

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION
CENTER FOR MENTAL HEALTH SERVICES**

**NATIONAL ADVISORY COUNCIL
SUBCOMMITTEE ON CONSUMER/SURVIVOR ISSUES
ROCKVILLE, MARYLAND
FEBRUARY 14-15, 2005**

Welcome and Introductions

Larry Fricks, Chair, Subcommittee on Consumer/Survivor Issues, Substance Abuse and Mental Health Services Administration (SAMHSA)/Center for Mental Health Services (CMHS) National Advisory Council, called the meeting to order on February 14, 2005, at 9:35 a.m. Other Subcommittee members present included D.J. Ida, Ph.D., J. Rock Johnson, J.D., Maria Maceira-Lessley, Patrick Risser, and Paula Stockdale.

Members reported on their activities and interests, and members of the audience introduced themselves. Ms. Johnson stated that Nebraska plans to close two of its three State mental hospitals. Dr. Ida noted that the National Asian American Pacific Islander Mental Health Association plans to develop a national consumer network. Mr. Risser reported that Oregon is contemplating building a new State hospital building. Mr. Fricks noted that Georgia State offices have reorganized, and he now serves as director of the Office of Consumer Relations and Recovery. Ms. Maceira-Lessley explained that California's new Mental Health Services Act taxes millionaires 1 percent of their income, with the funds earmarked for mental health services. Ms. Stockdale stated that uncertainty about the future of TennCare leads to concerns that Tennessee consumers may lose their insurance and assistance with medications.

Old Business

Update on Subcommittee Vacancies. *Chris Marshall, Consumer Affairs Specialist, CMHS*, reported that CMHS has submitted the Subcommittee's three nominations for membership to SAMHSA Administrator Charles Curie for his approval. Ms. Maceira-Lessley's term expires in November 2005.

Status of Recommendations. Mr. Marshall described the status of selected Subcommittee recommendations to the National Advisory Council. Regarding trauma, CMHS is nearing completion of trauma training curricula; a consumer leadership program is developing a Trauma Champions Institute; increased access is anticipated for consumers to the Department of Justice's crime victims' compensation fund; and CMHS is engaging in negotiations with the Health Resources and Services Administration (HRSA) and the Centers for Disease Control (CDC). CMHS has awarded a contract to begin development of a consumer-operated website for

consumers, and the Recovery Self-Report Instrument is close to readiness for field testing. CMHS has held meetings to develop a strategy for consumer direction, initiated a self-direction education project, and engages in regular collaboration with the Centers for Medicare and Medicaid Services (CMS). In response to a recommendation that States fund the application of evidence-based research findings under the transformation State Incentive Grants (SIGs), CMHS has developed a draft crisis residential treatment manual; comments were solicited.

Minutes, Subcommittee Meeting, August 30-31, 2005, and Miscellaneous. Consideration of the minutes of the previous Subcommittee meeting was tabled. Plaques were sent to former Subcommittee members Sharon Yokote, Sylvia Caras, Ph.D., and Jon Brock in appreciation for their contributions.

Status of Recommendations (cont.) Mr. Fricks reported that the CMHS National Advisory Council adopted all Subcommittee recommendations submitted at the September 2004 meeting. CONTAC will host a meeting on peers and trauma in April. Release of the curriculum is to be released this year. Mr. Fricks noted that \$20 million in FY2005 transformation SIG grants will be released soon and urged that CMHS engage in activities to bridge silos, focus on strengths-based recovery, and strengthen peer services to reflect consumer-driven models. Mr. Risser stated his hope that transformation SIG grants will reflect attitudinal shifts toward recovery. Dr. Ida emphasized the values of consumer driven and cultural competence, urging that communities of color be represented in discussions of service delivery design.

User Movement in the United Kingdom

Professor Antony Sheehan, Director, Care Services, Department of Health, United Kingdom, described the “user” movement in the United Kingdom, analogous to the U.S. mental health consumer movement. He considers the best definition of recovery to be “individual journeys with some unknown destinations, with stopping-off points such as use of the mental health system.” He noted that recovery is built into UK efforts and that understanding recovery is a challenge. Mental health services in the UK are based on inclusion, choice of services, and a resulting personalization of the journey to recovery.

In discussion, Mr. Risser noted the importance of the mental health system focusing on health, not illness. Ms. Johnson expressed interest in challenges that exist to getting supports. Ms. Stockdale noted that people of color often do not access traditional services, but that mutual support is often offered and found online. Mr. Fricks noted that supported employment is an important need of many consumers. Prof. Sheehan stated that the U.S. consumer movement has informed his country about vocational issues. Most mental health services in the United Kingdom employ people who are consumers; consumer input informs most training curricula; challenges include eligibility for aid and having a voice at the table; among the best service providers are those established by consumers who were dissatisfied with other services; and trauma is a major issue for consumers. Prof. Sheehan noted that mental health services account for 12 percent of the National Health Service budget. Reforms are sought to shift the system more to prevention and to work across the government.

