U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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Center for Mental Health Services
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Region VI Meeting

CMHS Regional Consumer/Survivor Meeting

Summary Report

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Department of Health and Human Services Region VI Consumer/Survivor Meeting

Oklahoma City, OK
March 27, 2008

Overview of the Meeting

The day-long regional meeting of mental health consumers/survivors held in Oklahoma City, OK, on March 27, 2008, was convened by the Office of Consumer Affairs of the Substance Abuse and Mental Health Services Administration, Center for Mental Health Services (SAMHSA/CMHS).

Each year SAMHSA/CMHS convenes two consumer/survivor regional meetings. The meetings focus on the needs of, and challenges faced by, consumers in receiving mental health services and supports, progress made on transforming mental health care systems, and specific goals spelled out in the President's New Freedom Commission on Mental Health Final Report. The meetings provide consumer advocates and attendees an opportunity to network and discover what is working in each State. The information gathered is disseminated throughout CMHS, the mental health leadership of the States attending the meeting, and meeting participants.

This regional meeting included presentations from consumer representatives of each of the five States that comprise the U.S. Department of Health and Human Services' (DHHS) designated Region VI: Arkansas, Louisiana, New Mexico, Oklahoma, and Texas.

Through small group discussions and audience participation, the meeting also served as a conduit for receiving suggestions on four of the specific goals (goals 1, 2, 3, and 6) proposed by the President's New Freedom Commission.[1]

More than 70 people attended the meeting. The speaker list is attached as the Appendix.

Welcome, Introductions, and Report on SAMHSA/CMHS Activities

Welcome from the SAMHSA/CMHS Office for Consumer Affairs

Ms. Carole Schauer, R.N., M.S., Senior Consumer Affairs Specialist, welcomed attendees and explained that the purpose of the meeting was to find out the needs and concerns of consumers in each State, what is working well, and suggestions for improvement.

[1] In July 2003, the President's New Freedom Commission (established in April 2002) released a report containing 19 formal recommendations, organized under six proposed national goals for mental health. The Commission's emphasis was on recovery from mental illness, consumer and family-centered care, and its recommendation that States develop a more comprehensive approach to mental health.

She conveyed greetings from Michael O. Leavitt, Secretary of DHHS; and Terry Cline, Ph.D., former Secretary of Health for the State of Oklahoma, currently the Administrator of SAMHSA.

Ms. Schauer acknowledged the members of the meeting's planning group. This event was the first time SAMHSA/CMHS reached out to leaders in the consumer community to seek their active participation in the planning of a regional meeting. Ms. Schauer acknowledged and introduced Stacey Lesko, M.S.W., CMHS Consumer Affairs Specialist, the staff person responsible for planning the meeting.

Welcome from Oklahoma Department of Mental Health and Substance Abuse Services

Terri White, M.S.W., Commissioner

Ms. White brings a wealth of experience to the Oklahoma Department of Mental Health and Substance Abuse Services. She has been the Executive Director of a community mental health center, Director of Services for those with co-occurring illnesses, and Director of Communications and Policy.

Ms. White acknowledged that Oklahoma City has had a recent history of tragedy, including the bombing of the Murrah Federal Building in 1995 and the destruction caused by the tornados in 1999 and 2003. These tragedies provided a tremendous opportunity for Oklahomans to display their ability to manage a disaster and show how they work together. During these devastating times, mental health issues moved to the forefront of the public health agenda in Oklahoma. This shift raised the visibility of mental health issues and led to widespread acknowledgment of the need for services. People began to understand that mental illness is a disease like any other disease and that when people with mental illnesses are provided with the appropriate services and support, they can recover.

Ms. White described highlights of mental health activities in Oklahoma.

