point in time. Within the structure of NASMHPD are 6 divisions made up of directors of special populations/services (Consumer, Children/Youth/Families, Older Persons, Forensic, Legal, and Financing/Medicaid) as well as a Medical Directors Council. The purpose of these entities is to provide technical assistance and expert consultation to the Commissioners/Directors related to issues specific to those populations/services.

NASMHPD is uniquely suited to identify, assess, and recommend mental health policies and best practices. It is the only organization representing the state-level public mental health authorities in every state and territory. NASMHPD's members are unique in that they simultaneously represent a broad array of viewpoints - as funders of health care, regulators of healthcare, and direct providers of health care – and, must balance the interests of all three viewpoints. NASMHPD and its membership have a been able to effectively organize at bringing together a wide and diverse array of stakeholders to address the complicated issues involved in behavioral health, primary health care and public health programming. A number of stakeholders are consistently included in such policy development and implementation endeavors including: primary consumers, family members, advocates, providers, professional organizations, accreditation bodies, federal partners, and sister organizations that represent substance abuse, behavioral health, and health. NASMHPD has built coalitions that have succeeded in addressing and moving the field forward on many new programs including co-occurring disorders; the reduction/elimination of seclusion and restraint; trauma; smoking cessation; promotion of evidence based practices; mortality related to serious mental illness (SMI); and the integration of mental health with primary care.

NAC/SMHA:

Organized as an independent 501(c)(3) and recognized by NASMHPD under a joint Memorandum of Understanding (MOU) as the consumer affairs division, the National

Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) represents state mental health department senior managers who serve as the principle points of contact within state mental health authorities for consumer services and representation. Most of the offices represented by NAC/SMHA are staffed by individuals who self-identify as current or former recipients of mental health services. The primary goal of the organization is to provide its members with technical assistance and consultation. The association has been an active partner with NASMHPD and the Center for Mental Health Services (CMHS), the Federal agency within the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA), in advancing the involvement of consumers in policy, restraint and seclusion reduction, employment, civil rights protections, self-help/peer support, smoking cessation, reduction of morbidity and mortality, and the concepts of recovery.

The NAC/SMHA organization serves as a vehicle for networking and peer support, and is committed to expanding the participation of consumers/survivors in all aspects of the public mental health system. The Association offers technical assistance to state mental health departments who are interested in developing offices of consumer/ex-patient relations.

NASMHPD Medical Directors Council:
The NASMHPD Medical Directors Council, which conducts its work under the auspices of the National Association of State Mental Health Program Directors (NASMHPD), was authorized by the Board of Directors in 1995 and its membership includes medical directors of state mental health authorities from across the country. The NASMHPD Medical Directors Council has developed over 16 technical papers (8 over the past 4 years) addressing key areas of clinical policy for the public mental health system including Polypharmacy, Pharmacy Utilization Management, Seclusion and Restraint, Prevention and Integrating Primary Care and Behavioral Health Systems and Reducing Excess Mortality in Persons with Severe Mental Illness. These technical papers have guided recent policy changes and practices in the public mental health system.

The Substance Abuse and Mental Health Services Administration (SAMSHA):
This report was funded by the Substance Abuse and Mental Health Services Administration (SAMSHA) and SAMSHA also served as a collaborating partner. SAMHSA's mission is to reduce the impact of substance abuse and mental illness on America's communities. SAMHSA, in collaboration with other Federal agencies, States, Tribes, local organizations, and individuals including consumers and the recovery community, has demonstrated again and again in research and practice that prevention works, treatment is effective, and people recover from mental and substance use disorders. Behavioral health is an essential part of health service systems and community-wide strategies that work to improve health status and lower costs for families, businesses, and governments. Through continued improvement in the delivery and financing of prevention, treatment, and recovery support services SAMHSA, with its partners, can advance and protect the Nation's health.

Definitions

Assertive Community Treatment or ACT – is a model in which services are provided exclusively in the community through mobile teams comprised of psychiatrists, nurses, case managers, and other staff).

Certified Peer Specialist – a paid staff person in recovery from mental illness who has successfully completed training and certification. A CPS works within Assertive Community Treatment, Intensive Residential Treatment, Crisis Stabilization, Peer Centers, Peer Support Whole Health and Resilience Programs and other Adult Mental Health Rehabilitative programs. A CPS promotes self-determination, personal responsibility and empowerment inherent in recovery.

Consumer – a person who currently or formerly received mental health services and who self-identifies as a person living in recovery with a mental illness. Many individuals choose to identify with a variety of titles including patient, consumer, ex-patient, and survivor. However, for the purposes of this publication the term "consumer" will be used for simplicity recognizing that individuals should be referenced by the term that they find most appropriate. In light of the current economic downturn, many mental health professionals are identifying their own mental health use in attempts to be hired in consumer (peer) positions. Peer positions should employ individuals who have similar backgrounds and experiences to the group that they are providing services to (i.e. peers working with inpatients should have experience as an inpatient receiving mental health services, peers working with forensic clients should have forensic system experience including similar types of crimes as the individuals they work with). Without the similar backgrounds, an individual consumer is not a peer and cannot provide role modeling which is a critical component of peer support.

Helper Principle – suggests that working for the recovery of others facilitates one's own recovery.

Intentional Peer Support – is a form of peer support that avoids the psychiatric or medical model based around a diagnosis and instead starts with people's own stories.

Peer – See "consumer"

Peer/Consumer Operated Service Provider (POS) – These are organizations that are peer-run self-help organizations or groups or are administratively and financially controlled by persons participating in mental health services (consumers), and are not simply mental health services delivered by consumers, but are independent, peer-run programs. They generally offer mutual support, community-building and advocacy. Several types of models exist and include, but are not limited to:

- **Mutual Support Programs:** 1-on-1 or group. Organized, empowering, recovery focused support between persons with mental health challenges where each individual gives and receives support.

- **Drop-in Centers:** Places where persons with mental health challenges may come and go as they please that offers a hopeful environment and voluntary services.
- **Education and Advocacy Training Programs:** Programs which use a set curriculum to teach individuals about mental health, recovery and advocacy.
- **Multi-Service Agencies:** Organizations that provide benefits counseling, housing, economic self-sufficiency, employment support, recovery support and case management.
- **Specialized Supportive Services:** Organizations that focus on crisis respite, employment and housing.
- **Warm Lines:** Peer support by telephone.

Peer Principle – emphasizes the equality and reciprocity that should exist within the peer relationship, with both peers sharing and learning with each other.

Peer Specialist - provide information, support, assistance and advocacy for recipients, and/or caregivers/family members of consumers of mental health services.

Peer Support – operates from the position of experiential knowledge, knowing because the individual has shared a similar experience and can model for others a willingness to learn and grow. These individuals come together with the intention of changing unhelpful patterns, getting out of difficult places and building relationships that are respectful, mutually responsible, and potentially mutually transforming.

Recovery Coach –help individuals gain access to needed resources, services, or supports that will help them achieve recovery from their substance use disorder. These individuals help individuals address multiple domains in the their life that have been impacted by their substance use disorder, but are difficult to address within the structure of most addiction treatment programs, such as returning to employment or finding stable housing. Recovery coaches can also help individuals transition through the continuum of addiction treatment (i.e., from detox to aftercare). Finally, recovery coaches can help individuals sustain their recovery after the formal addiction treatment component has been completed through consultation, skills training, and, of course, coaching.

State Mental Health Authority (SMHA) – is the state authority for administering mental health services within said state.

Wellness Coach –a wellness coach is a person trained to help peers establish a link to primary health care and health promotion activities. The wellness coach assist peers in reducing high risk behaviors and health risk factors through a strength based focused on wellness.

History

The history of consumer involvement is included in this report because it sets a context for the rationale for involving consumers as partners with the SMHA, methods of engagement, strategies and potential outcomes. Consumers have learned through the experience of living with a mental disorder the principles of recovery, which encompass wellness, resiliency and whole health. For the past 30 years, consumers have been reshaping the mental health system to move from an illness, institutional, maintenance-based approach to an approach of recovery, wellness, and resiliency which enable each person to lead a full and satisfying life in the community of their choice.

To begin a discussion of the historical evolution of consumer involvement it seems important to define the goals and motives of each stakeholder (the individual consumer, consumer organizations, and the SMHA). This is important because the motives, philosophy, and power differentials have been a key source of tension, as well as areas where collaboration has begun and partnerships have formed.

The general goal of the SMHA is to design and deliver services that are: effective, accessible, acceptable, and fiscally responsible. The SMHA is responsible to implement public policy, and maintain public safety. To achieve this, the SMHA works to obtain more resources, and increase its public and political support. Consumers have overlapping but different goals. Consumers want services which are effective and accessible to allow them to experience mental health recovery and live normalized lives with the freedom to be treated with dignity and respect, and not to have their rights violated. In exploring opportunities for consumer involvement it is important to look for areas where overlap of goals exist and let each group (consumers and SMHA) go their separate ways in those areas of discordance.

Consumer involvement started when groups organized, such as the 1845 Alleged Lunatics Friend Society in England, and spoke out against atrocities they and their peers encountered, including human and civil rights violations. Clifford Beers is most noted as a consumer who worked to create change by becoming engaged, involved and a leader. Judi Chamberlin's book, "On our Own" became an organizing document for early consumer groups along with numerous other leaders, some included in Table 1 and others highlighted in the volumes of publications produced over the years (see references). Consumer groups initially became involved in the system mostly as civil rights advocates. Some of the key issues addressed by early consumer groups included:

- People were being excluded and stigmatized, and subject to practices preventing them from having equal access to reach their full potential, and contribute equally within society;
- They faced stigma and discrimination and were prevented from the same opportunities, freedom, and access which other citizens enjoy;
- People having freedoms denied by the labeling and dehumanizing and stereotypical images propagated by the mental health system and society; and
- Many people receiving mental health services experienced trauma as a result of the system, or were retraumatized by practices, such as restraint and seclusion, in the

system, thus aggravating rather than reducing the impact of their mental health conditions.

The consumer survivor/ex-patient movement organized around the notion of **empowerment**. Empowerment emerged as a means to correct those violations and the pervasive debilitating consequences individuals encountered with the traditional mental health system. Empowerment is a process by which individuals who generally have lesser social power gain control over their lives and the ability to influence the organizational and societal structures within which they live in order to gain mastery and authenticity. Empowerment continues to be an organizing construct. Evidence of this can be found through peer run organizations such as the National Empowerment Center[4]. Howie the Harp (1994) presented empowerment at four levels. The following outlines these areas and where consumers continue to make an impact:

1) freedom of choice regarding services (e.g., self-directed care models, alternatives and complementary approaches);
2) influence over the operation and structure of service provision (creation of Consumer Operated Services (COS), employee roles within state, county government and federal offices);
3) participation in system-wide service planning; and
4) participation in decision-making at the community level (provider, city- and county-boards).

Consumer involvement was evident during the 1970s, when the principles of the civil rights movement were applied to the problems of people living in mental hospitals. Consumers (survivors & ex-patients) formalized the 'consumer survivor/ex-patient movement'. This movement was a political paradigm that developed out of societal discrimination, as well as disenchantment with the delivery of medical model services. The discrimination was based on misunderstanding and misconceptions about individual needs. This group was organized by people who experienced emotional distress, had freedoms denied by the labeling and dehumanizing systems and society. This group viewed the conventional 'system' as dehumanizing and unresponsive to individual needs. Some factions of the movement insisted on complete liberation from psychiatry, because they rejected the medical models of mental illness (opposed the concept of mental illness), professional control, and forced treatment. They were dissatisfied with the traditional system, which they viewed as paternalistic and lacking in a range of options and opportunities. *Social Justice* was and is a key organizing principle of the consumer/survivor movement. Groups organized because people were being excluded, stigmatized, and subjected to practices preventing them from having equal access to reaching their full potential and contributing equally within society. They faced stigma, and discrimination and were prevented from achieving the same opportunities, freedom and access other citizens enjoy, such voting, parenting, and choosing a health provider. These persons were and are not fully *participating* in the community as active citizens in roles like employees, students, volunteers, teachers, careers, parents, advisors, and residents. *Social justice* through advocacy became the focus to correct historical violations. Some groups organized around the human rights violations, and others acted

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[4] Can be found at www.power2u.org.

as watchdogs to prevent people from being unnecessarily excluded from society. Public mental health policy changed by ending commitments that were not determined to meet the criteria for being a threat of dangerousness to self of others. SMHAs accelerated the 1950s and 1960s trend of downsizing large paternalistic institutions in favor of expanding community services.

Consumer-Operated Services (COS) was another outcome of *social justice* efforts of early leaders. COS were an outgrowth of dissatisfaction with professionally run treatment programs that were perceived as problem-based, rather than focused holistically on mental health recovery and wellness. Reacting to their experiences of inadequacies with the mental health system and the indignities it engendered, service users organized to empower one another by producing their own service alternatives (Chamberlin, 1978).

The 1980s saw further growth and impact in terms of advocacy, consumer voice and further expansion of peer run services/supports. This was a time where consumers shared life stories, and began to create roles to establish visibility for personhood. Self-help and mutual aid were another organizing principle, leading to services and technical assistance resources (National Mental Health Consumers' Self-help Clearinghouse[5]). Drop-In Centers, Clubhouses and other forms of formally organized consumer self-help gained federal and SMHA funding becoming an entirely new service option that was not previously available in the public mental health system.

While some advocates attacked and aimed to dismantle the mental health system, others aimed to engage in making changes to the system. Some focused on effecting alternative and complementary approaches. Many of the consumer leaders who became active in the 1970s have transitioned to "the inside of the system," assuming roles that have influenced policy, practice, research, and innovation.

In the 1990s, the pace expanded, and consumers started taking more action, establishing roles and services. During this time and into the new millennium, they became more involved collecting data, designing and directing research, and "establishing legitimacy" for the COS and the peer movement. SAMHSA and SMHA responded by establishing the Office of Consumer Affairs model of implementing consumer involvement with agency operations.

In summary there seemed to be key phases in the evolution of the consumer role.
- In the 1970's: The National Institute of Mental Health (NIMH) launched the Community Support Program (CSP), an initiative focused on assisting and empowering persons with long-term mental illness to meet their needs and help them to develop their personal potentials without being unnecessarily isolated or excluded from their communities (Carling, 1995; Stroul, 1986). The Community Support Program (CSP) addressed the need for organized, community-based systems of care for adults with long-term mental illness (Stroul, 1987). The CSP aimed to develop a network of community support systems and declared that "empowerment" would be a

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[5] Found at: http://mhselfhelp.org/

fundamental goal (Stroul, 1986). The CSP also strengthened the active involvement of key stakeholders, which included mental health consumers and their family members, in the service delivery design.

- The early 1980's: Telling Life Story which established visibility and occurred in special focus meetings involving both consumers and family members. This had a major impact to enlighten the audience and establish visibility.
- The Early 1990s: Taking Action to Establish Roles, a phase, where consumers started self-help and peer support efforts and were invited events such as to the Mental Health Statistics Improvement Program (MHSIP) Workgroups; Consumer-Commissioner Dialogues.
- The Early 2000s: Collecting Data/Doing Research to Establish legitimacy, a phase, where consumers became involved collecting data, and conducting research, first, through expert opinion then involvement in designing and implementing both qualitative and quantitative designs.