Public Comment

Ramiro Guevara, Director, NAMI Support, Technical Assistance, and Resource Center (STAR), discussed the need for culturally relevant materials; the overarching goal is to provide technical assistance to ensure that consumer-operated programs have relevant information. The center will host teleconference calls, one-day events, forums for networking, and leadership opportunities. He asserted that Web-based technology can help people reach out anonymously.

CMHS Director's Report

A. Kathryn Power, M.Ed., described CMHS activities to transform the nation's mental health system, organized by the goals identified by the President's New Freedom Commission on Mental Health (see sidebar). Regarding Goal 1, CMHS has initiated the National Anti-Stigma Campaign, Elimination of Barriers Initiative, ADS Center, National Strategy for Suicide Prevention, and efforts to strengthen Medicaid's role in mental health care as a payer. For Goal 2, CMHS engages in discussions about individualized recovery plans, hosted a national consensus dialogue meeting in December 2004 on recovery, and focuses on consumer-operated and peer support services. CMHS convened a Consumer Direction Initiative summit to elicit recommendations from consumers and other stakeholders; Ms. Power asked Council members for their input. Other activities include the Community Mental Health Services Block Grant program with its 10 new outcome measures, diversion from the criminal justice system, and in-service training on seclusion and restraint.

Goal 3 activities include training grants for providers who serve minority populations and increased funding for the Minority Fellowship Program for FY2005 and FY2006; Ms. Power urged outreach to encourage participation. CMHS activities in support of Goal 4 include early mental health assessment, and referral; youth violence prevention, including an anti-bullying campaign; COSIG grants that integrate mental health and substance abuse treatment; a Policy Academy on co-occurring mental health and substance abuse disorders; services for older adults; and primary care research on services for the elderly.

Goal 5 activities include continuing a variety of work to encourage practitioners to implement evidence-based and best practices to reflect what consumers want and need, Annapolis Coalition activities to develop a SAMSA national strategy for workforce development, and launching the Women and Trauma Service Resource Center to offer technical assistance to States. Goal 6 activities include the Web-cast Rural Mental Health Grand Rounds Training Series.

New Freedom Commission Goals

1. Americans understand that mental health is essential to overall health.
2. Mental health care is consumer and family driven.
3. Disparities in mental health services are eliminated.
4. Early mental health screening, assessment, and referral to services are common practice.
5. Excellent mental health care is delivered and research is accelerated.
6. Technology is used to access mental health care and information.

In 2005 and beyond, CMHS will create a Transformation Action Center to provide comprehensive, coordinated technical assistance to support transformation SIGs. Technical assistance will focus on specific proposed activities to promote sustained consumer leadership development, development of comprehensive mental health plans, individualized plans of care, reduction/elimination of disparities, continuation of the National Registry of Effective Programs and Practices (NREPP), and workforce development. New toolkits for evidence-based practices will be developed for supported housing, aging, consumer-operated services, and children. CMHS will collaborate to develop a model comprehensive State mental health plan to enable States to engage in an enhanced planning process through collaboration with other stakeholders. CMHS will develop a strategic plan with key constituents to provide the workforce of the future. Ms. Power stated that all CMHS's work in FY2005 will focus on transformation. All grant opportunities will be posted at www.grants.gov.

Discussion. Mr. Fricks stated that the Subcommittee encourages SIG grants to fund recovery-oriented initiatives. Mr. Risser stated that consumers are often not diverted from jail. He suggested using the term *multiply diagnosed* to reflect a holistic approach. He urged learning about leadership development not only from academics, but also from consumer leaders and consumers in the workforce. Ms. Power responded that CMHS plans to develop a curriculum based on theory and practice, not only experience. She stated that *dual diagnosis* is important from a treatment standpoint, and that it be important in the transformation process to develop healing and therapeutic relationships that do not isolate a particular diagnosis.

Ms. Power reported that consumers at the Mental Health Policy Forum stated that they want opportunities to demonstrate their leadership and to be providers. Ms. Maceira-Lessley noted that leadership among consumers of color is different from the mainstream. Ms. Stockdale noted the need to look at the needs of people who live in poverty. Ms. Power stated that CMHS is looking broadly at the needs of people who are uninsured and underinsured, barriers to full coverage, public payer programs, and private insurance. Ms. Johnson urged strong consumer involvement in selecting evidence-based practices, including attention to innovation. Ms. Power stated that a large consumer group worked on identifying best practices, and selection of toolkits was based on consumer input. She concurred with the need for openness to consumer experiences. Mr. Fricks offered Subcommittee members' services in briefing grant reviewers on the concepts of recovery and consumer power.