- First and foremost, the inclusion and expansion of peer and recovery support services are a priority in Oklahoma and **key** to recovery.
- The evidence is beginning to show that peer supports work. Creating a peer workforce is critical to solving the problem of not enough providers to take care of all our mental health service needs.
- Partnerships have developed with the Oklahoma Mental Health Consumer Council, the Oklahoma chapter of the National Alliance on Mental Illness (NAMI), the Depression and Bipolar Support Alliance (DBSA), and the State's Consumer Affairs Office in the Department of Mental Health and Substance Abuse. The synergy that has been created, and the collaborative work with those in substance abuse treatment, have been outstanding.
- Public education is expanding and helping people understand that mental illness is truly a disease and is just as treatable as a physical illness. Ms. White said, "We would never send our children to school with untreated asthma and say, 'Well, we hope everything will be OK and that you will still learn.' We need to create the same norm for mental illness, which means that we would never send our children to school with untreated mental illness."

Brief Report of CMHS Initiatives

Ms. Schauer and Ms. Lesko provided the audience with updates on the following CMHS initiatives.

- What a difference a friend makes: SAMHSA is conducting a 3-year public education campaign that includes TV, radio, and print ads which educate the public to encourage, educate, and inspire people between the ages of 18 and 25 to support their friends who are experiencing mental health problems. The prevalence of serious mental health conditions in this age group is almost double that of the general population, yet young people have the lowest rate of help-seeking behaviors. This group has a high potential to minimize future disability if social acceptance is broadened and they receive the right support and services early on. The campaign is turning its attention to internet-based approaches and is focused on four major racial/ethnic groups. See http://www.whatadifference.org.

- Consumer scholarships: One hundred and sixty scholarships have been awarded to recipients who have attended 10 different meetings each year. There is a written application process and any consumer may apply.

- Wellness and the 10 by 10 campaign: The aim of the campaign is to reduce premature mortality by 10 years over the next 10 years. The life expectancy for individuals with serious mental illnesses is about 25 years less than for the general population. Data shows that male consumers are likely to die at 53 years of age and female consumers at age 59. The National Association of State Mental Health Program Directors (NASMHPD) Medical Director's Council recently reported that people with serious mental illnesses are more likely than the general population to die of treatable medical conditions caused by such modifiable risk factors as smoking, obesity, substance abuse, and inadequate access to medical care. Through a variety of initiatives, the campaign emphasizes supporting mental health care providers to be more attentive to physical issues, medical doctors being more attentive to mental health issues, and consumers taking more responsibility for their total health and well-being.

- CMHS National Advisory Council, Subcommittee on Consumer/Survivor Issues: The subcommittee's main purpose is to serve as a fact-finding body and make recommendations to the advisory council on issues from the consumer/survivor perspective. Subcommittee meetings are open to the public and are generally held 2 days before the CMHS National Advisory Council meeting, which is convened twice each year. The most recent meeting was held March 18, 2008; topics discussed were the Shared Decision Making project, wellness initiatives, mental health first aid, and mental health disparities. A new member representing New Mexico, Gilberto Romero, is particularly interested in wellness and presented his perspective later in the meeting. SAMHSA/CMHS is always looking for nominees, should a space become available.

- Shared Decision Making project: Shared decision-making is an interactive and collaborative process between individuals and their health care providers about decisions pertinent to treatment and recovery. It is shared because the practitioner brings information about the condition and treatment options, while the consumer brings experience, knowledge, and preferences. The Office of Consumer Affairs currently has a 3-year contract to create decision-making aids in a variety of formats (e.g., pencil-and-paper, audiovisual, and computer assisted) that provide information and a structured process for making shared decisions.

Facilitator's Remarks

Kathy Muscari, Ph.D.
Director of the Consumer Organization and Networking Technical Assistance Center (CONTAC), Charleston, WV

Dr. Muscari emphasized how important it is to hear from consumers about their States' mental health activities, and said that throughout the day she would summarize the themes expressed. She told the group briefly about some of the events that led to the discussion of certain topics at the meeting.

- To clearly define recovery – the process by which people are able to live, work, learn, and participate fully in the communities they choose despite disabilities they may be experiencing – SAMHSA 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. The full National Consensus Statement on Mental Health Recovery can be found on SAMSHA's Web site at http://mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/.