Consumers have changed the focus and reframed state and federal mental health policy by defining mental health *recovery and wellness* as organizing principles for community mental health services. They have brought to the system the need to consider *social determinants of health*[6]*, and resiliency*. Consumer leaders proposed and demonstrated by example the notion of mental health recovery – a sense of belonging, an adequate income, and a decent place to live. Wellness views a person holistically, focusing on the dimensions/domains of the whole person physical, emotional, intellectual, social, environmental, occupational, financial and spiritual[7]. The Wellness Recovery Action Plan (WRAP), introduced by Mary Ellen Copeland[8] demonstrates how consumers have created an effective self-care strategy to promote mental health recovery. Wellness is so very important because the traditional system has not adequately addressed overall health, especially physical health and the pervasive effects of poverty and unemployment. Of particular concern is the increased morbidity and mortality largely due to treatable medical conditions that are caused by modifiable risk factors such as smoking, obesity, substance abuse, inadequate access to medical care[9] , and the ill health effects of the medications prescribed for psychiatric conditions.

Consumers have led the way with transformation – bringing the concept of mental health recovery, wellness, and social inclusion to the table. Consumers have effectively been able to propose service innovation, should rightfully take a lead facilitating the dialogues, and are key stakeholders in decision making, policy planning, and strategic planning. The establishment of the National Association of Consumer/Survivor Mental Health Administrators (NAC/SMHA) is clear evidence of consumer leadership[10].

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[6]Found at: http://www.who.int/social_determinants/thecommission/finalreport/en/index.html and
  http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf
[7]Swarbrick, M. (2006). A wellness approach. *Psychiatric Rehabilitation Journal, 29*(4), 311–314.
  Swarbrick, M. (1997). A wellness model for clients. *Mental Health Special Interest Section Quarterly*, *20*, 1–4.
[8]Copeland, M (1997). Wellness Recovery Action Plan.
[9]Parks, J., Svendsen, D., Singer, P., & Foti, M.E. (2006). Morbidity and mortality in people with serious mental illness. National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council, Alexandria, VA. From www..org/_files//__/%%%inal%%.18.08.pdf (accessed January 21, 2010).
[10]Found at: http://www.nasmhpd.org/nac_smha.cfm

The following two tables present how consumers have become involved and assumed leadership roles to influence behavioral health treatment/services, policy direction, management, and administration.

Table 1 provides a historical context for the consumer survivor movement, a movement responsible for consumer involvement in the current system of care[11].

Table 1: Timeline of Consumer Involvement History[12]

1845	1. Alleged Lunatics Friend Society is formed.
1908	1. Mental hygiene movement developed based on social activism and confidence in ability of human beings to prevent disease and other social ills. 2. Clifford Beers founds National Committee on Mental Hygiene (NCMH) - Initially anti-mental health system, later supportive of mental health system.
1940's	1. A group of ex-patients from Rockland Psychiatric Center in New York State formed a support group that met on the steps of the New York City Public Library in Manhattan. The support group members called themselves We Are Not Alone (WANA). 2. In 1948 - We are Not Alone (WANA) becomes Fountain House.
1960s	Community Mental Health Construction Act (PL 88-164).
1970s	1. Community Support Program (CSP) in 1977, a project of the National Institute of Mental Health supported and strengthened the consumer movement and helped consumers influential and participate more collaborate on designing and delivering their services. 2. Psychiatric Survivors. 3. Conference on Human Rights and Against Psychiatric Oppression.
1980s	1. Focus on Advocacy. 2. Establishment of self-help/peer run programs. 3. People organize and tell their stories to establish visibility for personhood and problems with services, policies and oppressive practices. 4. Alternatives conference Baltimore Maryland. 5. Community Support Programs Demonstration grants.
1989	1. NASMHPD position paper- recognized the unique contributions that consumers can make to the improvement of quality of services – recommended contributions in the area of program evaluation policy formation, Quality Assurance (QA), systems design education of staff and service provision. 2. 1989 The Well Being Project added to understanding the concept of quality of life from the perspectives of consumers.
1990's	1. Taking Action and Establish Roles, Services and Involvement in Research. 2. (1993) SMHA support of consumer and family-run programs." Arlington, VA, National Association of State Mental Health Program Directors. 3. (1993) From lab rat to researcher: The history, models, and policy implications of consumer/survivor involvement in research. Paper presented at the fourth annual national conference of state mental health agency services research and program evaluation, Annapolis, MD by Jean Campbell, Ruth Ralph, and Robert

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[11] Chamberlin, J. (1978). *On our own: patient-controlled alternatives to the mental health system.* New York, NY: McGraw-Hill. Chamberlin, J. (1990). The ex-patient's movement: Where we've been and where we're going. *Journal of Mind and Behavior, 11*(3,4), 323-336.

[12] An excellent comprehensive historical timeline of this movement, entitled "Our Story of Commitment: A Living History" can be found at: http://www.theopalproject.org/ourstory.html

		Glover.
	4.	Technical Assistance Centers funded.
	5.	Offices of Consumer Affairs established.
	6.	Consumer Survivor Research and Policy Workgroup.
	7.	MH Statistics Improvement Program () Consumer Oriented Mental Health Report Card.
	8.	$19.6 million dollars allocated to examine consumer—operated services (COSP).
2000-2010	1.	Roles and involvement expands and consumers are taking a lead impacting transformation and service innovation.
	2.	Peer Support Specialists role- Certified Peer Specialist.
	3.	The First National Survey "Survey of Organized Consumer Self-Help Entities was conducted in 2002 and published in 2004.
	4.	On Our Own Together (Clay, 2005)[13].
	5.	Fidelity Assessment Common Ingredients Tool (FACIT).
	6.	New Freedom Commission Report (2003).
	7.	Recovery Components (2004).
	8.	National Association of Peer Specialists.
	9.	Wellness Summit 2007.
	10.	Social Inclusion 2009.
	11.	Government Funding for Consumer Groups.
	12.	Public Law 102-321 requires all states to have Mental Health Planning Council's with consumer representation.
	13.	Peer Specialist services added to CMHCs.

Table 2 presents a summary of consumer involvement models under the current system of care.

Table 2: Models of Consumer Involvement (Services)

Model	Description/Example
Research	• Participatory Action Research- involvement in formulated the research question, the design, implementation, analysis and dissemination.
Employee	• Consumers assuming employee roles- individuals who fill designated unique positions peer advocate, peer specialist, consumer case manager, and peer companion) as well as peers who are hired into traditional positions.
Administrative Policy	• Independent local and statewide advocacy groups invited to decision making tables and/or asserting their right to be included and involved. • The establishment of Office of Consumer Affairs departments positions within the state authority. • Office of Consumer Affairs- SAMHSA, CMHS. • Advisory boards- state, county provider levels. • Consumers assuming CEOs or other administrative and management roles within consumer operated and traditional provider and social service organizations.

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[13] Based on scientific sampling, using the Kessler population frames, they found that there are 7,500 consumer organizations; 3,300 mutual support groups; 3,000 self-help organizations; and 1,100 consumer operated support programs

Consumer operated Services	Planned, operated, administered and evaluated by individuals living with a disability: • Independent of a traditional provider organization. • Peers control board of directors, staff and budget (over 51% of board identified as living with a disability). • Services types include: *drop-in or self-help centers*, which provide varied services such as meals and housing assistance for members, as well as a place to meet friends and relax; *peer-support programs,* consisting of self-help groups and services in which users provide services to one another; and *education programs*, which include training programs during which consumers learn recovery or advocacy skills.
Consumer Partnership	Services or programs within non-consumer-operated agencies. Fiduciary responsibility within a non-peer organization. • Peer presence on agency governing bodies • Self-help groups under a professional-run agency umbrella. • Peer volunteers providing added services at provider agencies. • Peer-run program in a provider agency, such as drop-in centers/resource centers.
Empowered Consumer	The most fundamental level is an empowered consumer. An empowered consumer has sufficient opportunities to exercise maximal control of her or his recovery, including choosing which mental health professionals are on the team, sharing in decisions, and having the option to agree with, modify, or reject the service or treatment plan. The system offers appropriate education, enforcement of respect for individuals self-determined choices, useful information to make relevant choices, and specific tools and models that assure empowerment remains in effect (including share medication decision making tools, person centered planning, etc.). In the end, each person is his or her own "peer provider," by practicing "personal medicine".

For a full review of the above listed model types see *Persons in Recovery as Providers of Psychiatric Rehabilitation: The Wisdom of Experience* (2010). UPSRA.

Although under-developed in many areas throughout the country, consumer involvement has produced real impacts.   Through advocacy and opportunities to impact the system externally and internally, consumers are helping to transform the face and landscape of the service delivery system. Consumers have been included at decision making tables impacting policy, services, funding, and management. There has been clear progress as evidenced by consumer impact on reframing and transforming service delivery. Other peers have been engaged and become leaders at making significant impacts regarding service innovation, such as certified peer support, housing, peer run respites and alternatives, self-help models and wellness coaching for whole person health. Consumer involvement in decision-making roles and policy, management (e.g., SMHA, Offices of Consumer Affairs) and advocacy has been and will continue to be a very important driver of change and innovation within SMHAs. Consumers are assuming key leadership roles in state and federal agencies.

Some progress has been made in broadening the focus of services from narrow treatment approaches to a focus on recovery and now wellness and inclusion of consumers in the

design and delivery of services. Consumers are now involved in many policy and decision making circles. Some are employed by SMHAs and local provider agencies, and others hold leadership positions within the federal government. Consumer leaders are clearly involved in system and program design and evaluation. However some consumer involvement in system and program design and evaluation is merely tokenism. Continuing progress on including consumers as full partners in leadership or power positions where they can exert more meaningful lasting influence and lasting impact will drive SMHAs to continue to improve access and acceptability of current services and to develop new innovative and effective services. More will be said about this in the coming pages of this report.

Future Directions – Health Care Reform – Social Determinants of Health:
There are many opportunities for consumers to partner, collaborate and lead. Healthcare reform will surely change the landscape, focus, and outcomes of the service delivery system. Consumer's advocates are in a clear position to keep a clear focus on empowerment and mental health recovery and to help assure services are designed and delivered to address social determinants of health. Consumers and professionals should continue to partner, focusing on envisioning how communities can be empowered to promote positive health and resilience and help craft a community as a protective device.

Consumers have led the way in the transformation of our public mental health system, and they have introduced the concept of mental health recovery. For instance primary care and subsequently health care reform have just recently "discovered" the person centered, strengths-based approach decades after consumers have taught it to SMHAs. Both are major contributions to National Health Reform. However, the attitude data need to give us pause. National Health Reform will promote integration into environments where poor attitudes are held about persons with mental illness. Creating a consumer office at the highest level of authority can assist to validate the concepts of self-directed and integrated care.

Active consumer involvement in a broad range of roles will be an essential antidote to these attitudes. Visible and vocal consumers are important public and political constituency for SMHAs. Increasing consumer involvement in SMHA funded treatment, policy, and administration will make consumers more sophisticated and credible advocates for the SMHA mission and goals in the future "reformed" healthcare system.

Evidence

Offices of Consumer Affairs Survey:
In anticipation of this report, NAC/SMHA conducted a survey of the 43 Offices of Consumer Affairs (OCA) by contacting the state's designated person in each office.

- Six offices (14%) are currently vacant
- Three offices (7%) are contracted with local consumer organizations outside of state government.
- Twenty-six (61%) of the offices responded to the survey. No survey responses were received from any of the states where the OCA was housed in a contracted organization.
- Nine (17%) states (including territories) do not have an office.

Position descriptions for the designated consumer staff vary greatly among states and range from Special Assistants to the Commissioners to Advocates.

- Two-thirds of the OCA's (14) have position descriptions of Special Assistants to the Commissioner
- Two-thirds (15) report directly to a Commissioner (7) or Executive Deputy Commissioner (8).
- The remaining OCA designates vary in job titles and report to Program Managers (4), Division Directors (4), or team leaders (2).
- Eleven of the OCA leaders were not considered part of the State Mental Health Authorities senior management team.

Two-thirds of all the OCA leaders had been in their positions for less than 5 years.
Over the past ten years, since the last NAC/SMHA survey,

- 5 out of 8 states that previously had their OCA contracted out have converted their offices to staff employed directly by the state. Since the last survey,
- 3 out of 4 states that previously had part-time staff, have also converted to full-time positions with only one state currently having only part-time staffing for an OCA.

All states have their staff on a salary basis since the last survey which noted several states paying hourly rates (one just above minimum wage).

All respondents stated technical assistance was needed and would further support their efforts since NAC/SMHA is a volunteer organization without funding.

Although a dramatic shift has occurred since the last survey of OCAs, it still appears as though some states have created an office of one person (8 or 31% - states that responded to the survey), not of senior management authority (11 or 42% - states that responded to the survey), having no budget authority (10 or 38% - states that responded to the survey), focused on dealing with complaints (3 or 11% - states that responded to the survey).

Evidence Base for Peer-Provided Services:
There is a growing body of evidence demonstrating the types and benefits of peer provided services. A recent publication presented a review of consumer led programs

around the world [14] Peer-provided services take a number of forms, and Salzer et al. (2002) describes three types of consumer-delivered mental health service programs.

- Consumer-operated service programs, which are planned, managed, and staffed entirely by consumers.
- Consumer partnership service programs, in which consumers deliver services and share control of the program with non-consumers, especially regarding fiscal and administrative functions.
- Consumers as employees in programs which employ consumers and non-consumers alike, but which are managed and administered by non-consumers (Salzer et al., 2002).

The list below reflects this diversity:

- Self-help/mutual support groups (Recovery, GROW, Depression & Bipolar Support Alliance);
- Peer-to-peer services (Georgia Certified Peer Specialists);
- Peer-to-peer education (BRIDGES, Vision for Tomorrow);
- Recovery and wellness self-management (WRAP, HARP, Taking Charge);
- Person-centered planning;
- Peer addiction recovery services (AA, NA, Double Trouble);
- Employment of peers in traditional programs (ACT, ICM); and
- Research-based peer services: supported socialization, consumer advocacy, and broad-based case management.

Writing in 2004, Solomon characterized the level of evidence for consumer-provided services as including "At least 5 published studies with scientifically rigorous designs (randomized clinical trials, well-controlled quasi-experimental designs) using a variety of meaningful outcome measures."

A review by Cook (2005) concludes that peer provided services produce outcomes as good as, and in some cases superior to, services provided by non-peer professionals.

1. Paulson and his colleagues (Clarke, Herinckx, Kinney et al., 2000; Herinckx, Kinney, Clarke et al., 1997; Paulson, Clarke, Herinckx et al., 1999) randomly assigned community mental health center clients to one of three conditions. The first was a consumer-staffed Assertive Community Treatment (ACT) team. The second was an ACT team staffed by non-consumers. Both teams were operated by a consumer-run agency. In the third condition, participants received treatment as usual. Results revealed no differences between the two ACT teams in symptomatology, or any clinical or social outcome for the first two years of service delivery. However, both ACT teams had significantly greater treatment retention than usual care, and both had significantly higher hospitalization rates which were thought to result from closer monitoring of clients that occurs in the ACT model.

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[14] Doughtey, C., & Tse, S. (2010). Can consumer-led mental health services be equally as effective? An integrative review of CLMHS in high income countries. *Community Mental Health Journal.*

2. Solomon and her colleagues (Solomon & Draine, 1995a, 1995b) randomly assigned clients of a community mental health center to consumer-run intensive case management in comparison to a non-consumer intensive case management team. At two years, clients of both teams had equivalent behavioral symptomatology, quality of life, and a variety of clinical and social outcomes. Service delivery patterns differed, however, in that the consumer case management team provided more face-to-face services and services outside of an office setting than the control condition.