Public Comment (cont.)

Judene Shelley, Director, Consumer Technical Assistance Center, announced that the National Empowerment Center will host the Alternatives Conference to be held October 26-30, 2005, in Phoenix, following an October 25 meeting of statewide networking grantees. Scholarships for Alternatives are available from SAMHSA and NAMI. The national advisory board includes 19 consumer/survivors in planning, and a call for papers soon will be posted on the website.

Kathy Muscari, Director, Consumer Organization and Networking Technical Assistance Center (CONTAC), described CONTAC's consumer leadership opportunities, including Leadership Academies, training on providing trauma-informed peer support, and collaboration with the National Empowerment Center to help peers understand basic research and evidence-

based practices in the context of grants and RFAs. CONTAC expects to pilot a training series on wellness and recovery in relation to housing programs, forensic units, and peer programs.

Sara Thompson, Director, National Mental Health Association Consumer Supporter Technical Assistance Center (NCSTAC), reported that NCSTAC introduced new consumer advocacy director Dianne Dorlester. NCSTAC will offer grants to help consumer organizations achieve 501(c)(3) status and to enhance existing consumer organizations.

Chris Simiriglia, Director, National Mental Health Consumers' Self-Help Clearinghouse, stated that the Clearinghouse is helping to develop consumer-driven services programs around the country by creating a directory, promoting recovery and community integration, and working to transform systems from maintenance to hope. Its Recovery Institute works with municipalities to develop opportunities for peer-support services, to fund consumer-driven programs and services, and then to certify people to work in the programs. The Clearinghouse also works with the University of Pennsylvania's Rehabilitation, Research, and Training Center to develop learning materials on community integration issues. The Clearinghouse also is engaged in a project to establish the evidence for Internet-based peer services as an evidence-based practice. The Clearinghouse will add a research component to its ongoing efforts.

Anne Rossheim, Advocate, explained that adult children of parents with mental illnesses are organizing in mutual support through local NAMI chapters. She noted that people in the mental health system often are not asked whether they are parents, and children who need support often fall through the cracks.

Mr. Risser asked technical assistance representatives to discuss their western U.S. activities. Ms. Muscari stated that CONTAC del Oeste operates in the West; CONTAC will sponsor the 2006 Alternatives Conference in the Northwest; and CONTAC has conducted trainings in Idaho, New Mexico, Arizona, Texas, Kansas, and California. She urged CMHS to stay focused on the large rural component in western States. Ms. Thompson stated that NCSTAC will provide onsite technical assistance to grantees in Washington and California, and has provided training in the West on how to work with media. Mr. Guevara stated that STAR hosted a forum in San Francisco on needs of the Asian American/Pacific Islander population and plans another in Arizona on the needs of American Indian community.

Alvin Golub, Advocate, Family Links, urged attention to the needs of aging persons with diagnoses of long-term, serious mental illnesses, for whom recovery as an option has not been considered. Family Links works to provide places for adult children to spend time where they can learn remedial reading, balance a checkbook, and other survival skills.

Defining Consumer-Driven Care

*Elizabeth Sweet, Public Health Advisor, Child, Adolescent, and Family Branch, CMHS, and David Osher, Ph.D., Managing Research Scientist, American Institutes for Research, set the context for a discussion of the definition of *consumer-driven care*. Ms. Sweet stated that she serves as the project officer for the Statewide Family Network Program, and that the definition of *family involvement* is an evolving process undertaken under contract by the Federation of Families for Children's Mental Health with input from program grantees.*

A member of the Federation, Dr. Osher described the process and progress of the definition of *family involvement*. He stated that *family driven* pertains to changing the power relationships between families and young people who are consumers on one hand, and providers on the other, in order to have meaningful relationships and to avoid marginalizing families and children. Consumer-driven approaches have relevance to family-driven approaches. Dr. Osher noted that a group led by young people is developing youth-guided approaches.

Dr. Osher explained that data show that active participation in advocacy by families and youth can improve conditions for young people, in part by presenting their needs holistically to a system dominated by silos and in part because of motivation to persist in their advocacy. In the 1990s Dr. Osher and Trina Osher began to advocate for system-level decisions driven by needs of the child and family, not first by the needs of agencies. The *family-driven* approach means that the needs, concerns, goals, and values of families, along with those of children (which become increasingly important as children approach adulthood, drive agencies) service planning.