- The growing research on resilience, defined as personal and community qualities that enable us to rebound from tragedy, trauma, threats, and other stresses and to go on with life with mastery and a sense that we can make a difference, with competence and hope.

- Some of the findings reported by the President's New Freedom Commission are that our mental health care system is fragmented, that there are unmet needs and that many barriers impede care for people with mental illnesses. The full report is available online at http://www.mentalhealthcommission.gov/reports/reports.htm.

  The New Freedom Commission agreed on six overarching goals, and several recommendations for a transformed mental health system. The planning group for this meeting decided to focus on the following four goals.

  Goal 1: Americans understand that mental health is essential to overall health. The planning committee said we have to do more about stigma and discrimination, specifically, what is working and what we can do to make a difference.

  Goal 2: Mental health care is consumer and family driven. The planning committee suggested looking at collaborations (how States, the Federal government, and self-help groups are partnering; how we are doing with shared decision-making; and what is working with consumer-driven care).

  Goal 3: Disparities in mental health services are eliminated. The planning committee suggested we look at how to engage diverse communities and how we address different backgrounds, cultures, and geographical areas (rural and frontier). We want to learn more about effective communication strategies, particularly with groups that experience disparities in "mental health illnesses." Also, not all of us believe we have illnesses. This point is supported by the professional literature that has not conclusively shown that these are physiological causes.

Goal 6: Technology is used to access mental health care and information. The planning committee recommended looking at accessing information through technology, including online activities, Web sites, and drop-in centers. How are we getting across information using technology?

The discussion throughout the day was focused on the following questions:

- What challenges, barriers, and positive things are happening in each State?
- What recommendations can the Federal government consider for next steps?
- How will we make a difference together?

State Presentations

Arkansas

Eddie Smith
Peer Support Specialist, Veterans Administration Medical Center

Mr. Smith described the peer support program being implemented in the Veterans Administration (VA) system in Arkansas.

- Strength 1: Peers receive ongoing training from the University of Massachusetts at Boston to learn what does and does not work in providing peer support. Veterans from different wars are coming to the VA to help in the process of recovery using a psychosocial rehabilitation approach. In addition, they conduct site visits to provide training and education to providers on recovery and to spread the message that recovery is possible.
- Strength 2: The VA agreed to continue funding when the initial grant for the peer support program ended.
- Strength 3: The program has established communication with the statewide consumer network (NARRSD) and the VA established a consumer council. In rural areas, peers meet with people at outpatient clinics.
- Strength 4: Consumer/survivor-driven services are based on the understanding that consumers will take action on what they believe will move them toward a goal. Peers help consumers begin that action and work toward that goal. Peers create relationships that promote recovery; are fully committed to the consumer's recovery; support the consumers' lead; and help measure and provide rewards for making progress.

The greatest challenge has been to learn how to work together with providers as staff. In their system, peers are considered to be staff members and they have focused on clarifying roles and responsibilities. For example, they clarified that as staff, peers are able to go into records. They developed two codes of ethics: staff codes and peer codes. A current focus is developing effective teams; they are looking forward to moving ahead to recovery.

Linda Donovan, M.A.P.
Director, Network of Arkansans for Rights, Recovery, and Self-Determination

Arkansans are in the process of forming a statewide consumer network; even though they are late bloomers in forming a 100 percent consumer-driven organization, they do have several consumer organizations throughout the State. They recently received a national TA mentorship grant to help form their network.

The biggest barrier is a mental health care delivery system that does not provide for unique recovery, which means people are not able to do what they know they need to do for recovery. There are extremely limited types of services due to the restrictions that Medicaid places on reimbursement.

Strengths

One of the strengths in Arkansas is a consumer/survivor network that is 100 percent consumer-driven, that networks with the VA peer support services, and has strong support from providers who understand trauma-informed care. The network is developing partnerships with community organizations with common values. They have identified groups of diverse people with great needs, such as lesbian/gay/transgendered/questioning communities and people from the delta region who have difficulty accessing services. They are identifying approaches to locate consumers/survivors as there are no drop-in centers where people congregate. Consumers are hard to locate after they no longer receive clinical services.