3. Another study randomly assigned patients released from a specialized inpatient program to a condition in which consumer and non-consumer staff worked to enhance social network development in the community and a control group that did not receive the network enhancement (Edmunson, Bedell, Archer et al., 1982). Both groups received comparable discharge planning and referral to community-based outpatient programs. Those in the consumer-delivered network enhancement condition had fewer and briefer hospitalizations than the control participants, and a significantly higher proportion of experimental participants were able to function without contact with the formal mental health system than the control condition.

4. In another controlled study (Kaufmann, 1995); participants were assigned to a consumer self-help vocational program that worked in partnership with non-consumer professional providers versus services as usual condition that was enhanced by provision of information regarding locally available employment programs. The two-phase experimental treatment began with non-consumer professionals who provided job training, placement and support. Next, consumer-run and peer support services were delivered to enhance job seeking and provide support for commonly encountered employment difficulties. A significantly higher proportion of experimental program subjects than controls achieved employment and attained higher vocational status as measured by an ordinal ranking of steps toward competitive employment. Among unemployed participants, experimental group participants were more likely to be looking for a job, working as a trainee or volunteering. Among employed participants, the experimental group worked a greater number of hours.

Since Cook's review in 2005, additional studies have been published showing similar results.

- The Consumer Operated Service Programs (COSP) multi-site randomized controlled trial (RCT) examined the effects of a number of different peer-provided models including drop-in centers, mutual support programs, education curricula, and advocacy programs (Campbell et al., 2004 and Rogers et al., 2007). They found that subjects who received COSP plus traditional mental health services reported higher levels of personal empowerment than those in the control condition who received only traditional services.

- In a study by Davidson et al. (2004), a 3-arm RCT compared: 1) a financial stipend only; 2) a stipend plus supported socialization with a peer; and 3) a stipend plus supported socialization with a non-peer. This study found that consumers receiving

peer-delivered services achieved outcomes as good as those in the other two conditions in areas such as symptoms, well-being, self-esteem, social functioning, and employment. Similarly, Sells and colleagues (2006) conducted an RCT comparing "broad based" peer and non-peer case management. Participants reported that they perceived higher positive regard from peer case managers than non-peer case managers at 6 months but not at 12 months.

- Finally, an RCT study by Druss and colleagues (2010) examined peer-led chronic medical disease self-management program for participants, using a model adapted from Lorig and colleagues' (1999) well-known chronic illness self-management. Called the Health and Recovery Peer (HARP) program, this intervention focuses on helping participants cope more effectively with physical health conditions. At 6-month follow-up, compared to controls receiving services as usual, HARP participants reported significantly greater improvements in physical activity, visits to primary care doctors, medication adherence, physical health related quality of life, and perceived ability to manage one's illness and health behaviors.

In conclusion, outcomes of peer-provided services are typically as good as or better than services from non-peers. While there is still much research work to be done, the evidence in support of peer delivered services cited in this report qualifies as Level 1b ("Evidence obtained from at least one randomized controlled trial") using the United States Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research) guidelines published in 1992. There is a growing body of empirical support for the effectiveness of this mode of service delivery.

Discussion of Consumer Roles

A variety of consumer roles have been created to ensure the perspective of the person who uses mental health services and who benefits from the work of mental health authority is heard. These roles are identified below.

Consumers as Providers:
Over the last several decades a number of new positions for consumers to actually provide services to other consumers in a variety of settings have been created (Bluebird, 2008). Prior to the publication of the conclusions of the President's New Freedom Commission report on Mental Health Services, many opportunities for consumers were voluntary positions or resident advocates in hospital settings that were not always filled by consumers themselves (Bluebird, 2008). Now it is well-known that consumers in recovery can help transform systems into environments that promote empowerment, hope, respect, and healing (Bluebird, 2008).

Presently, consumers take on a wide-variety of roles, such as those of: advocates, counselors, educators, and evaluators with some being targeted to provide peer support and counseling to others. Peer advocate positions were created and address complaints and grievances and assure the continued protection of patient rights. In addition, peer-run drop-in centers are a type of Consumer-Operated Service (COS) that allow peers to provide a place for other consumers to find respite, recreation, socialization, and greater independence. Peers are utilized to help consumers transition from inpatient settings to community-based setting or back to their home when they are ready for discharge. Peer specialists are utilized to provide support to people who arrive at the emergency room in psychiatric crisis. Peers are valuable in helping to influence the physical environment so that environment can be developed to encourage comfort and healing.

A variety of specific roles and titles have been emerging. These include:
- Peer Specialist or Peer Support Specialist;
- Peer Mentor/Peer Counselor;
- Recovery Support Specialist;
- Recovery Aide;
- Client Liaison or "De-briefer";
- Peer Bridger ; and
- Office of Consumer Affairs Director or Recipient Affairs Director.

In addition, career ladders for consumers performing these roles are expanding.

The role of peer support services has been expanding. The Centers for Medicare & Medicaid Services (CMS) in August 15, 2007, issued a letter to State Medicaid Directors to provide guidance to states interested in peer support services under the Medicaid program (Attachment H). This letter designated peer support as a billable service and outlined the minimum requirements that should be addressed for supervision, care

coordination, and training when electing to provide peer support services. Key factors outlined by CMS include the following:[15]

1. Supervision must be provided by a competent mental health professional (as defined by the State). The amount, duration and scope of supervision will vary depending on State Practice Acts, the demonstrated competency and experience of the peer support provider, as well as the service mix, and may range from direct oversight to periodic care consultation.
2. As with many Medicaid funded services, peer support services must be coordinated within the context of a comprehensive, individualized plan of care that includes specific individualized goals. States should use a person-centered planning process to help promote participant ownership of the plan of care. Such methods actively engage and empower the participant, and individuals selected by the participant, in leading and directing the design of the service plan and, thereby, ensure that the plan reflects the needs and preferences of the participant in achieving the specific, individualized goals that have measurable results and are specified in the service plan.
3. Peer support providers must complete training and certification as defined by the State. Training must provide peer support providers with a basic set of competencies necessary to perform the peer support function. The peer must demonstrate the ability to support the recovery of others from mental illness and/or substance use disorders. Similar to other provider types, ongoing continuing educational requirements for peer support providers must be in place.

Consumer Directed Mental Health Organizations:

Consumers participate significantly in these organizations which are run by consumers for the purposes of providing service to other consumers, with a principle underlying value being empowerment. These organizations conduct the following activities:
- Promoting the right of the individuals, or advocacy;
- Providing support to peers, as well as case management services and assistance to access additional services needed;
- Improving the quality of life of peers;
- Reducing stigma;
- Promoting self-help activities;
- Assisting with employment, housing and education;
- Conducting public and community education and outreach; and
- Designing and implementing research and evaluation.

A Center for Mental Health Services Survey initiated in 2002 found there were 7,500 consumer organizations. Of these organizations, 3,300 were mutual support groups, 3,000 were self-help organizations, and 1,100 were consumer operated support programs. These organizations share the following characteristics:
1. About 86% are incorporated as nonprofit corporations;

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[15] From: http://www.parecovery.org/documents/Pillars_of_Peer_Support.pdf.

2. It has an operating budget and pays staff primarily out of grants and/or contracts the organizations received and participants are heavily involved in decisions about how the money is spent;
3. Participants are involved in making decisions about how the funding is spent in 83.4% of these organizations;
4. The board of directors or governing board is made up of greater than 50% consumers;
5. It provides opportunities for volunteers to serve;
6. A majority of referrals (93.1%) come from the existing mental health system; and
7. Participants view the services provided by these organizations as complementary to those provided by psychiatrists and therapists.

Consumer Involvement in the Evaluation of Treatment Services:

Evaluation of treatment has tended to examine clinical indicators such as symptom reduction, length of stay, and hospital re-admission rates. Routine measures generally do not reflect what is really important to help foster mental health recovery and overall wellness considering social determinants of health and well-being.

According to Happell (2008), there is limited research describing the effectiveness of services from the perspective of the consumer of mental health services. Happell examined factors that help and hinder recovery and found that when consumers had input treatment was viewed as more effective. Happell (2008) found that spiritual approaches, crisis management plans and counseling were identified as 'helpful factors' and factors that hindered recovery included: staffing issues and narrow focus on symptoms rather than needs.

An excellent example of consumer involvement is Consumer Quality Initiatives (CQI). CQI is a mental health consumer-operated research, evaluation and quality improvement organization based in Massachusetts. The mission of CQI is to "give mental health consumers a greater voice and integral role" in evaluating their treatment. CQI utilizes a Community-based Participatory Action Research (PAR) framework, with an emphasis on protocols that are designed to impact policy and practice directly. CQI also consults locally and nationally on achieving significant involvement of consumers in the "change" process to promote mental health systems transformation and quality improvement.[16]

Consumers can help design and direct studies that can meet the needs of the target population and promote their recovery and reintegration into the community. Participatory Action Research (PAR) offers a promising, relevant approach for the future of evaluation efforts designed to evaluate treatment services. PAR is designed and executed by consumers; is highly meaningful to consumers (addresses challenges faced by people who experiences the treatment). The active involvement of people whose lives are affected by the issues under study is incorporated in every phase of the research process (formulation of questions, selection of indicators, instruments and methodology, implementation of protocols, analysis of data and dissemination). PAR is a democratic non-coercive process whereby those to be helped, determine the purposes and outcomes

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[16] From: http://www.cqi-mass.org/

of their own inquiry (Wadsworth, 1998). The What Helps and What Hinders report is an excellent example of PAR.[17]

Offices of Consumer Affairs:
These offices play a lead role in developing and implementing consumer information activities, supporting consumer-operated networks, and coordinating anti-stigma efforts. These offices typically exist to enhance the voice of recipients of mental health services by promoting and facilitating meaningful consumer participation in all aspects of mental health services administration. These offices have a leadership role in both policy and program development. They may coordinate with local peer support chapters, individual consumers, and primary consumer advocacy groups in efforts to improve services, and empower consumers throughout their recovery. In addition, these offices, in conjunction with local Core Service Agencies, can assist consumers with their complaints and/or concerns regarding services received or treatment options.

Hospital Level Involvement:
One study by Linhorst, Eckert, and Hamilton highlighted that people with mental illness traditionally have been thought of as powerless due to remnants of the historical practice of providing care and treatment in large institutional settings and the application of the medical model of providing psychiatric treatment. Despite this perception, this study found that five formal structures or processes existed to involve consumers in the decision making of a publically operated long-term psychiatric hospital. Clients and staff identified these five formal structures as:
1. Consumer Council's interaction with committees and executive staff;
2. Filing grievances through the client grievance system;
3. Interactions with protection and advocacy;
4. Participation in the hospital's performance improvement system; and
5. Participation in the hospital's policy review process.

Informal means identified in the study included:
1. Contact with an executive staff member;
2. Filing a lawsuit against the hospital;
3. Contact with a member of the treatment team; and
4. Writing or calling the main office.

This study identified some common obstacles to consumer participation in these structures. These include:
1. Many consumer's lack information about hospital policies, which policies were current being considered, and how to provide input;
2. Some important policies that affected consumers were made at the administrative or legislative level;

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[17] Onken, S. J., Ph.D., Dumont, J. M., Ph.D. Ridgway, P., M.S.W., A.B.D., Dornan, D. H., M.S. (2002). Mental Health Recovery: What Helps and What Hinders? *National Technical Assistance Center for State Mental Health Planning*, *National Association of State Mental Health Program Directors.*

3. Executive staff and program managers simply did not seek consumer input on issues affecting consumers;
4. Some consumers feared retaliation from staff for voicing opinions; and
5. The feedback loop after consumers had provided input was often incomplete.

Statewide Consumer Networks (SCNs):
These networks provide direct services, advocacy, and technical assistance to smaller consumer-operated services with the goal to improve services for persons living with mental illnesses. SMHAs can play an important role in the institution and survival of these networks by providing funding and technical assistance.

The Therapeutic Alliance - Roles Revisited:
Mental illness cannot be adequately treated solely with either "professional treatment" or "personal medicine" alone. A healthy and strong alliance between consumer and professional treatment service providers is required. With the current emphasis on new medications on the one hand and consumer empowerment on the other hand we have forgotten the power and importance of the therapeutic alliance in achieving recovery and wellness. Therapeutic alliance does not mean that both parties always agree on the action of the moment but rather focuses on the ultimate goals of recovery and wellness in environment of mutual respect and mutual learning. A redefinition of these roles will be needed to achieve and maintain equality between the therapist and the consumer.

Other Roles:
The following examples of consumer roles were provided by the State of Nebraska to reflect additional options for consumer participation:
- OCA Peer Support Training Facilitator's Circle;
- People in Recovery Council;
- Advisory Councils;
- General Public via OCA Town Hall Meetings, surveys, and conference calls;
- General Public via Division of Behavioral Health surveys;
- Legislative Hearings and Oversight Commissions;
- State Hospitals;
- Division of Behavioral Health Workgroups;
- State Chapters of NAMI, MHA, Family Organizations;
- State Consumer Conferences and Scholarships;
- Advocacy Services;
- Strategic Planning groups;
- Suicide Prevention Coalitions;
- Consumer Contractors;
- Nebraska Regional Behavioral Health Committees and Advisory Boards;
- Community Behavioral Health Program Peer Specialists;
- Law Enforcement: CIT training, Omaha Police Department peer position;
- Co-Occurring Task Force in Omaha;
- ACT Programs
- Consumer Run Programs;

- Local Outreach to Suicide Survivors Teams;
- Regional consumer specialists;
- Regional support group chapters; and
- Trauma Survivor groups.

In summary, since the 1970's there has been significant but uneven progress achieving consumer involvement in the public mental health system administration and operations in the following areas:
- Operation of independent advocacy groups;
- Participation in internal advisory bodies;
- Expansion of independent self-help groups/programs;
- Operation of non-professional consumer/peer services including drop-in centers, clubhouses, and peer specialists; and
- Creation of Offices of Consumer Affairs.

Conversely, there has been little or no activity in the areas of:
- Formal mechanisms to incentivize hiring recovered consumers in regular staff positions;
- Formal involvement of consumers in regulatory functions such as certification and licensure; and
- Creation of benchmark metrics to measure the degree of consumer involvement in SMHA and its impact on outcomes.

Strategies and Solutions to Optimizing Consumer Involvement

The following are **some challenges** related to optimizing consumer involvement in the areas of services, policy, funding and strategic planning, followed by strategies and solutions.

<u>Challenges:</u>
- The stigma of living with mental illness diagnosis/disorder remains a real and distinct barrier[18] that leads to discrimination, limiting participation in services, policy, funding and strategic planning. Policy makers, providers, and their staff are often resistant to seeing the recovered consumer as a colleague within the mission of the organization. In addition, consumers have historically been disenfranchised and had little political influence or socioeconomic power to have meaningful roles in the design and delivery of services.

- Consumers also have rarely held the political clout needed to influence major decision making. This challenge comes at all levels, from lacking negotiation skills and political savvy to not having the right clothes or resources to be at the tables with people in suits and ties. Many people may not have the resources to access meetings (transportation, bus, train or car fare, etc.).

- Consumers usually lack the formal degrees and credentials that other stakeholders depend on for credibility and influence.

- Many consumers choose to remain invisible. This includes persons who are involved in the public mental health system but choose not to identify themselves as consumers mental health system leaders, employees, and stakeholders who choose to remain silent regarding their personal history of mental illness in their own recovery. There is also the large group of recovered consumers who choose to minimize their contact with the mental health system as much as possible preferring to pursue other causes and professions once they have gained recovery.

- Real or imagined liability and confidentiality concerns of mental health care providers related to the employment of consumers as staff or in regulatory functions.