The Federation convened a culturally and linguistically diverse expert panel, predominantly of family members and also professionals. Three small focus groups discussed family-driven care and developed a draft document that described the practice in action and in its absence. Feedback from leaders in the field and others has been received on a series of subsequent drafts in the consensus process to develop a working definition. Next stages include more active dissemination, to make sure the definition is culturally and linguistically appropriate, and outreach to help people in mental health and allied systems adopt the principle.

Dr. Osher stated that the definition of *family-driven care* should be accompanied by a series of guiding principles. To date *family-driven care* means that families have a primary decision-making role in the care of their own children as well as the policies and procedures governing care for all children in their community, State, tribe, territory, and nation. Guiding principles suggest that information is key to change; family and youth networks are important; decision making should be shared; providers embrace the concept of sharing decision-making authority and responsibility for outcomes with families and youth; providers shift their approach to family-driven practices; system administrators allocate resources to support family-driven care; peer support activities; community stigma reduction efforts; cultural differences embraced; and everyone who connects with children, youth, and families advances cultural and linguistic responsiveness as the population served changes.

Discussion. Dr. Osher explained the multiple approaches that elicited national input, including the Internet, focus groups, teleconferences, and meetings and presentations for children's mental

health. The process has focused on reaching beyond the mental health arena. Mr. Risser stated his concern about abuse, trauma, and neglect among youth. Dr. Osher responded that the children's mental health movement talks about families rather than parents; in every child's life someone who is not abusive can help build resilience. He asserted the importance of addressing abuse when it happens. He observed the need to develop guidance for child-serving agencies that depicts family-driven care, and observed that *children, youth, and families* are the proper order of mention. Dr. Osher stated the need to hear the voices of young people in abusive contexts.

Mr. Fricks noted that CMHS asks Subcommittee help in defining *consumer-driven care*. He suggested that the project coordinate with work on a consensus definition of recovery. Mr. del Vecchio stated that a definition of *recovery* is expected in about six months. Mr. Marshall explained that several Subcommittee members have worked on the issue, and CMHS has provided assistance in distribution, synthesizing comments, and hosting teleconferences for discussion. Mr. Fricks suggested that CMHS broadcast the news that the Subcommittee is soliciting suggestions for guiding principles. Mr. del Vecchio asked for ideas for focus groups to discuss, suggesting regional consumer meetings as a forum for discussion. CMHS also can sponsor national teleconferences to elicit feedback. He urged the Subcommittee to suggest activities for the project. Ms. Maceira-Lessley recommended a multipronged approach, including focus groups, teleconferences, and Web-based information gathering. Ms. Johnson suggested enlisting consumer technical assistance centers, whose resources include e-mail lists. Ms. Muscari suggested that the centers' websites can publicize information, can discuss it during training sessions, and can gather information for synthesis. Ms. Maceira-Lessley urged including meaningful input at every level from consumers of color. Mr. Risser and Ms. Maceira-Lessley volunteered to develop a first draft of a definition of *consumer-driven care*. Ms. Johnson suggested conducting a literature search on *consumer driven*. Dr. Ida identified the need to determine uses for the definition. Mr. Fricks recommended seeking input from accreditation bodies. Mr. del Vecchio added that the definition will contribute to developing performance methods, educating providers, and incorporating into grants and other policy documents. Dr. Ida urged defining outcomes that can measure change meaningfully. Ms. Maceira-Lessley stated the need for clarity. Mr. Marshall noted that grant announcements provide guidelines for community and family participation, an example of how the term will be used. Consumer advocate Yvonne Keyes expressed support for the mission. CMHS Senior Consumer Affairs Specialist Carole Schauer stated that the Transformation Action Center will use key definitions for *recovery*, *consumer-driven care*, and *family-driven care*. She asked Subcommittee members to consider ways to engage providers and professionals.

Mr. Risser noted that not everyone identifies with the term *consumer*. Ms. Maceira-Lessley asked meeting attendees for feedback on *consumer-driven care*. Ms. Keyes stated that it means to be in the driver's seat. Nancy Allen suggested a system whereby psychiatrists are consultants and consumers are deciders. Ms. Johnson referred to the Universal Declaration of Human Rights, Article 25, on health care. Mr. Golub urged thinking about the definition in terms of people who receive care, as well as those who want to drive the care. Mr. Risser suggested including the option to choose *no* or *none of the above* regarding treatment modalities. Ms. Maceira-Lessley and Dr. Ida underscored the importance of consumers' culture, language, and community. Ms. Stockdale urged attention to empowerment, control of one's self, and choice. Dr. Ida noted that for many communities and consumers, successful training and skills are needed to achieve

empowerment. Dr. Osher stated that the important characteristic is *person driven*, not *agency driven*. Mr. del Vecchio suggested engaging other federal agencies in partnership with CMHS.

Mr. Risser stated that a best practice appears to be helping others to recover, for example, consumer-operated services. Subcommittee members identified other characteristics and issues related to consumer-driven care: assertiveness; the role of caregivers to be involved productively without detracting from the consumer role; access by caregivers to medical information in relation to privacy concerns; community of choice that includes coach, community supports, family members, and caregivers, and respecting a person's choice; determining true consumer power in recovery plans; stigma reduction/elimination; training in successful advocacy; valuing life experience as expertise on a par with other kinds of expertise; educating policy makers in mental health and primary health care, including consumers as faculty; broadened definition of systems of care and reforming systems that involve mental health (e.g., education and criminal justice); strategy to operationalize the definition; inclusion at all levels of design, planning, and implementation; importance of innovation recognized; and cultural relevance of the definition.

Recovery-Oriented Evidence-Based Practices

John B. Allen, Jr., Director, and Amy Colesante, Deputy Director, Bureau of Recipient Affairs, New York State Office of Mental Health, described New York State's (NYS) White Paper on evidence-based practices. Mr. Allen stated that the process has enabled peers, especially in NYS, to influence how services are delivered. NYS's Winds of Change initiative fosters all components of the service delivery system in implementing and using evidence-based practices. The White Paper began as series of educational forums attended by more than 4,000 users of mental health services and resulted in dialogues that produced the characteristics peers wanted in a mental health system driven by science.

Ms. Colesante summarized the principles in the White Paper: genuine, informed choice, including long- and short-term side effects, and alternatives to clinical treatment; person-centered, holistic, promoting choice and recovery, with goal development by the person using services; free access to records; recovery focused, with the possibility of recovery known to the community, and outcome-based payments to providers; knowledge based, including getting to know the person, not the label, and service providers knowledgeable about all alternatives; based on partnership, choice in provider selection, and not punishment; focus on cultural values, with ethnicity addressed, sensitive treatment to differences, and a recovery culture; based on trust, 100 percent adherence to confidentiality, and clinicians trusting persons to make their own decisions; do no harm, including elimination of seclusion and restraint, proactive and not reactive treatment (involves outpatient commitment); and equal access to treatment regardless of benefits, including second opinions, with treatment not dictated by payment benefits.

Mr. Allen stated that the goal was to ensure that the White Paper process was owned by its grassroots constituents, while NYS provided resources. More than 15,000 people have validated the document. NYS's commissioner authorized adoption and implementation of the White Paper's principles. The steering committee has been asked to develop concrete, measurable objectives for the guiding principles to track whether the system remains faithful to its founding values. Next steps are identifying objectives in inpatient settings, clinics, housing, community-based services, and administrative structures, centrally and decentralized, through field offices and local government units. Research-outcome experts will guide the steering committee in its work on measurement. The process has begun with medical records opened through regulatory processes, in an effort to make the system more responsive to the White Paper. Webpages are under development to provide informed choice and choice of providers, and system changes in funding are underway to enable peers to choose their own provider.

Discussion. Mr. Risser questioned whether negative practices were identified as not being evidence based, such as pharmacological therapies with negative side effects. Mr. Allen responded that the White Paper focuses on what peers want from the system, irrespective of the nature of the science. Ms. Colesante observed that in discussions among contributors to the White Paper, the theme of informed choice emerged regarding medications, including whether or not to take them. In NYS a process for informed choice would include literature and training for providers and teaching self-advocacy skills to peers to help them talk to their providers. Mr. Allen noted that psychiatric centers are asking for assistance to change their service culture, and training materials are being created. He stated that representatives of NYS diverse population who use NYS's services informed the process. Mr. Allen suggested that the White Paper should be disseminated in its entirety with credit to NYS.

Sara Thompson, Director, Adult Mental Services, National Mental Health Association, and Joel Miller, Acting Director, Policy Research Institute, NAMI, discussed findings of a small focus group held jointly by NMHA and NAMI on evidence-based practices. Participants discussed toolkits, best practices, emerging practices that work for consumers, and how consumers can become more involved in research, implementation, and evaluation. The group found that consumer participation at all levels is critical to the success of the evidence-based practices movement; evidence-based practices must focus on a broad array of programs and services and link to all aspects of living with a mental illness; current evidence-based practices do not address adequately the needs of consumers or incorporate promising practices developed by consumers; and consumers believe that consumer-led practices have a strong evidence base. Consumers called for integration of consumer preferences, needs, and values into the recovery process to achieve buy-in and ownership. A report of the meeting is available.

Recommendations for consumer involvement at all levels of evidence-based practices included recognition of consumers as allies and partners; integrating recovery from consumers' perspectives into evidence-based practices; training consumers to research promising practices to determine what is effective and to develop implementation strategies; changing practice and addressing workforce shortages; assessing outcomes of services and supports; and developing the capacity to access easily research on what works. Consumers would like and need to be involved in the evidence-based practices process; consumer-driven programs are effective,

relevant, and widely applicable within the system of care; and further advancement of evidence-based practices requires more focus on participatory action research. Next steps include broad dissemination of the report to private and public decision makers, and setting priorities for future action steps.