- Perceived limited ability to advertise and hire consumers in various roles due to predefined state job specifications which do not typically include personal experience of having used services as an occupational job requirement.

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[18] Found at: http://www.encyclopedia.com/doc/1P3-2054934501.html
Attitudes Toward Mental Illness - 35 States, District of Columbia, and Puerto Rico, 2007
MMWR. Morbidity and Mortality Weekly Report | May 28, 2010 Manderscheid, R; Delvecchio, P; Marshall, C; Palpant, R G; Bigham, J; Bornemann, T H; Kobau, R; Zack, M; Langmaid, G; Thompson, W; Lubar, D.

The history of excluding and not involving consumers in meaningful ways and roles is changing, although mental health providers, policy-makers, and advocates need to pay attention to the above stated challenges as progress continues.

Strategies and Solutions:
The following strategies and solutions are intended to help address the challenges identified above and thereby optimizing consumer involvement.

Education and training - to help consumers be able to develop skills and resources to function in systems advocacy roles and other leadership roles within and beyond the SMHA. There are many roles at the local and state level (including proposal evaluation, serving on Government boards and committees, and serving on provider agency boards), and we often see a small subset of people trying to cover too many duties. One strategy for improvement would be to involve and include a diverse group of peers including younger consumers and those from various diverse ethnic and cultural groups.

Resource allocation should support training and mentoring of consumer leadership. Peer provider roles and peer delivered services are not for every consumer, and not every peer providing role is right for everyone. People need to (and many or may not need help to) decide if this is the role for them, and get help looking at what kinds of positions may fit their needs. The mental health system evaluates the capability of matching personal characteristics with certain kinds of peer provider positions. Similarly, people will vary in the extent of their need for peer provider employment supports. Some may need only job banks or access to peer mentoring, while others may need services which are more like the full Supported Employment evidence based-practice (EBP) to help them choose, get, and keep peer provider positions. The right continuum of services in each state can allow people to maximize their satisfaction, satisfactoriness, and tenure in peer provider roles, without creating a burdensome system for people who do not need such supports. Federal vocational rehabilitation (VR) funding and Ticket-to-Work funding can be a viable way to support these kinds of services.

The system should consider various kinds of affirmative action so that historic inequities can begin to be righted, and consumer involvement can become mainstream, even in settings which are historically not as inclusive. Research and publications are needed describing best practices to help people best integrate into peer provider roles, and for programs to adapt to the new roles in their organizations. Statewide peer provider organizations could be a promising source of mutual aid in this area.

It is important to help peers to have meaningful career ladders inside and outside of their organizations. Peer provider training is an important area. Ideally, as much of the training as possible should be via college courses, so people can acquire skills and at the same time accumulate credits which lead to degrees which could lead to jobs inside and outside of mental health.

Hiring - The ability to recruit and hire individuals with lived experience in using services is often complicated by state job specifications and the perception that including that requirement might violate Equal Employment Opportunity Commission (EEOC) regulations. The EEOC and US Department of Justice have said that in rare cases, discrimination on the basis of protected categories is allowed if a bona fide occupational qualification exists, such as might for a peer counselor for disabled clients where they need to role model recovery. These agencies have indicated that the Age Discrimination in Employment Act (ADEA) does not apply to federally funded or state programs designed to enhance employment of individuals with "special employment problems". Such programs include those designed to enhance employment of the long-term unemployed, individuals with disabilities, members of minority groups, older workers, or youth. For additional guidance on this exemption, refer to Policy Statement on *Specific Exemptions from Coverage Pursuant to § 9 of the Age Discrimination in Employment Act*, EEOC Compliance Manual, Volume II (1988). Many states have established bona fide occupational requirements such as those employed at Independent Living Centers where individuals must have the lived experience of the disability in order to perform the job functions associated with role modeling.

A number of states have established job titles that require individuals have lived experience for positions such as "peer counselors". In hiring a Director of a Consumer Affairs Office, some states have used civil service exempt titles such as "Special Assistant to the Commissioner" in order to include the job responsibilities and occupational requirements associated with lived mental health experience.

Recommendations

Based on the review of the consumer involvement literature, materials, presentations and commentary from work group participants at the meeting held on June 21-22, 2010 in Arlington, VA, meeting participants drew the following conclusions and recommendations. This list is recognized to be limited in its scope as it does not include every conclusion and recommendation made within the body of this report; however, it does represent those priorities determined at the meeting for national and state level authorities as well as consumer organizations and providers.

Recommendations are directed specifically at key stakeholders, though most if not all, will require collaboration between many kinds of stakeholders at all levels. The recommendations below can affect the delivery of treatment services, administration and management of programs, policy and funding, and lend a consumer voice to each. There needs to be a clear focus to work more collaboratively; breaking down silos and focus on the future, especially by looking at how all can partner to inform, impact, and effectively implement HCR. A focus on mental health recovery, resilience, health promotion, early intervention and prevention as well as wellness is relevant and important areas for collaboration. Mental health recovery, wellness, and resilience should be key concepts that are operationalized. For all groups, key themes that are clearly relevant.

- Share responsibility, power, authority, decision-making, and accountability
- Attention to integrate with and impact HCR.
- The mental and behavioral health care delivery system is not an island, and changes/initiatives need to pay attention to interfacing systems such as medical care, education, social services, housing, spiritual concerns, family involvement, income/benefits, and criminal justice.
- Systems and providers must acknowledge differences in power and aim to involve and engage recipients in meaningful and equitable ways.
- Mental health integrated into health- good mental health is necessary for good overall health.
- Focus on a person's strengths, promoting self-help alternatives that nurture mental health recovery, self-direction, and wellness rather than overreliance on medications and costly institutional services that foster dependence and learned helplessness.
- Consider the economic impact of all issues, including "recovery oriented program financing." It is clear that the model of fees by the day or hour creates a financial disincentive for programs to help people reduce their need for services. Peer Operated Services and self-help, while generally cost-effective, need to have ways to demonstrate their efficacy and derive economic benefit. Self-directed care models are a key way of maximizing consumer empowerment and they need to be funded and increased.
- If we come together, partner, and focus on where an impact can be made in collaboration with wellness concepts, we can truly make significant strides in health care reform implementation. Wellness is something that providers, consumers, and the general populace can all grasp allowing for shared communication, coordination and collaboration with the same language - which can be powerful.

System-wide recommendations:
- Maximize consumer involvement in boards and committees at all levels. This may include creating incentives for high rates of consumer involvement and disincentives (including loss of eligibility) for poor compliance with the need for meaningful consumer involvement in the state mental health boards/planning councils.

National level - NASMHPD:
- Provide technical assistance to Offices of Consumer Affairs to assist in maximizing opportunities to facilitate consumer involvement at every level of the mental health system.

National level - Federal:
- A mental health consumer advisory or advisory panel should be developed to advise and inform the health care reform debate on issues pertaining to mental health in the larger reform of health care.
- Require federally funded vocational rehabilitation and employment programs to contract with peer run programs and report amount spent on programs.
- Require all federally funded programs in mental health to employ consumers to a meaningful extent, and create and track metrics to ensure that this mandate is being implemented.
- Purchase Federal Agency supplies from companies whose workforce is comprised of a certain percentage of people with disabilities.
- Make maximal efforts to make the political process, including federal and state legislative hearings, accessible to consumers.
- National Institute of Mental Health (NIMH), Food and Drug Administration (FDA), National Institute for Disability and Rehabilitation Research (NIDDR), etc. should perform or sponsor broad research on the efficacy of medicine, non-medical treatments, self-help, and Complementary and Alternative Medicine (CAM) for mental health disorders, and make the resulting information available and accessible to consumers via a consumer guide.
- Maximize the inclusion of consumers in federal advocacy roles, including the staffs of SAMHSA, NASMHPD, and the Annapolis coalition.
- CMS should require that state Medicaid plan include use of peer specialists and prevention services as covered services.
- Provide sustainable funding through block grant allocation so consumer groups are able to support statewide advocacy in all levels of HCR at state and federal levels.
- Consider the creation of a "National Mental Health Job Corps" – At least 100 consumers in each congressional district available to take on service provision and systems advocacy roles in federally funded positions.
- Take affirmative action to ensure that state and large cities maintain strong offices of consumer affairs (OCAs), using state funding, or block grant funds if needed.
- Develop and implement policy to mandate and maximize the prevalence of peer providers.

- In order to remain eligible for block grants, each SMHA must establish an affirmative action program to increase the prevalence of people who disclose a current or prior mental health diagnosis or issue in their workforce. This includes the total workforce of the SMHAs, as well as the proportion of all Government and agency programs funded by mental health grants.
- SAMHSA should develop national standards and metrics for measuring consumer involvement. Methods of measuring and accountability for follow through should be clearly defined, transparent and publicly reported. Recommended standards and metrics include:
    o Programs and agencies need to be required to make public the amount of money and other resources spent on peer run support;
    o Require that states utilize the Quality Interagency Coordination Task Force (QuIC) Standards for the Involvement of Consumers, Youth, and Family Members in Mental Health Quality Improvement Activities for consumer involvement in systems as self-rating tools with results reported to SAMHSA. The Quality Interagency Coordination Task Force (QuIC) was established in 1998 in accordance with a Presidential directive. The purpose of the QuIC was to ensure that all Federal agencies involved in purchasing, providing, studying, or regulating health care services were working in a coordinated manner toward the common goal of improving quality care;
    o Percentage of the SMHA funded workforce who disclose a current or prior mental health diagnosis or issue;
    o Percentage of the SMHA funded workforce who disclose a current or prior psychiatric disability (i.e., current or previous recipients of SSI, SSDI, and/or VA benefits on the basis of a psychiatric disability);
    o SAMHSA should acknowledge and assist states who are small in population and very large in demographic miles to provide technical assistance, training and or funding in order to facilitate consumer involvement within the states;
    o Insure that a wide range of consumers from demographically challenged states (rural, frontier states) are represented at National meetings, councils, workgroup, etc.; and
    o SAMHSA needs to leave no state behind when it comes to funding and technical assistance (some states without consumer network organizations have noted the inability to receive technical assistance due from the TA centers due to the fact that they lacked a statewide network).

SMHA:
The existence, types and level of meaningful consumer involvement in the state mental health authorities varies significantly across the nation. The following are general recommendations sorted into the categories of leadership, administration and management, policy and funding. Each state should establish as a clear priority for the SMHA to strengthen a commitment (which includes pledging support to fund, execute, and carry out) a concrete and transparent plan to expand consumer involvement in all aspects of planning, decision making, policy development and service design, delivery and evaluation. SMHAs are in the unique position to support

and ensure consumer driven and delivered services become the norm rather than the novel methods for delivering care.

Leadership:
- All states should have a full-time, state employed, consumer leading their Office of Consumer Affairs and that position should be on an executive level.
- Take steps to give peer advocacy leaders regular access to elected officials and to SMHA and department-level leadership.
- Proactively involve consumer groups- and be sure that there is significant consumer representation on governing boards and meaningful workgroups of the state and subdivisions.
- States that do not have consumer organizations should fund a statewide organizing effort and seek the support from other states that are further along.
- Fund a pilot consumer-run organization similar to Soteria[19] House.
- Have consumers on the boards of directors of private provider agencies including health care providers. Nonprofit mental health agencies should be required to have 50 % consumer representation on board of directors.
- SMHA Medical Directors should be actively teaching and promoting the use of therapeutic alliance and shared decision making in the treatment system.

Administration and Management:
- The SMHA should take a leadership role in a comprehensive workforce development – with targets for number of consumers. (See metrics listed previously.)
- Ensuring that jobs for consumer providers are available both within set-aide roles (homeless outreach, crisis diversion, warm lines, and peer support centers) and mainstream mental health programs.
- Develop and maintain a COS/peer support directory at the state level and ensure that the information is widely disseminated, and is included in any information and referral websites or help lines which may have previously focused only on "professional services."
- The SMHA should routinely use consumer employees or contractors in onsite program licensure and certification review functions.
- OCA should make sure that youth are involved in meaningful and respectful ways
- SMHA should engage in comprehensive programs to maximize the prevalence, retention, role variety, and career opportunities for consumer providers. This should include:
  o Developing/enhancing academic and non-academic training programs for consumer providers;
  o Developing/enhancing vocational service programs which help consumer providers choose, get, and keep desired jobs in the field;

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[19] a community service that provides a space for people experiencing mental distress or crisis
Ciompi L (1997). "The Soteria-concept. Theoretical bases and practical 13-year-experience with a milieu-therapeutic approach of acute schizophrenia". *Seishin Shinkeigaku Zasshi* **99** (9): 634–50. PMID 9396381. More information can be found at: http://www.moshersoteria.com/soteri.htm#SP

- o Establishing targeted affirmative action practices that require hiring consumers at all levels - including commissioner;
- o Developing/enhancing regulations which create valid credentials and Medicaid billability for non-licensed/degreed consumer providers and recognize the value of lived experience;
- o Supporting the operation of a statewide consumer provider professional and advocacy organization;
- o Ensuring that consumer providers in the system represent a wide variety of backgrounds, cultural and ethnic groups, and other unique populations, including veterans, people with histories of incarceration, and people currently on long-term hospital stays; and
- o Creating incentives for the use of consumer providers in the defined mental health benefits under the Health Exchange.
- Provide sensitivity training focused on including peers in the workforce for all new hires.
- Involve consumers in the training of members of the workforce.
- Have consumer run agencies host college interns whose major is in behavioral health.

Policy and Funding:
- All states should fund Consumer Operated Services (COS) (Utilizing a meaningful portion of block grant for COS). If limited or no funding for peer operated services is available then allocate funds. This is a metric which should be publicly visible. (See previous metrics recommended.)
- Fund adequately Technical Support and Assistances programs to assess POS and self-help resource gaps and developing a resource for developing, implementing, and sustaining peer-operated services. Utilize the Quality Interagency Coordination Task Force (QuIC) Standards for the Involvement of Consumers, Youth, and Family Members in Mental Health Quality Improvement Activities (Attachment F) for consumer involvement in systems as self-rating tools with results reported to SMHA leadership and stakeholders. QuIC was established in 1998 in accordance with a Presidential directive. The purpose of the QuIC was to ensure that all Federal agencies involved in purchasing, providing, studying, or regulating health care services were working in a coordinated manner toward the common goal of improving quality care.
- Involve consumers and consumer groups in the development and review of regulations, evaluation of programs, and evaluation of program proposals.
- Offer consumer advocates support such as training on public speaking and advocacy so consumers can be more effectively and involved in decision making and policy.
- Develop formal and specific human resource policies and procedures for hiring that recognizes consumer lived experience as some level of equivalent experience for traditional credentials/work history required for staff positions.
- The state should be required to match federal block grant funds for COS.

State-Level Consumer Organizations:

Likewise, recommendations to state-level consumer organizations could be organized into the categories of leadership, administration and management, policy and funding as well as treatment services, and consumer voice.

Leadership:
- Be a lead in creating a forum between various entities d organizations which can partner with other groups, especially around a common agenda for healthcare reform.
- Focus efforts on fitness and good health and wellness practices, including taking a lead at developing health and wellness promotion materials - Become a leader to develop and sustain an agenda to reduce co-morbidity.
- Partner with civil rights organization- to address issues (and include) people who have criminal justice involvement.
- Encourage employment within state authorities.

Administration and Management:
- Seek, manage, and employ the variety of talents in the state's consumer community – marketers, accountants, computer professionals, etc.
- Utilize the QuIC Standards for the Involvement of Consumers, Youth, and Family Members in Mental Health Quality Improvement Activities for consumer involvement in systems as SMHA and provider agency rating tool with results reported to SMHA leadership and stakeholders.
- Set up peers as Health Navigators and Disability Program Navigators.