Crystal Blyler, Ph.D., Social Science Analyst, CMHS, presented an overview of the intersection of evidence-based services with recovery. She described recovery services as services that lead toward an outcome of recovery or are delivered in a way that resonates with recovery principles. Evidence-based practices are a technique for achieving a certain outcome, but they do not determine appropriate outcomes. She asserted that evidence-based practices should be used to achieve outcomes identified as goals by individuals as part of their recovery. Good measures have been developed for recovery in recent years, and recovery principles should be infused in the ways that people receive services. Measures about outcomes, the degree of focus on recovery, and how well services contribute to recovery could be used as a fidelity assessment as to whether services are achieving recovery principles in the way they are delivered. Dr. Blyler asserted that services specifically designed to facilitate recovery should be developed as evidence-based practices, with choice built into the selection of public mental health services.

Dr. Blyler noted that complaints have been expressed about lack of consumer involvement in developing evidence-based practices toolkits. She asserted that the toolkits should only support individuals' recovery goals, for example, employment or symptom reduction. Consumer choice is an evidence-based principle that improves outcomes (e.g., supported employment). The importance of the practitioner-consumer relationship in recovery is reflected in the toolkits. Findings emerging from pilot tests on toolkits show that creation of hope among consumers and practitioners is an outcome. Staff is staying longer in their positions as they see people improve. The need exists to develop more evidence for the effectiveness of recovery services and to determine how to integrate multiple evidence-based practices for an individual to avoid conflict in achieving goals. Ultimately all practices should be both evidence based and recovery oriented.

Discussion. Mr. Risser stated that adherence is an issue for consumers, which might negatively influence assumptions about outcomes. Most mental health systems in his experience equate positive outcome with no community disturbance. Certain programs are not guided by overarching values or philosophies about how to treat people, so outcomes reflect differing staff values regarding self-determination or compliance. Dr. Blyler concurred regarding the limited extent to which recovery principles are infused in evidence-based practices. She stated that the core principles of each of the six toolkits were examined for recovery-related content, and some was found in supported employment and ACT. Dr. Blyler suggested that the Consumer-Operated Services Project's fidelity measure related to structure and underlying principles can serve as a model to build recovery into a fidelity measure. She suggested conducting evaluations on both evidence and recovery principles. Ms. Johnson and Dr. Blyler discussed the possible disconnect between good science and a positive impact on people. Dr. Blyler stated that the first six toolkits are to be released in February 2005. Mr. Golub raised the issue of indicators for recovery, and Mr. Fricks noted that indicators relate to holistic quality of life.

Wanda Finch, CMHS, presented a brief overview of the 2004 Statewide Consumer Network Grant Program.

The meeting recessed at 4:45 p.m. and Subcommittee members reconvened at 9:00 a.m. the following day.

CMHS Block Grant Program

Marie Danforth, M.S.W., Chief, State Planning and Systems Development Branch, CMHS, explained that the mental health block grant was created in the early 1980s under President Reagan, following declining Federal support for the network of community mental health centers established by President Kennedy. Under the program, States must develop plans to provide comprehensive community mental health services to adults with serious mental illness and to children with serious emotional disturbance. The value system consists of five criteria set forth in Section 1912 of the block grant law.

Consumer involvement in the block grant includes comment on the *Federal Register* notice for the Performance Partnership Grant (PPG) program and participation in State planning councils. Ms. Danforth acknowledged that criticism has been lodged regarding limited consumer influence in some State planning councils. Mr. Fricks noted, however, that Texas family members and consumers have received funds from the block grant. Ms. Danforth noted that in FY2000-2001, Congress increased funding levels, which many States used to improve quality of care, evidence-based practices, and other programs. Mr. Fricks explained that Georgia's consumers prompted service reforms and a majority membership of consumers and families on its planning councils.

In FY2000 Congress mandated SAMHSA to develop a plan for block grants to move to PPGs, with an emphasis on data collection. In submitting FY2005 applications, each State is expected to report on 10 core performance indicators. Changes in the review process will account for the new data and changes in the value system, which Ms. Danforth hopes will include quality of care and evidence-based practices. The data have developed over time to be known now as national outcome measures. Ms. Danforth stated that recovery measures relate to level of functioning. Mr. Risser noted that in Oregon and Washington, the mental health system reported that only four people had improved to a level of functioning where they were considered recovered.