Policy and Funding:
- Partner with local research entities to drive research that involves consumers in all level of design, methods, process, interpretation of findings and dissemination. This also includes working on initiatives to create a cadre of consumers who can engage in Participatory Action Research (PAR).
- Advocate for improvement in policy, procedure, and methods for transparent and effective data collection and dissemination.

Treatment Services:
- Provide resources for consumers to be involved in evaluation of recovery, wellness, & resilience efforts and also training (best practices) - for optimal consumer involvement.
- Become engaged and involved in cross system discussion at local levels, for example Federally Qualified Health Centers, involvement in training police, and involvement with criminal justice system.
- Support the development and proliferation of more recovery and wellness oriented products- such as eCPR, Wellness Recovery Action Planning, financial literacy training and warm lines.
- Get youth advocacy organizations involved to bridge silos.
- Expand service such as peer run respite, financial literacy and warm lines.
- Require trauma informed services from treatment providers.

- Develop/enhance systems for peer-to-peer mentoring – each one teaches one.

Consumer Voice:
- Ensure that all recommendations and initiatives work with the inclusive "broad tent" of consumers. This includes:
  - People who are disenfranchised by and avoid the APMHS;
  - People with co-occurring substance, developmental ,communicative, and/or medical disorders;
  - People living in institutions for a long term;
  - People with justice system co-involvement;
  - Mental health consumers in the active duty military and the VA system;
  - Youth, transition-age youth, and older adults; and
  - Various ethnic, sexual orientation and cultural minorities.
    An example of the last is that one attendee recommended that efforts be made to extend NASMHPD report recommendations to deal with the health disparities and unique health disparities faced by African-Americans.
- Diversify and outreach for leadership, management and communities served.
- Outreach to universities- clinical and medical student training to discuss the value of the lived experience and self-help approaches.
- Regularly visit your elected officials to tell them about your programs and priorities. For those that support you, support them with volunteer time and endorsements and political donations, if possible.
- Devote time to help with voter registration and help peers become more involved in political process.
- Lead local anti-stigma campaigns through positive publicity.
- Help individual consumer advocates becoming and staying involved in state hospital oversight, Olmstead advisory committees, and related committees and boards of the SMHA.
- Obtain or develop self-determination tools, including Shared Decision Making tools that can flesh out how to exercise rights for care.
- Engage in social inclusion activities based on census and community mapping.
- Get involved in evaluation of publicly and privately run programs – This includes being on site visit committees, providing inputs to JCAHO and other accreditation bodies, and conducting secret shopper visits and report findings.
- Learn advocacy and legislative skills through other state organizations – to become more effective on legislative and regulatory issues.
- Meet with community groups to help understand strength-based employment.

Providers:
Similarly, recommendations to provider organizations could be organized into the categories of leadership, administration and management, policy and funding as well as treatment services, and consumer voice.

Administration and Management:
- Make sure that peer provider and support roles are valued and integrated.
- Seek consumer leadership on program design, delivery and evaluation

- Hire consumer groups to do quality control, quality improvement, and program evaluation.

Policy and funding:
- Institute Continuous Quality Improvement process to encourage consumers to rate and review service experiences, and make information publically available.
- Develop and implement policies regarding promoting disclosure of employees' personal history of mental illness and recovery in the workplace.
- Make sure that state and county-level provider organizations involve COS.
- CEU'S – content on recovery consumer issues and multi- cultural.
- Provide pay equity for peer providers.
- Provide career paths for consumer providers. Some may come in at part-time and want to move up; others may be seeking full-time employment on hire. Consumer providers should have access to academic opportunities/tuition reimbursement so they can grow into various competitive non set-aside roles.
- Develop formal and specific human resource policies and procedures for hiring that recognize consumer lived experience as some level of equivalent experience for traditional credentials/work history required for staff positions.

Treatment Services:
- Offer peer providers appropriate vocational services to maximize their career values through close conformance to the Supported Employment EBP.
- Assist peers to access training, mentoring, and continuing education.
- Integrate peer support into the service structure.

Consumer Voice:
- 50 % of the board of non-profit agencies should be consumers.
- For profit agency advisory boards to have consumer representation.
- Provider boards involve consumers in hiring and decisions.

References

Barrett, N. M., Pratt, C. W., Basto, P. M., Gill, K. J. (2000) Integrating consumer providers into a service delivery system. *Psychiatric Rehabilitation Skills, 4*(1), 82-104.

Basto, P. M., Pratt, C. W., Gill, K. J., & Barrett, N. M. (2000). The organizational assimilation of consumer providers: A quantitative examination. *Psychiatric Rehabilitation Skills 4*(1), 105-119.

Beard, J.H., Propst, R., & Malamud, T.J. (1982). The Fountain House model of psychiatric rehabilitation. *Psychosocial Rehabilitation Journal, 5*, 47-53.

Beers, C.W. (1953). *A mind that found itself.* New York: Doubleday.

Bloom, S. L., M.D. (2006). Organizational stress as a barrier to trauma-sensitive change and system transformation. Downloaded from: http://www.nasmhpd.org/general_files/publications/ntac_pubs/Organizational%20 Stress%202010%20formatted%20NTAC.pdf

Bluebird, Gayle (2008). Paving New Ground, Peers working in Inpatient Settings. *Supported by the National Technical Assistance Center, National Association of State Mental Health Program Directors.*

Campbell, J. & Adkins, R. E. (2007). Fidelity assessment common ingredients tool e-FACIT workbook users' guide. St. Louis, MO: Missouri Institute of Mental Health, Behavioral Health Division, Program in Consumer Studies & Training.

Campbell, J. & Adkins, R. E. (2007). Fidelity assessment common ingredients tool e-FACIT workbook users' guide. St. Louis, MO: Missouri Institute of Mental Health, Behavioral Health Division, Program in Consumer Studies & Training.

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

Campbell, J. (2005). Fidelity assessment common ingredients tool (FACIT): FACIT score sheet. Retrieved January 24, 2009 from http://www.psych.uic.edu/uicnrtc/nrtc4.webcast1.jcampbell.transcript.pdf

Campbell, J., & COSP Steering Committee. (2004). Consumer-Operated Service Program (COSP) Multi-site Research Initiative: Overview and preliminary findings. St Louis, MO: author.

Campbell, Jean Ph.D. , Leaver, Judy M.A. (2003). *Emerging New Practices in Organized Peer Support.* Prepared for: (NTAC), (NASMHPD), under contract with the

Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA).

Carling, P. (1995). Return to community: Building support systems for people with psychiatric disabilities. New York: Guilford Press.

Center for Mental Health Services (2005). *Building Bridges: Consumers and Representatives of the Mental Health and Criminal Justice Systems in Dialogue.* DHHS Pub. No. (SMA) 05-4067. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

Center Mental Health Services. (2007). USA issues guidelines on Medicaid funding of peer support. *CMHS Consumer Affairs E-New, 07(126).* August 16, 2007, http://www.mindfreedom.org/kb/mental-health-alternatives/peer-support/medicaid.

Chamberlin, J. (1978). *On our own: Patient controlled alternatives to the mental health system*. New York: McGraw-Hill.

Chamberlin, J. (1984). Speaking for ourselves: An overview of the ex-psychiatric inmates' movement. *Psychiatric Rehabilitation Journal, 2*, 56-63.

Chamberlin, J. (1990). The ex-patient movement: Where we've been and where we're going. *The Journal of Mind and Behavior, 11*, 323-336.

Chamberlin, J. (1995). Rehabilitating ourselves: The psychiatric-survivor movement. *International Journal of Mental Health, 24*, 39-46.

Chamberlin, J. (1997). A working definition of empowerment. *Psychiatric Rehabilitation Journal, 20*, 10-14.

Chamberlin, J., Rogers, J., & Sneed, C. (1990). Consumers, families and community support systems. *Psychosocial Rehabilitation Journal, 12*, 93-106.

Chamberlin, J., Rogers, S.E, & Ellison, M. L. (1996). Self-help programs: A description of their characteristics and their members. *Psychiatric Rehabilitation Journal, 19*, 33-42.

Chinman, M., Hamilton, A., Butler, B., Knight, E., Murray, S., & Young, A. (2008). *Mental health consumer providers: A guide for clinical staff*. Retrieved July 23, 2009 from http://www.rand.org/pubs/technical_reports/2008/RAND_TR584.pdf

Clarke, G. N., Herinckx, H. A., Kinney, R. F., Paulson, R. I., Cutler, D. L., Lewis, K., et al. (2000). Psychiatric hospitalizations, arrests, emergency room visits, and homelessness of clients with serious and persistent mental illness: findings from a

randomized trial of two ACT programs vs. usual care, Mental Health Services Research, 2, 155-164.

Clay, S. (2005). On Our Own Together: Peer programs for people with mental illness. Vanderbilt Press.

Clay, S. (2005). *On our own together: Peer programs for people with mental illness.* Vanderbilt Press.

CMHS. Building Bridges: Co-Occurring Mental Illness and Addiction: Consumers and Service Providers, Policymakers,and Researchers in Dialogue. (2004) DHHS Pub. No. (SMA) 04-3892. Rockville, MD. Substance Abuse and Mental Health Services Administration.

Cook, J.A., (1995). Patient-Centered" and "Consumer-Directed" Mental Health Services. Report prepared for the Institute of Medicine to Committee on Crossing the Quality Chasm – Adaptation to Mental Health and Addictive Disorders.

Dain, N. (1989). Critics and dissenters: Reflections on 'anti-psychiatry' in the United States. *The Journal of the History of Behavioral Sciences, 25*, 3-25.

Daniels, A., Grant, E., Filson, B., Powell, I., Fricks, L., Goodale, L. (Ed), Pillars of Peer Support: Transforming Mental Health Systems of Care Through Peer Support Services, Taken from www.pillarsofpeersupport.org in January 2010.

Davidson, L, Shahar, G, Stayner, DA, Chinman, MJ, Rakfeldt, J, Tebes, JK. (2004). Supported socialization for people with psychiatric disabilities: lessons from a randomized controlled trial. Journal of Community Psychology, 453–477.

Davidson, L., Chinman, M., Kloos, B., Weingarten, R., Stayner, D., & Tebes, J. (1999). Peer support among individuals with severe mental illness: A review of evidence. *Clinical Psychology: Science and Practice, 9*(2), 165-187.

Deegan, P. E., & Drake, R. E. (2006). Shared decision-making and medication management in the recovery process. *Psychiatric Services, 57*, 1636-1639.

Doughtey, C., & Tse, S. (2010). Can consumer-led mental health services be equally as effective? An integrative review of CLMHS in high income countries. *Community Mental Health Journal.*

Druss, B.G., Zhao, L., von Esenwein, S.A., Bona, J.R., Fricks, L., Jenkins-Tucker, S., Sterling, E., DiClemente, R. & Lorig, K. (2010). The Health and Recovery Peer (HARP) Program: A peer-led intervention to improve medical self-management for persons with serious mental illness. Schizophrenia Research 118, 264–270.

Edmunson, E. D., Bedell, J. R., Archer, R. P., et al. (1982). Integrating skill building and peer support in mental health treatment: the Early Intervention and Community Network Development projects.

Emerick, R. (1990). Self- help groups for former patients: Relations with mental health professionals. *Hospital and Community Psychiatry, 41*, 401-407.

Everett, B. (1994). Something is happening: The contemporary consumer and psychiatric survivor movement in historical context. *The Journal of Mind and Behavior, 15* (Winter and Spring), 55-70.

Fisher, D. M.D., PhD. (2007). How consumers step up to design a truly recovery-based mental health system. *National Council Magazine 2007: Vol. 3.*

Fisher, D. B., M.D., Ph.D., Chamberlin J. (2004). Consumer-Directed Transformation to a Recovery-Based Mental Health System. Downloaded from: http://download.ncadi.samhsa.gov/ken/pdf/Transform.pdf.

Free To Choose: Transforming Behavioral Health Care to Self-Direction. (2005) DHHS Publication No. SMA-05-3982. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

Gelernter, M. (1988). Zealous self-help groups as adjuncts to psychiatric treatment: A study of Recovery, Inc. *American Journal of Psychiatry* 145(10), 1248-1253.

Goldstrom, I.D., Campbell, J., Rogers, J. J., Lambert, D. B., Blacklow, B., Henderson, M. J., & Manderscheid, R. W. (2006). National estimates for mental health mutual support groups, self-help organizations, and consumer-operated services. *Administration and Policy in Mental Health and Mental Health Services Research (33)*1, 92–103.

Happell B., (April 2008). *Determining the Effectiveness of Mental Health Services from a Consumer Perspective: Part 1: Enhancing Recovery.* International Journal Mental Health Nursing. (2) pp. 116-112.

Happell B., (April 2008). *Determining the Effectiveness of Mental Health Services from a Consumer Perspective: Part11: Barriers to Recovery and Principles for Evaluation.* International Journal Mental Health Nursing. (2) pp. 123-130.

Harp, H. (1994). Empowerment of mental health consumers in vocational rehabilitation. *Psychosocial Rehabilitation Journal, 17*, 83-90

In A. M. Jeger, & R. S. Slotnick (Eds.), Community Mental Health and Behavioral- Ecology: A Handbook of Theory, Research, and Practice. New York: Plenum.

Ingoglia, Charles (2001). Promoting Collaboration: An Exploration of Successful Partnerships Between Mental Health Planning and Advisory Councils. *Prepared for: National Technical Assistance Center for State Mental Health Planning (NTAC) and the National Association of State Mental Health Program Directors (NASMHPD).*

Johnsen, M., Teague, G., & McDonel-Herr, E. (2005). Common ingredients as a fidelity measure for peer run programs. In S. Clay (Ed.), *On our own together. Peer programs for people with mental illness.* Nashville, TN: Vanderbilt University Press.

Jorgenson, J., Schmook, A. Office of Consumer Affairs: Establishing, developing, & expanding the role in State, Regional and local Government: Facilitator's Guide. *Developed for the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.*

Jorgenson, J., Schmook, A. Office of Consumer Affairs: Establishing, developing, & expanding the role in State, Regional and local Government: Training Curriculum. *Developed for the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.*

Kaufman, C. L. (1995). The self-help employment center: Some outcomes from the first year, Psychosocial Rehabilitation Journal, 18(4), 145-162.

Knight, E. (1997). A model of the dissemination of self-help in public mental health systems. *New Directions for Mental Health Services, 74*, 43-51.

Levison, J.R. (2003). Elisabeth Parsons Ware Packard: An advocate for cultural, religious, and legal change. *Alabama Law Review, 54 (3)*, 987-1074.

Linhorst, D. M., Eckert, A., & Hamilton, G. (2005). Promoting participation in organizational decision making by clients with severe mental illness. *Social Work: Vol. 50, Number 1.*

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, Jr. B. W., Ritter, P. L., González, V. M., Laurent, D. D., & Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing utilization and costs: A randomized trial, Medical Care, 37(1), 5-14.

McCabe, S., & Unzicker, R. (1995). Changing roles of consumer/survivors in mature mental health systems. *New Directions in Mental Health Services, 66*, 61-72.

McGill, C. W., & Patterson, C. J. (1990). Former patients as peer counselors on locked inpatient units. *Hospital and Community Psychiatry, 41*, 1017-1019.

McLean, A. (1995). Empowerment and the psychiatric consumer/ex-patient movement in the United States: Contradictions, crisis and change. *Social Science Medicine, 40*, 1053-1071.

Mead, S., & MacNeil C. (2006). Peer support: What makes it unique? *International Journal of Psychosocial Rehabilitation, 10* (2), 29-37.

Mental Patients Liberation Front. (2005) A chronology of the disability rights movements 1800 to 1998. http://mplf.org/text1/chronology.html.

Minkler, M. & Wallerstein, N., (Eds), *Community Based Participatory Research for Health* (pp. 419-428). San Francisco: Jossey-Bass.

National Mental Health Association. *Increasing Involvement in Healthcare Reform:* Recommendations from Stakeholders.

National Technical Assistance Center for State Mental Health Planning**.** (2000). The Change Agent's Tool Box Series. From: http://www.nasmhpd.org/publicationsOTA.cfm.

Nelson, G., Ochocka, J., Griffith, K., & Lord, J. (1998). "Nothing without me without me": Participatory action research with self-help/mutual aid organizations for psychiatric survivors. *American Journal of Community Psychology, 26,* 881-912.

New Freedom Commission on Mental Health. (2003). *Achieving the promise: Transforming mental health care in America. Final Report.* DHHS Pub. No. SMA-03-3832. Rockville, MD.

Onken, S. J., Ph.D., Dumont, J. M., Ph.D. Ridgway, P., M.S.W., A.B.D., Dornan, D. H., M.S. (2002). Mental Health Recovery: What Helps and What Hinders? *National Technical Assistance Center for State Mental Health Planning*, *National Association of State Mental Health Program Directors.*

Petr, C., Holtquist, S., & Martin, J. (2000). Consumer-run organizations for youth. *Psychiatric Rehabilitation Journal, 24*, 142-148.

Rissmiller, D.J., Rissmiller, J.H. (2006) Evolution of the antipsychiatry movement into mental health consumerism. *Psychiatric Services*, *57 (6),* 863-866.

Rogers, E., S., Chamberlin, J., Ellison, M., L., & Crean, T. (1997). A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatric Services, 48*, 1042-1047.

Rogers, E.S., Teague, G.B., Lichenstein, C., Campbell, J., Lyass A., Chen, R., & Banks, S. (2007). Effects of participation in consumer-operated programs on personal and

organizationally-mediated empowerment: Results of multi-site study. *Journal of Research and Rehabilitation Development, 44,* 785-800.

Rogers, S., & Palmer-Erbs, V. (1994). Participatory action research: Implications and evaluation in psychiatric rehabilitation. *Psychosocial Rehabilitation Journal, 18,* 3-12.

Sabin, J., & Daniels, N. (2003). Strengthening the consumer voice in managed care: VII. The Georgia peer specialist program. *Psychiatric Services, 54(*4), 497-498.

Salzer, M. S. (2002). Consumer-delivered services as a best practice in mental health care delivery and the development of practice guidelines. *Psychiatric Rehabilitation Skills, 6*(3), 355-382.

Schmidt, L. T. (2005). Comparison of service outcomes of case management teams with and without a consumer provider. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 66,* 7B.

Schmidt, L. T., Gill, K. J., Solomon, P. & Pratt, C. W. (2008).Comparison of service outcomes of case management teams with and without a consumer provider. *American Journal of Psychiatric Rehabilitation, 11*(4), 310-320.

Schmidt, L. T., Gill, K., Solomon, P., & Pratt, C. (2008). Comparison of service outcomes of case management teams with and without a consumer provider. *American Journal of Psychiatric Rehabilitation, 77,* 310-329.

Sells, D., Davidson, L, Jewell, C, Falzer, P, Rowe, M. (2006). The treatment relationship in peer-based and regular casemanagement services for clients with severe mental illness. Psychiatric Services.

Solomon, P. (2004). Peer support/peer provided services: Underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal, 27*(4), 392–402.

Solomon, P., & Draine, J. (1995a). The efficacy of a consumer case management team: 2-year outcomes of a randomized trial, Journal of Mental Health Administration, 22, 135–146.

Solomon, P., & Draine, J. (1995b). One-year outcomes of a randomized trial of consumer case management, Evaluation & Program Planning, 18(2), 117-127.

Solomon, P., & Draine, J. (2001). The state of knowledge of the effectiveness of consumer provided services, Psychiatric Rehabilitation Journal, 25, 20-27.

Stastny, P., & Lehmann, P. (2007). *Alternatives beyond psychiatry*. Berlin: Peter Lehmann Publishing.

Stroul, B. (1986). Approaches to helping persons with long-term mental illness. Rockville, MD: National Institute of Mental Health.

Swarbrick, M. (2007). Consumer-operated self-help centers. *Psychiatric Rehabilitation Journal, 31,* 76-79.

Swarbrick, M., Schnmidt, L., & Gill, K. (2010). Persons in Recovery as Providers of Psychiatric Rehabilitation: The Wisdom of Experience (2010). UPSRA.

The National Association of Mental Health Planning and Advisory Councils. (2007). Promising practices handbook: Strategies to improve the effectiveness of your planning council. From: http://www.namhpac.org/PDFs/PPhandbook.pdf.

U.S. Agency for Healthcare Policy and Research. (1992). Evidence rating guidelines. Washington, DC: Author.

U.S. Department of Health and Human Services (1999). *Mental Health: A Report of the Surgeon General—Executive Summary*. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

Unzicker, R. (1989). On my own: A personal journey through madness and reemergence. *Psychosocial Rehabilitation Journal, 13*(1), 71-77.

Van Tosh, L., & del Vecchio, P. (2000). *Consumer-operated self-help programs: A technical report*. Rockville, MD: U.S. Center for Mental Health Services.

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

Wohlers, M. (2002). *Developing evaluation indicators for consumer and community participation.* Health Issues. No. 72, pp. 24-29.

Zinman, S. (1987). Definition of self-help groups. In S. Zinman, Howie the Harp, & S. Budd (Eds.). *Reaching across: Mental health clients helping each other,* (pp. 7-15). Riverside, CA: California Network of Mental Health Clients.

Zinman, S., Howie the Harp, & Bud, S. (1987). *Reaching across: Mental health clients helping each other.* Riverside, CA: California Network of Mental Health Clients.

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Appendix I
Health Care Reform Recommendations

Health Care Reform recommendations identified by the deliberations of the workgroup were as follows:

- HHS should support piloting of consumer directed integrated medical health homes- funded by reprogramming of block grant funds.

- Health Information Technology efforts need to consider consumer empowerment and access needs. For instance, some mental health peers may need computer training to maximize their use of health information technology. Computer equipment (including personal devices) needs to been more available to people disabled by psychiatric illness and poverty. Taken to a state level, computer assets for patients need to be brought into those psychiatric hospitals and units which do not have them so that people can engage in informed healthcare consumption in those settings.

- Work with insurance commissioner to coordinate the new health benefit – with relevant insurance wraparounds.

- Partner to train new enrollees in use of health insurance.

- With increased reliance on Medicaid risk of losing recovery-based social supports due to medical necessity requirements.

- Partnership between SMHAs and consumers to maintain these needed services.

- Convene a summit that focuses on fully implementing the 2008 Domineci Wellstone Mental Health Parity Bill and behavioral healthcare future.

- With HCR at a bigger level than mental health, and mental health issues being broader than SAMHSA, HHS should develop mechanisms to integrate mental health issues into health care reform including a mental health disparity prevention and review office.

Appendix II
Additional Recommendations for Improving Services and Outcomes

During the deliberations of the workgroup there was a broad ranging discussion of the current state of the national mental health system and strategies for its improvement. The following Recommendations while not directly related to the topic of this report were deemed sufficiently important to our future progress to merit listing here:

- HUD and SAMHSA should work together to mandate anti-discrimination policies and efforts in housing.
- Continue and enhance public information/anti-stigma campaigns, and make sure that they include COS.
- Ensure that contracts and programs require indicators of wellness/health and multi-cultural inclusion.
- Involve NIMH and National Institute on Drug Abuse (NIDA) - in developing and maximizing services to transition age youth, and in ensuring that a tactical plan for HCR maximizes consumer involvement and collaboration.
- Examine EBPs and best practices to reduce "consumer disempowerment." Manualizing coercion n ACT, "secondary coercive measures" in IDDT, and pressuring patients towards injectable antipsychotics in Medication Management all need to be looked at carefully. Similarly, best practices in hospital care which mandate shared decision making, access to advocates, and crisis avoidance/de-escalation need to be manualized and enforced.
- Maximize the collaboration between mental health and public health, including the establishment of medical health home projects.
- Maximize the collaboration between mental health and homeless services.
- Maximize the collaboration between mental health and addiction treatment services to ensure best access to best practices.
- Establish/enhance peer run respite programs.
- Mandate efforts to move people from nursing and adult homes and similar dependent care settings.
- Focus on affordable housing – consumer involvement in public housing options and on boards of directors of public housing authorities.
- Support the national movement toward a holistic approach.
- Partner to become an FQHC.
- Make sure that prescribers use shared decision making and informed consent, and establish a common forum to discuss self directed care and facilitate shared decision making.
- Require prescribers and other mental health provider employees to consult with primary care providers in treatment.
- Consumers should design and facilitate wellness dialogues to retrain existing providers in wellness and recovery.
- Make sure that sites have at least one clinician who has both appropriate skills and training for treating PTSD and the lived experience of combat.
- Offer consumers clear descriptions and "menus" of services offered and what they can and should expect from each service.
- Offer treatment and service planning which addresses the social determinants of health.

Attachment B[20]
10 Components of Recovery

The SAMHSA within the U.S. Department of Health and Human Services and the Interagency Committee on Disability Research in partnership with six other Federal agencies convened the National Consensus Conference on Mental Health Recovery and Mental Health Systems Transformation on December 16-17, 2004.

Over 110 expert panelists participated, including mental health consumers, family members, providers, advocates, researchers, academicians, managed care representatives, accreditation organization representatives, State and local public officials, and others. A series of technical papers and reports were commissioned that examined topics such as recovery across the lifespan, definitions of recovery, recovery in cultural contexts, the intersection of mental health and addictions recovery, and the application of recovery at individual, family, community, provider, organizational, and systems levels. The following consensus statement was derived from expert panelist deliberations on the findings.

Mental health recovery is 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 full potential.

The 10 Fundamental Components of Recovery:

1. **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.

2. **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.

3. **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

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[20] Found on the SAMHSA website at: http://mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/

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.

4. **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.

5. **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.

6. **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, and employee). The process of recovery moves forward through interaction with others in supportive, trust-based relationships.

7. **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.

8. **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.

9. **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.

10. **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.

Resources
www.samhsa.gov
National Mental Health Information Center
1-800-789-2647, 1-866-889-2647 (TDD)

Attachment C
SAMHSA 10 Strategic Initiatives

While in draft form at the time of the workgroup meeting and likely to change, SAMHSA presented the following 10 Strategic Initiatives to focus the Agency's work on improving lives and capitalizing on emerging opportunities. The 10 Initiatives are described below with the Agency lead identified.

1. Prevention of Substance Abuse and Mental Illness - *(Fran Harding, Director, Center for Substance Abuse Prevention)*
Create prevention prepared communities where individuals, families, schools, workplaces, and communities take action to promote emotional health and prevent and reduce mental illness, substance abuse including tobacco, and suicide across the lifespan.

2. Trauma and Justice - *(Larke Huang, Senior Advisor to the Administrator)*
Reduce the pervasive, harmful, and costly health impact of violence and trauma by integrating trauma-informed approaches throughout health and behavioral healthcare systems and to divert people with substance use and mental disorders from criminal and juvenile justice systems into trauma-informed treatment and recovery.

3. Military Families – Active, Guard, Reserve, and Veteran - *(Kathryn Power, Director, Center for Mental Health Services)*
Support of our service men and women and their families and communities by leading efforts to ensure needed behavioral health services are accessible and outcomes are successful.

4. Health Reform - *(John O'Brien, Senior Advisor for Health Finance)*
Broaden health coverage and the use of evidence based practices to increase access to appropriate and high quality care, and to reduce disparities that currently exist between the availability of services for substance use and mental disorders and other medical conditions.

5. Housing and Homelessness - *(Kathryn Power, Director, Center for Mental Health Services)*
Provide housing and reduce the barriers that homeless persons with mental and substance use disorders and their families experience to accessing effective programs that sustain recovery.

6. Jobs and Economy - *(Larke Huang, Senior Advisor to the Administrator)*
Promote the behavioral health of individuals, families, and communities affected by the economic downturn; the employment of people with mental and substance use disorders, and policies for employers that support behavioral health in the workplace.

7. Health Information Technology for Behavioral Health Providers - *(Westley Clark, Director, Center for Substance Abuse Treatment)*
Ensure the behavioral health provider network, including prevention specialists and consumer providers, fully participates with the general health care delivery system in the adoption of health information technology.

8. Behavioral Health Workforce – In Primary and Specialty Care Settings - *(Westley Clark, Director, Center for Substance Abuse Treatment)*
Provide a coordinated approach to address workforce development issues affecting the behavioral health and general health service delivery community to promote the integration of services and

the training and use of behavioral health screening, brief intervention and referral for treatment in primary care settings.

9. Data, Outcomes, and Quality – Demonstrating Results - *(Pete Delany, Director, Office of Applied Studies)*
Realize an integrated data strategy that informs policy, measures program impact, and results in improved quality of services and outcomes for individuals, families, and communities.

10. Public Awareness and Support - *(Mark Weber, Director, Office of Communications)*
Increase understanding of mental and substance use disorder prevention and treatment services to achieve the full potential of prevention and help people recognize and seek assistance for these health conditions with the same urgency as any other health condition.

Attachment D
Dimensions of Wellness

According to Dr. Bill Hettler[21] when most of us think of wellness, we automatically think of physical health. We try to maintain a healthy body and hope that will ward off serious illness in the future. However, while physical health is crucial to good health, wellness has many dimensions beyond the physical. In fact, many experts believe there are 6 dimensions of wellness.

1. **Emotional health**

The emotional dimension recognizes awareness and acceptance of one's feelings. Emotional wellness includes the degree to which one feels positive and enthusiastic about oneself and life. It includes the capacity to manage one's feelings and related behaviors including the realistic assessment of one's limitations, development of autonomy, and ability to cope effectively with stress. The well person maintains satisfying relationships with others. Awareness of and accepting a wide range of feelings in yourself and others is essential to wellness. On the wellness path, you'll be able to express feelings freely and manage feelings effectively. You'll be able to arrive at personal choices and decisions based upon the synthesis of feelings, thoughts, philosophies, and behavior. You'll live and work independently while realizing the importance of seeking and appreciating the support and assistance of others. You'll be able to form interdependent relationships with others based upon a foundation of mutual commitment, trust and respect. You'll take on challenges, take risks, and recognize conflict as being potentially healthy. Managing your life in personally rewarding ways, and taking responsibility for your actions, will help you see life as an exciting, hopeful adventure. Emotional wellness follows these tenets:

- It is better to be aware of and accept our feelings than to deny them.

- It is better to be optimistic in our approach to life than pessimistic.

2. **Spiritual health**
The spiritual dimension recognizes our search for meaning and purpose in human existence. It includes the development of a deep appreciation for the depth and expanse of life and natural forces that exist in the universe. Your search will be characterized by a peaceful harmony between internal personal feelings and emotions and the rough and rugged stretches of your path. While traveling the path, you may experience many feelings of doubt, despair, fear, disappointment and dislocation as well as feelings of pleasure, joy, happiness and discovery - these are all important experiences and components to your search and will be displayed in the value system you will adapt to bring meaning to your existence. You'll know you're becoming spiritually well when your actions become more consistent with your beliefs and values, resulting in a "world view." Spiritual wellness follows these tenets:

- It is better to ponder the meaning of life for ourselves and to be tolerant of the beliefs of others than to close our minds and become intolerant.