Mr. Fricks suggested the need for funds for incubators to help start consumer-operated businesses. Ms. Danforth responded that States have some flexibility in allocating block grant funds. Ms. Danforth noted that Subcommittee members will receive a trends report that describes States' activities. She stated that Congress sets the criteria for States to address with block grant funds. Subcommittee members expressed frustration that declining funding impacts consumer-operated services negatively. Ms. Danforth noted that the FY2006 budget will cut funds for CMHS discretionary grant programs, making funding for consumer-operated services more difficult. The block grant formula is based on annual State population, cost of services index, and taxable income. Review for the Protection and Advocacy (P&A) Program involves encouraging States to improve P&A reports and the relationship between the advisory council and governing board.

Ms. Danforth explained that planning councils serve in an advisory capacity to influence State activities. The law mandates that half the council members be consumers, family members, and others, and that the State agency and other entities also be represented. Planning councils must

review and be asked to comment on State mental health plans and implementation reports. Mr. Risser noted the extreme disparity in consumer representation among States. Ms. Danforth stated that CMHS convenes State planners for technical assistance and showcases States that do well, noting that CMHS works with State planners who want to do a better job. Ms. Johnson pointed out that planning councils do not necessarily receive the reviewers' summary statements and urged requiring planning council members to view a training video on flexible funds and planning council discretion.

SAMHSA's Dare to Act Trauma Conference and Women's Study

Pat Risser, Activist, Member, Subcommittee on Consumer-Survivor Issues, described his own background of trauma and the epidemic of trauma that affects boys and men as well as girls and women. He stated that the new Center on Women, Violence, and Trauma will include a focus on men with histories of trauma. He observed that certain practices used in the mental health system, such as seclusion and restraint, re-traumatize trauma survivors.

Susan E. Salasin, Director, Women's Mental Health Program, CMHS, described events that led to the Dare to Act Trauma Conference, including old legislation that called for programming for women that CMHS had not implemented broadly. President Carter's 1979 Commission on Mental Health discussed physical and sexual abuse, but no action was taken. Many trauma survivors were frustrated in talking about their experiences in therapy and being accused of making them up. But survivors began to talk to one another, and these women consumers made a difference in creating a program. Studies showed that 75 percent of women who enter psychiatric hospitals have backgrounds of physical and sexual abuse; studies began to look at women instead of generalizing from men's studies. CMHS convened an agenda-setting meeting in summer 1994 attended by 250-300 people, of whom about a third were consumers. Many consumers with backgrounds of abuse told their stories about retraumatization and seclusion and restraint in psychiatric hospitals. It became clear that the issue must be addressed.

CMHS formed an expert center on physical and sexual abuse, a third of whose members were consumers. Women with substance abuse problems were not receiving attention to what they considered to be their most serious problem, which resulted in symptoms of depression and substance abuse as a self-medication activity. Women with co-occurring disorders and a background of trauma could not obtain integrated treatment; providers did not want to deal with them. CMHS and CSAT created and tested a treatment system for women with co-occurring disorders, and they funded 14 sites nationally over five years. The study found that coordinated treatment for trauma that integrated mental health and substance abuse treatment addressed symptoms effectively. Study findings opened the door for more work and also work on men. A second conference, Dare to Act, brought consumers and providers together again to reveal findings and discuss the issue. Ms. Salasin stated that the Trauma Center will serve as a mechanism for technical assistance to build capacity in the field.

Rene Andersen, M.Ed., Associate Executive Director, Western Massachusetts Training Consortium Project, described a peer approach to recovery from childhood sexual abuse that was designed by trauma survivors based on their experiences. They determined that the road to wellness required meeting basic needs for food and clothing, physical safety, empowering relationships, valued social roles, skill development, recontextualization, and altruism/activism.

Components of the project include a holistic approach, physically safe space, peer-led groups that address addiction and trauma, peer resource advocates, opportunities for valued social roles, trauma liaisons to change the system, Community Initiative Grants, and supports for child care, transportation, and stipends.

Roger D. Fallot, Ph.D., Director of Research and Evaluations, Community Connections, described some steps in recovery for men who have experienced trauma. Historically men's trauma issues were recognized as shell shock, combat fatigue, and PTSD. Recently attention has extended to physical and sexual abuse of boys and men. Dr. Fallot described the characteristics of trauma and its ensuing vicious cycle of violence that includes incarceration, homelessness, mental health problems, and substance abuse. Men are exposed to different types of trauma (more physical than sexual) and trauma with different characteristics (negative coercion) from women. Men use different coping skills, make different attributions about trauma, and experience different trauma sequelae.