- It is better to live each day in a way that is consistent with our values and beliefs than to do otherwise and feel untrue to ourselves.

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[21] Developed by Dr. Bill Hettler, Cofounder and President of the Board of Directors of the National Wellness Institute. Found at: http://www.nationalwellness.org/index.php?id_tier=2&id_c=25

3. **Social health**

The social dimension encourages contributing to one's environment and community. It emphasizes the interdependence between others and nature. As you travel a wellness path, you'll become more aware of your importance in society as well as the impact you have on multiple environments. You'll take an active part in improving our world by encouraging healthier living and initiating better communication with those around you. You'll actively seek ways to preserve the beauty and balance of nature along the pathway as you discover the power to make willful choices to enhance personal relationships, important friendships, and build a better living space and community. Social wellness follows these tenets:

- It is better to contribute to the common welfare of our community than to think only of ourselves.

- It is better to live in harmony with others and our environment than to live in conflict with them.

4. **Occupational health**

The occupational dimension recognizes personal satisfaction and enrichment in one's life through work. At the center of occupational wellness is the premise that occupational development is related to one's attitude about one's work. Traveling a path toward your occupational wellness, you'll contribute your unique gifts, skills and talents to work that are both personally meaningful and rewarding. You'll convey your values through your involvement in activities that are gratifying for you. The choice of profession, job satisfaction, career ambitions, and personal performance are all important components of your path's terrain. Occupational wellness follows these tenets:

- It is better to choose a career which is consistent with our personal values interests and beliefs than to select one that is unrewarding to us.

- It is better to develop functional, transferable skills through structured involvement opportunities than to remain inactive and uninvolved.

5. **Intellectual health**

The intellectual dimension recognizes one's creative, stimulating mental activities. A well person expands their knowledge and skills while discovering the potential for sharing their gifts with others. Using intellectual and cultural activities in the classroom and beyond the classroom combined with the human resources and learning resources available within the university community and the larger community, a well person cherishes intellectual growth and stimulation. Traveling a wellness path, you'll explore issues related to problem solving, creativity, and learning. You'll spend more time pursuing personal interests, reading books, magazines, and newspapers, while keeping abreast of current issues and ideas. As you develop your intellectual curiosity, you'll actively strive to expand and challenge your mind with creative endeavors. Intellectual wellness follows these tenets:

- It is better to stretch and challenge our minds with intellectual and creative pursuits than to become self-satisfied and unproductive.

- It is better to identify potential problems and choose appropriate courses of action based on available information than to wait, worry and contend with major concerns later.

6. **Physical health**

The physical dimension recognizes the need for regular physical activity. Physical development encourages learning about diet and nutrition while discouraging the use of tobacco, drugs and excessive alcohol consumption. Optimal wellness is met through the combination of good exercise and eating habits. As you travel the wellness path, you'll strive to spend time building physical strength, flexibility and endurance while also taking safety precautions so you may travel your path successfully, including medical self-care and appropriate use of a medical system. The physical dimension of wellness entails personal responsibility and care for minor illnesses and also knowing when professional medical attention is needed. By traveling the wellness path, you'll be able to monitor your own vital signs and understand your body's warning signs. You'll understand and appreciate the relationship between sound nutrition and how your body performs. The physical benefits of looking good and feeling terrific most often lead to the psychological benefits of enhanced self-esteem, self-control, determination and a sense of direction. Physical wellness follows these tenets:

- It is better to consume foods and beverages that enhance good health rather than those which impair it.

- It is better to be physically fit than out of shape.

Two additional dimensions are relevant to mental health recovery [22]
1. **Environmental**
The environmental dimension includes our living, learning, and working spaces and the larger communities where we participate as citizens. Good health can be fostered by occupying pleasant, stimulating environments that support our well-being. Additionally, good health can be enhanced by places and spaces that promote learning, contemplation and elicit the relaxation response. Being able to be and feel physically safe, in safe and clean surroundings, and able to access clean air, food, and water.

2. **Financial**
The financial dimension refers to the *objective* perceptions and *subjective* indicators of individuals' personal financial status. *Objective indicators may i*nclude measures such as income, debt, savings and aspects of financial capability such as knowledge of financial products and services, planning ahead and staying on budget. Subjective indicators may include an individuals' perception of satisfaction with current and future financial situation.

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[22] Swarbrick, M (2010, January 18). Defining wellness. *Words of Wellness,* Volume 3, No. 7.

Attachment E
Additional Resources

National Center for Mental Health Services Technical Assistance Centers
National Consumer Supporter Technical Assistance Center
This center supports organizations providing services for mental health consumers, survivors and ex-patients by providing technical assistance in the forms of research, informational materials, and financial aid. Based in Alexandria, VA. (800) 969-6642. Website located at: http://www.ncstac.org/

National Empowerment Center
This independent group, including survivors of mental institutions, advocates, civil rights activists, mental health workers, and lawyers, exposes abuse and promotes alternatives to the mental health system. Based in Lawrence, MA. (800) 769-3728. Website located at: http://www.Power2u.org

National Mental Health Consumers' Self-Help Clearinghouse
This consumer-run Philadelphia-based resource center, the first of its kind, specializes in self-help and advocacy. The clearinghouse offers technical assistance, publication, toolkits and maintains a directory of Consumer-Driven Services. The directory provides consumers, researchers, administrators, service providers, and others with a comprehensive central resource for information on national and local consumer-driven programs. (800) 553-4539. Website located at: http://www.mhselfhelp.org

Support Technical Assistance Resource (STAR) Center
This center, based in Arlington, VA, develops, produces, disseminates, and stores a wide range of culturally appropriate materials, resources, and tools for consumers, consumer-operated programs and self-help groups that strengthen skills, organizational capabilities, and service capacity. All materials and technical assistance services are accessible through this website a national toll-free telephone number, (866) 537-STAR (7827), E-newsletters, and a resource library. The website offers resources by community (from African American to Asian, Latino, and more), and is also translated into Spanish El Centro STAR. Website located at: http://www.consumerstar.org/

Attachment F
Quality Interagency Coordination Standards

The Quality Interagency Coordination Task Force (QuIC) was established in 1998 in accordance with a Presidential directive. The purpose of the QuIC was to ensure that all Federal agencies involved in purchasing, providing, studying, or regulating health care services were working in a coordinated manner toward the common goal of improving quality care. QuIC Standards for the Involvement of Consumers, Youth, and Family Members in Mental Health Quality Improvement Activities follow.

Individual Consumer and Youth Level:

1. Consumers and youth are informed about what they might expect and possible outcomes of the services and/or supports available to them.
2. Consumers and youth are informed about alternatives and service and support options, including those available through other agencies or organizations.
3. Consumers and youth are involved in making decisions with providers about their goals, their recovery plan, and the services and/or supports they will use.
4. Consumers and youth are involved in the scheduling of meetings and appointments to discuss the care provided to them.
5. Consumer and youth availability, transportation, and childcare needs are considered to ensure them the opportunity to attend scheduled meetings.
6. Consumers and youth are encouraged to include family members, friends, and other people they consider supportive in planning and implementing their care.
7. Consumers and youth are offered opportunities to provide direct feedback to providers regarding the quality of care at the time it is delivered.
8. Consumers and youth are informed of how and whom to contact when they have concerns or wish to make changes in their care.
9. Consumers and youth are informed about and have ready access to formal grievance procedures to address their dissatisfactions with care.
10. Consumers and youth receive a respectful and timely response when raising a complaint or filing a grievance.
11. Consumers and youth are assured that they will not suffer any consequences for offering their feedback or input regarding the quality of care received.
12. Consumers and youth are offered opportunities, and provided with resources, to integrate their cultural, racial, and ethnic affiliations and identity into their care. Culture is defined broadly to include sexual orientation, gender, religious preferences, and family members, including domestic partners, spouses, and siblings.
13. Consumers and youth are invited to report their level of satisfaction with care on a regular and ongoing basis.
14. Consumers and youth are invited to assist in designing the methods and measures the agency will use to determine satisfaction with care.
15. Consumers and youth are offered preparation and support if needed to participate in quality improvement activities.
16. Consumers and youth are invited to participate in the evaluation and monitoring of service outcomes.
17. Consumers and youth are invited to be involved in developing and conducting needs assessments.
18. Consumers and youth are invited to be involved in identifying priorities for resource allocation.

19. Consumers and youth are invited to be involved in the design and development of new services and supports.
20. Consumers and youth are offered reimbursement for participation in quality improvement activities.

Individual Family Member Level:

1. Family members are informed about what they might expect and possible outcomes of the services and/or supports available to them and to their loved ones.
2. Family members are informed about alternatives and service and support options for them and for their loved one, including those available through other agencies or organizations.
3. Family members are involved in all decisions about their loved one, his or her recovery plan, and the services and/or supports they will use, as their loved one chooses.
4. Family members are offered the opportunity to be included in support of their loved one's recovery and at meetings to the extent that their loved one chooses.
5. Family members are involved, to the extent that their loved one chooses, in the scheduling of meetings and appointments concerning their loved one's care.
6. Family members' availability, transportation, and childcare needs are taken into consideration to ensure them the opportunity to attend scheduled meetings.
7. Family members are offered opportunities to provide direct feedback to providers regarding the quality of care at the time it is delivered to them or to their loved one.
8. Family members are informed of how and whom to contact when they have concerns or wish to make changes in their care or in that of their loved one.
9. Family members are informed about and have ready access to formal grievance procedures to address their dissatisfactions with care.
10. Family members receive a respectful and timely response when raising a complaint or filing a grievance.
11. Family members are assured that they will not suffer any consequences for offering their feedback or input regarding the quality of care received by them or by their loved one.
12. Family members are offered opportunities, and provided with resources, to integrate their cultural, racial, and ethnic affiliations and identity into their loved one's care. Culture is defined broadly to include sexual orientation, gender, religious preferences, and family members, including domestic partners, spouses, and siblings.
13. Family members are invited to report their level of satisfaction with care on a regular and ongoing basis.
14. Family members are invited to assist in designing the methods and measures the agency will use to determine satisfaction with care.
15. Family members are offered preparation and support if needed to participate in quality improvement activities.
16. Family members are invited to participate in the evaluation and monitoring of service outcomes.
17. Family members are invited to be involved in developing and conducting needs assessments.
18. Family members are invited to be involved in identifying priorities for resource allocation.
19. Family members are invited to be involved in the design and development of new services and supports.
20. Family members are offered reimbursement for participation in quality improvement activities.

Agency Level:

1. Agencies inform consumers, youth, and family members about what they might expect and possible outcomes of the services and/or supports available to them.

2. Agencies inform consumers, youth, and family members about alternatives and service and support options, including those available through other agencies or organizations.
3. Agencies involve consumers, youth, and family members in making decisions about their goals, their recovery plan, and the services and/or supports they will use.
4. Agencies involve consumers, youth, and family members in the scheduling of meetings and appointments to discuss the care provided to them.
5. Agencies consider the availability, transportation, and childcare needs of consumers, youth, and family members to ensure them the opportunity to attend scheduled meetings.
6. Agencies encourage consumers and youth to include family members, friends, and other people they consider supportive in planning and implementing their care.
7. Agencies offer consumers, youth, and family members' opportunities to provide direct feedback to providers regarding the quality of care at the time it is delivered.
8. Agencies inform consumers, youth, and family members about how and who to contact when they have concerns or wish to make changes in their care.
9. Agencies inform consumers, youth, and family members about, and ensure their ready access to, formal grievance procedures to address their dissatisfactions with care.
10. Agencies ensure that consumers, youth, and family members receive a respectful and timely response to any concerns they raise or grievances they file.
11. Agencies ensure that consumers, youth, and family members are offered opportunities, and provided with resources, to integrate their cultural, racial, and ethnic affiliations and identity into their care. Culture is defined broadly to include sexual orientation, gender, religious preferences, and family members, including domestic partners, spouses, and siblings.
12. Agencies ensure that consumers, youth, and family members will not suffer any consequences for offering their feedback or input regarding the quality of care received.
13. Agencies invite consumers, youth, and family members to report their level of satisfaction with care on a regular and ongoing basis.
14. Agencies invite consumers, youth, and family members to assist in designing the methods and measures the agency will use to determine satisfaction with care.
15. Agencies offer consumers, youth, and family members' preparation and support, if and when needed, to participate in quality improvement activities.
16. Agencies invite consumers, youth, and family members to participate in the evaluation and monitoring of service outcomes.
17. Agencies invite consumers, youth, and family members to be involved in developing and conducting needs assessments.
18. Agencies invite consumers, youth, and family members to be involved in identifying priorities for resource allocation.
19. Agencies invite consumers, youth, and family members to be involved in the design and development of new services and supports.
20. Agencies offer consumers, youth, and family members' reimbursement for participation in quality improvement activities.
21. Agencies use various forms of input as well as findings of consumer, youth, and family member satisfaction surveys, to improve care.

System Level:

1. Systems establish and hold to standards for the meaningful involvement of consumers, youth, and family members in quality improvement activities at all levels of the system.
2. Systems ensure that consumers, youth, and family members are informed of the range of opportunities available for them to become involved in improving the quality of the system of care as a whole.

3. Systems value the contributions of consumers, youth, and family members to their quality improvement activities, make changes based on these contributions, and offer feedback to consumers, youth, and family members about changes made in response to their input.
4. Systems ensure that consumers, youth, and family members comprise at least 51% of representatives on all boards, steering and advisory councils, and workgroups making decisions about evaluations of the quality of care provided by the system.
5. Systems have a process in place that outlines what to do and who to contact when a complaint or concern is not addressed at the agency level in a timely manner.
6. Systems ensure that consumers, youth, and family members receive a respectful and timely response to any concerns they raise or grievances they file.
7. Systems ensure that consumers, youth, and family members will not suffer any consequences for offering their feedback or input regarding the quality of care received.
8. Systems invite consumers, youth, and family members to report their level of satisfaction with care on a regular and ongoing basis.
9. Systems invite consumers, youth, and family members to assist in designing the methods and measures the agency will use to determine satisfaction with care.
10. Systems ensure that consumers, youth, and family members are partners in the development and review of new policies and legislative initiatives.
11. Systems ensure that consumers, youth, and family members are partners in strategic planning, needs assessments, priority setting, and resource allocation decisions.
12. Systems ensure that consumers, youth, and family members are partners in establishing expectations for system performance.
13. Systems ensure that consumers, youth, and family members are partners in evaluating and monitoring the effectiveness of care and of efforts to promote awareness, health, and wellness.
14. Systems recruit diverse groups of consumers, youth, and family members who are representative of the populations served to take active parts in both ongoing and focused agency quality improvement activities. Diversity includes ethnic and cultural minorities; lesbian/gay/ bisexual/transgender individuals; religious preferences; and family members, including domestic partners, spouses, and siblings.
15. Systems prepare and support consumers, youth, and family members in the various roles they play in both ongoing and focused quality improvement activities.
16. Systems demonstrate the value they place on the contributions of consumers, youth, and family members to their quality improvement activities by reimbursing them financially and otherwise for their time.

Attachment G
Consumer Involvement Standards

The current version of these Consumer Involvement Standards is a draft as they are undergoing slight modifications by a sub-committee of the Evaluation Workgroup. Once all measurement tools have been developed these standards will become Final. The public comment period is closed and no changes will be made to the current version of the Consumer Involvement Standards as a result of the public (in any capacity) viewing this document.

Standards: Consumer Involvement in Transformation
08-07-2009; Consumer Involvement Study Team

Standards for Consumer Involvement in Transformation

Individual Rights at the Provider Level Consumer Involvement Standards

1) **Planning Recovery** – The individual consumer is the most important participant in the development of his/her individual recovery.
   Practices:
   a) Agencies submit a list of tools, assessments; tests to a Consumer Review Board (a board comprised of consumers in recovery and representative of state consumers) required of all state run and contracted facilities reviewed through certification process.
   b) Credentialed Peer Recovery Support Specialist (CPRSS) available at each Community Mental Health Center and or Substance/Addiction Centers and satellites for assistance in planning recovery.
   c) Individuals are given all information on tests, assessments, and diagnosis
      (1) Contract requirement – Community Mental Health/Substance Abuse Centers will have a form signed by the consumer to indicate they have received assessment and diagnosis (Check box on client data core (CDC).
      (2) The information received is presented in a strengths based clear and understandable manner (user-friendly considering global assessment of functioning (GAF) scores to incorporate/develop the delivery of information to the individual)
   d) Individuals are given the opportunity to complete a participant review or survey to contribute their feedback on their recovery plan development process for future program development.

2) **Support** – Individual consumers have the information to choose/select their support systems and or treatment options.
   Practices:
   a) Individuals are given all information about availability of treatment options, resources, and or recovery tools:
      (1) Advocacy agencies contact information and contact person
      (2) Treatment advocate
      (3) Credentialed Recovery Support Persons for assistance and support
      (4) Cognitive Behavioral Therapy (evidenced based practice - EBP)
      (5) Wellness Recovery Action Plan (WRAP), Evidenced Based Treatment (EBT)
      (6) Medications and medication management

(7) Available groups and internet resources

(8) Applicable trainings for all employment including community and employment assistance programs (EAP) Ex: Advocacy issues, laws, understanding legislature and leadership opportunities, managing work and health issues of any nature.

3) Have a RESOURCE room Open 8:00 a.m. to 8:00 p.m.

    i) Operated by consumers, family, Credentialed Peer Recovery Support Specialist et al

    ii) Stock/inventory is available through State Resource centers Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS), League of Blind, Department of Vocational Rehabilitation (DRS) , Advocacy agencies)

    iii) STATEWIDE Recovery Website: Governor appoints hosting agency yearly to achieve sustainability (state separate funding.)

    iv) Collaborative project with individuals receiving all statewide services – has interactive map to pinpoint services available.

    v) Blog for public comments

    vi) Bulletin board for updates throughout the state on recovery

    vii) HOW TO section on applying for services/benefits etc.

    viii)   In your community – updates on rural information (cultural diversity) Website – designed and run by consumers.

4) **Consumer Concerns** – Individuals know who to contact about concerns and complaints and how to resolve these issues.

    Practices:

a) Public service announcements – design input given by individuals who have received those services.

b) The intake process will include accounting for receiving information relating to advocacy, legal, contact information.

c) All American's with Disabilities Act and/or all other applicable laws followed

d) Confidential (survey monkey) survey question

e) Must sign receipt of information (unless incapacitated, then treatment advocate signs)

f) Must sign and make a selection for treatment advocate or sign that they decline same.

5) **Access** – Consumers are admitted at a single site for mental health, substance abuse and/or other addictive disorders (no wrong door).

    Practices:

a) When needing a resource or referral assistance in appointment setting and or contacting resource process is provided by Credentialed Peer Recovery Support Specialist

b) Staff completing an online confidential survey to evaluate ability to meet the needs of the individual (why or why not additional resources made)

c) Agency to report to funding sources results of staff/participants surveys

d) Agency keeps track of (%) percentage of Credentialed Peer Recovery Support Specialist staff (paid and volunteer) at agencies that would be available to assist in locating conducting groups with clients/families or selecting resources such as: client selecting resources such as:

    (1) Substance Abuse

    (2) Mental Health

    (3) Gambling

    (4) Other addictive disorders (eating, sexual, internet porn,)

    (5) Multicultural issues in seeking services

    (6) Trauma, sexual abuse, veterans, Post Traumatic Stress Disorder

    (7) Peer to peer for professionals living with (all of the above)

    (8) Self mutilation, Kleptomania, Compulsions,

(9) Co-morbidity, Mental Health, Substance Abuse other addictions and disabilities

(10)   Whether participant/inquirer received a follow up phone call/appointment

6) **Advocacy** – Individual consumers know what advocacy organizations will represent them to address their needs, concerns and or complaints and how to contact those agencies to resolve their issues:
   Practices:
   a) ALL state funded or state contracted providers in Oklahoma will publicly display as a service to the community brochures, flyers, fact sheets, from ALL advocacy agencies civil, military, drug court, mental health - substance abuse court, liaison and defense in clear accessible areas.
   b) Resources will be located again in the individual's personal intake materials folder/packet
   c) Reviewed evidence of receipts during certification site visits
   d) Consumer satisfaction surveys will ask and determine effectiveness of site's advocacy accessibility

Community Level Consumer Involvement Standards

For the purposes of this document, a community is a self defined and identified group (such as groups defined geographically, socially, demographically, or culturally)

1) **Community Boards** – Boards (relating to mental health, substance abuse and/or other addictive disorder services) adopt ongoing strategies that ensure consumer involvement.
   Practices:
   a) Communities will inform the CIAG of their coalition by enrolling in the outreach information exchange network. Participation from communities may be drawn from:
      i. Advisory Boards (4 Community Mental Health Center, Advocacy)
      ii. Substance abuse/de-toxification treatment centers
      iii. Drug Court
      iv. Mental Health court/transitional housing (residential)
      v. Sober Houses/assisted living/long term residential (Long Term Care)
      vi. Faith based housing
      vii. Grievance committee
      viii. Policy and program development
      ix. Leadership boards
   b) Communities will work with the CIAG to access training for the development of community level support groups (for example):
      i. peer support groups
      ii. Depression Bipolar Support Alliance trainers
      iii. Wellness Recovery Action Planning trainers
      iv. Question Persuade and Refer – Suicide Prevention Program

2) **Support Groups** – Consumer support group strategies and service delivery are based on continuous, on-going consumer involvement.
   Practices:
   a) Communities will ensure wellness programs and support groups are accessible (e.g., Suicide Brief Intervention Referral or Treatment, Question Persuade and Refer, Wellness Recovery Action Plan, et al).
   b) Communities designed outreach activities with the involvement of consumers.

3) **Health Services** – Communities will work with local healthcare providers to promote cross training of in Credentialed Peer Recovery Support Specialist's primary health care.
   Practices:
   a) Hospitals, Urgent Care, Home Health, Nursing Homes

4) **Community Based Behavioral Health Service Providers** – The community will facilitate connections between consumers and local community based service providers to co-design service delivery plans, how they are carried out and evaluated by using the input and needs of local consumers.
   Practices:
   a) Communities will submit to the CIAG annual reviews of services/programs to be evaluated by the CIAG for reporting on a statewide web-system.

State Level Consumer Involvement Standards

For the purposes of this document, behavioral health includes consumers of mental health, substance abuse, and other addiction disorder and trauma services.

1) **Development of a Consumer Involvement Advisory Group (CIAG) –** An independently funded CIAG will be developed with assistance of state agencies and will be provided with advisory and support staff as requested.
   Practices:
   a) A formalized statewide Consumer Involvement Advisory Group (CIAG) is established with input from Consumer Advocacy Organizations, this group will include:
      i) The CIAG is comprised of behavioral health consumers
      ii) At least one representative to speak for each region of the state
      iii) At least one representative to speak for rural and urban populations
      iv) At least one representative to speak for culturally/ethnically diverse populations
      v) At least one representative to speak for incarcerated populations
      vi) At least one representative to speak for all age groups
      vii) At least one representative to speak for all other historically under-served populations (example: veterans, deaf and hard of hearing, gay, lesbian and transgender, etc.)
      viii) The CIAG has a minimum of 20 voting members and a membership at large to assist when voting members are unavailable
      ix) CIAG officers will rotate yearly
      x) The CIAG meets at a minimum of quarterly and on an "as needed basis"
      xi) Electronic Communication utilized for full participation
         (1) Telecom/videoconferencing
         (2) Website
            (a) CIAG members have access to the following tools and are provided information on how to access and use them:
               (i) Internet capabilities
               (ii) Teleconference equipment
               (iii) Computers

2) **Funding and Allocations** – CIAG/Advocacy Organizations are directly involved in behavioral health strategic planning to include grant application submissions, funding and distribution processes.
   Practices:
   a) The CIAG will be provided copies of all grant applications at the time of submission.

b) For behavioral health grant applications, State agencies have consumer involvement strategies identified, planned, and documented for each stage/level of state behavioral health grant funded program development using input from the CIAG.

c) CIAG is notified of results of grant application submissions in a timely manner.

3) **Policy Development and Program Implementation** – To ensure effective program development and implementation consumers are involved, through the CIAG, in the development of state agency behavioral health policies, legislative initiatives, and strategies.
   Practices:
   a) State agencies, with input from the CIAG, have consumer involvement strategies identified, planned, and documented for each stage/level of state behavioral health program development.
   b) Consumer involvement strategies are planned and documented to address issues identified through the evaluation process.
   c) The CIAG is consulted early and through-out the process of establishing and revising behavioral health policies and/or programs.
   d) The CIAG is consulted early and through-out the process of the establishment of state agency behavioral health legislative initiatives.

4) **Needs Assessment and Evaluation** – Consumers are involved, through the CIAG, in the development of state-level behavioral health needs assessment.
   Practices:
   a) National Studies:
      i) When evaluations are conducted using national data sets, study results are provided to the CIAG and posted on a publically accessible web-site.
   b) State Agency and Advocacy Organization Studies:
      i) Evaluation instruments are developed and updated using input from the CIAG.
      ii) The CIAG will review existing assessment instruments on an annual basis.
      iii) State Agencies/Advocacy Organizations will present results of all needs assessments and evaluation studies to the CIAG.
      iv) Results of current studies will be posted on a publically accessible web-site.

5) **Outreach** – Outreach activities and public educational campaigns related to behavioral health are developed with involvement from consumers, through the CIAG.
   Practices:
      i) Media Work Group Outreach
         (1) A formalized statewide Media Work Group (MWG) is established as a sub-workgroup of the CIAG and has a minimum of 5 voting members but not more than 10 voting members.
      ii) The MWG is responsible for the establishment of a statewide theme operating with a unified consumer voice including grassroots, consumer-run messages. The MWG will utilize public service announcements and locally produced radio/TV programs and news media to promote the statewide theme.
      iii) The CIAG will identify and work with new and existing community resources to ensure consumer involvement in adopting community specific strategies relating to behavioral health.
         (1) The CIAG will develop and maintain an Outreach Information Exchange Network (OIEN).
      iv) Community Campaigns – State or federally funded education/media campaigns will be co-designed with the CIAG.
         Practices:

(1) Community campaign workgroups are lead by CIAG regional representatives to ensure rural/urban specific community coverage and messages are user friendly and easily understood. (jargon monitoring and community education).

(2) Samples of campaigns that affect consumers: Transportation, Housing, Adult Protective Services, Child Support Enforcement, Crisis Services, Department of Human Services, Faith Based Services., Aging Services, tribal providers and the providers in all 77 counties/communities.

6) **Ethics and Civil Rights** – A comprehensive process for the legal protection of individual rights and grievance procedures is developed and maintained with involvement from the CIAG.
   Practices:
   a) The CIAG will collaborate with the Oklahoma Law Disability Center for education/support.
   b) All state-operated/contracted provider facilities must have a grievance procedure prominently posted.
   c) All state-operated/contracted provider facilities must have a minimum of 2 consumers on their facility grievance team.

7) **Early Intervention/Prevention** – Consumers, through the CIAG, are involved in the development and implementation of intervention and prevention strategies for behavioral health disorder programs.
   Practices:
   a) Behavioral health service providers when developing Consumer Run Wellness Centers will seek collaboration and register with the CIAG.
   b) Behavioral health service providers will have Credentialed Peer Recovery Support Specialist or have training for wellness coordinators.
   c) Behavioral health service providers, in collaboration with the CIAG, will develop and implement strategies for behavioral health education, awareness, support group trainings, and networking for primary care providers in the provider service areas.
   d) Behavioral health service providers will make behavioral health education and support groups available for primary care providers offering opportunities for education and networking.
   e) The CIAG will collaborate with Council on Law Enforcement Education and Training (CLEET) to develop a behavioral health law enforcement training standard.
   f) The CIAG will collaborate with the Oklahoma State Department of Education to develop behavioral health education strategies.

8) **Consumer Satisfaction and Rating Services** – Behavioral Programs in collaboration with the CIAG will develop tools and processes to obtain annual feedback from consumers to measure the effectiveness of agency programs, which will be used to improve program performance.
   Practices:
   a) Behavioral health service providers, with collaboration from the CIAG, will develop a consumer satisfaction survey.
   b) Behavioral health service providers will conduct annual surveys to determine consumer satisfaction relating to the services provided during the year.
   c) Survey results will be provided to the CIAG for review within 120 days of the annual survey period.
   d) The CIAG will provide a suggested enhancement, remediation, or correction plan based on the results of the annual survey within 120 days.

9) **Consumer Employment** – With the assistance of the CIAG, state agencies that provide behavioral health services will develop and implement strategies for all levels of the workforce to remove stigma and discrimination practices related to behavioral health. State agencies that support/provide behavioral health services:
   <u>**Practices:**</u>
   a) **Recruitment, Training, and Retention**
      i) The CIAG will develop, with assistance from Behavioral Health State Agencies and Behavioral Health Service Providers, an Optimal Utilization Ratio (OUR) of Credentialed Peer Recovery Support Specialist staff to consumers. The Optimal Utilization Ratio will be incorporated into contracts in order to encourage agencies to strive to meet the Optimal Utilization Ratio standard established.
      ii) State agencies shall incorporate requirements to report Credentialed Peer Recovery Support Specialist staff to consumer ratio. Agencies falling 50% below the Optimal Utilization Ratio standard are required to establish and implement a plan to improve the Optimal Utilization Ratio.
      iii) The Credentialed Peer Recovery Support Specialist credentialing agency shall develop a public website, with input from the CIAG, to include at a minimum information on:
         (1) The benefits of becoming a Credentialed Peer Recovery Support Specialist
         (2) Education on the benefits of hiring Credentialed Peer Recovery Support Specialist staff
         (3) Credentialed Peer Recovery Support Specialist training and CEU opportunities
         (4) Employment Opportunities
         (5) Credentialed Peer Recovery Support Specialist Employer Training
      iv) The State shall develop programs to incentivize consumers to become Credentialed Peer Recovery Support Specialist's in Oklahoma.
      v) The State shall develop programs to incentivize Credentialed Peer Recovery Support Specialist's to seek further education in the behavioral health field.
      vi) State agencies will maintain the Credentialed Peer Recovery Support Specialist's Optimal Utilization Ratio by developing retention strategies.
   b) **Employee Assistance Programs (EAP)**: All State Agencies EAP's will integrate behavioral health, recovery services and best practices into its overall benefits.
      i) Employee Assistance Programs (EAP) includes Credentialed Peer Recovery Support Specialist's in some non-clinical or advisory capacity.
      ii) Employee wellness information workshops and support groups will be available and conducted by individuals with lived experience equally with clinical or professional speakers.
      iii) Recovery Relapse Support Programs are available.