Some steps in recovery include recognizing trauma among men, making trauma services welcoming for men, and offering gender-specific trauma recovery services for men. Trauma is under-reported and under-recognized among males. Trauma services should be delivered to men in settings that ensure safety, maximize consumer/survivor choice and control, establish and maintain clear tasks and boundaries, maximize collaboration and sharing of power, and emphasize empowerment and skill building. Obstacles to engagement in services by men include the "disconnection dilemma" of being male and a victim, lack of familiarity and/or comfort with emotional language, and lack of comfort with relationship-centered discussions.

Strengths for engagement in services include pride and self-esteem for having survived, proneness to figure out what has happened to them, and bias in favor of problem solving. Gender-specific trauma-recovery approaches include understanding relationships between gender role expectations and trauma, emotions and relationships, trauma and its impact, and recovery skills and their use. Rigid male stereotypes and emotional constrictions are problems, while drawing on strengths is part of the solution. Dr. Fallot noted that men need skills to talk about feelings and relationships, an understanding of trauma in general and of the relationship between trauma and psychological symptoms, and a focus on developing a range of recovery skills. For many men with limited contact with their children, reestablishing contact can serve as a powerful motive for their own substance abuse and mental health recovery. A major challenge is to provide the kinds of settings to enable people to overcome the impact of their experiences and to find the heroes within themselves.

Jacki McKinney, Director, Trauma Knowledge Utilization Project, described her experience with the Women and Violence Study, which progressed quickly from an “us and them” mentality between professionals and consumer/survivor/recovered women (CSRs) to a problem-solving partnership based on mutual respect and trust. The professionals encouraged consumers to tell their stories, which they then changed into the language of healing and change. By the end of the study, 200 consumers had interacted over a period of five years.

The National Trauma Consortium disseminated information from the study, and then a group of CSRs planned another conference at which consumers would have the opportunity to identify their own voice and response to the information. At a Trauma Champions Day, women told their trauma stories and developed a sense of camaraderie and identification. Ms. McKinney stated that plans are under way to replicate (culturally specific) trauma champion days in communities and in conjunction with other meetings. She solicited help from Subcommittee members and the audience to identify consumers and organizations to invite to participate. She underscored the need for such events for people of color and for working in partnerships with a range of stakeholders to mobilize a trauma constituency.

Discussion. Mr. Risser urged the mental health system to address trauma in terms of decontextualization, and to pay attention to perpetrators in order to move toward healing society. He asked for suggestions for next steps. Ms. McKinney stated that consumers need trauma-informed and trauma-specific services. Ms. Stockdale described her own background of trauma, emphasizing the need for more information, mutual support, and programming at conferences. Ms. Johnson noted the need for outcome measures related to recovery from trauma. Ms. Salasin stated that virtually everyone in the public health system has experienced physical and sexual abuse, but that no one receives treatment. Dr. Ida urged focus and information on trauma and torture experienced by refugees, an issue particularly relevant to many Asian Americans. Ms. Salasin responded that a study is ongoing on women of immigrant/refugee status with emphasis on intergenerational transmission and impacts on the next generation. Ms. Maceira-Lessley described the mental health system’s refusal to recognize her trauma history and consequent inappropriate treatment. Ms. Stockdale noted the relationship between trauma and suicide. Mr. Risser suggested the need for strengths-based research on trauma survivors who have not abused their children and how they broke the cycle. Ms. Anderson noted that people who experience mental health and substance abuse issues related to trauma are the same people, but they seek help through different portals. She urged SAMHSA to integrate its approach to persons who are homeless, in the criminal justice system, battered women, mental health and substance abuse clinics, and housing authorities. She recommended that all services and supports be trauma informed, under the rubric of transformation.

NAC Agenda and Recommendations. Subcommittee members made the following recommendations to the CMHS National Advisory Council:

- CMHS should ensure that mental health consumers are meaningfully involved in the design of the proposed consumer-operated services (COS) toolkit and include COS as a national outcome measure of the Mental Health Services Block Grant (MHSBG) program with guidelines to States on the utilization of MHSBG funding to promote these services.
- To ensure consumer-driven mental health systems transformation, CMHS should meaningfully include mental health consumers, including members of the Consumer/Survivor Subcommittee acting as individuals, in the planning, implementation, and evaluation of the CMHS Transformation Action Center.
- With vast majorities of consumers reporting trauma histories, CMHS should adopt trauma-informed approaches into every program and activity of the Center, including technical assistance centers, policy documents, grant announcements, and educational materials. CMHS should expand efforts – such as the Trauma Champions Institute developed by the CMHS Women, Violence and Trauma Center’s Consumer Leadership Program – to support the voice and participation of survivors of trauma.

Discussion. Mr. Fricks stated that he would like to learn about co-occurring academies.

Adjournment. Mr. Fricks adjourned the meeting at 1:55 p.m.

Next Subcommittee meeting: August 2005