Ms. Donovan is continually finding places to talk about the unique recovery journey and consumer-driven recovery planning:

- teaching an ongoing class that is now part of the State hospital infrastructure with great provider buy-in;
- leading an ongoing learning community with different providers on trauma-informed care (her goal is to have providers stop using the term "patients" and to think in terms of people who are in recovery); and
- serving on various committees at the State hospital and throughout the State, such as ethics and oversight committees, where she can insert consumer/survivor values such as having options for living a full life in the community and of a person's choosing.

The State has received technical assistance funding and mentorship, and has submitted proposals to have nationally recognized peer experts present at the annual meeting of the Behavioral Health Institute.

Another strength mentioned by one attendee is a psychiatric rehabilitation center in Arkansas.

Barriers

Ms. Donovan explained the challenges of the "reductionist mindset." This mindset includes the belief that everything can be explained in simplistic terms with one definition and one approach to recovery. This mindset can be overcome by including people from all communities, sharing stories, and changing from evidence-based practices to values-based recovery practices that are individualized. Other barriers are the limited reimbursement from Medicaid, and that the types of services consumers need are not available.

Louisiana

Carole Glover

President, Meaningful Minds of Louisiana

Ms. Glover congratulated the Louisiana Department of Mental Health for implementing the Wellness Recovery Action Plan (WRAP) and peer-to-peer services. Meaningful Minds, a nonprofit organization that has 360 members and six chapters around the State, receives State funds from the mental health block grant and from donations and grants. Ms. Glover is thankful for the opportunity to learn many things that other consumers have not, by sitting on various councils and advisory boards and committees. This has increased her self-esteem, empowered her to move forward, take on challenges, and given her the opportunity for self-advocacy and to advocate for others.

Frustrations

Ms. Glover expressed concern about the inability of consumers to expand, grow, and become independent of the State mental health system. For example, Meaningful Minds received only $32,000 this year. The contract was written by the Department of Mental Health without their input; thus, there was no funding for peer-to-peer programs or consumer-run/driven programs within mental health. She emphasized the importance of having a voice and to say what works, "nothing about us, without us."

There is a need for sources of funding from places other than the Department of Mental Health. Working under the influence of this department has served to separate consumers from their peers. The freedom to speak out and reach out to their peers is taken away once they are employed because of concern about their jobs and benefits.

Debra Bradley

Peer Support Specialist/Consumer Liaison, Mental Health Planning Council

Ms. Bradley began her presentation by noting that people think of Hurricanes Katrina and Rita and assume that the mental health system was devastated by these storms. However, the mental health system and its problems transcended these storms. Barriers continue to exist; facilities and ongoing treatment, housing, and transportation are very limited. Typically services begin only when a person becomes a danger to others or self. Long-term ongoing care is unavailable. The high costs of treatment make getting help impossible and force the person into public-sector funding. The American dream for those with mental illness is no different than for those without mental illness. Everyone wants a place to call home, a car, and the freedom to come and go as they please.

Louisiana is rural; people with mental illnesses are likely to live in a rural area, far from services. With no funds for services or transportation, they become isolated. Most can live productively as contributing, taxpaying members of this society with proper treatment.

Current insurance policies exclude mental health services. This also forces the person into publicly funded programs and reduces the incentive for professionals to go into the mental health care field, thus making the quality and quantity of care limited and very expensive for the consumer.

Comments from others in the audience from Louisiana

- There is an expanding awareness that we are working with people in recovery, not patients.
- A lot of effort went into supporting Meaningful Minds and getting it off the ground, including getting FEMA (Federal Emergency Management Administration) grants to provide peer support to find the people who needed help. Then the group lost $1.8 million to the Department of Mental Health and with those funds went the ability to provide peer support all across the State.

New Mexico

Marcia Prophet
Consumer Specialist, Behavioral Health Collaborative

The structure of the New Mexico mental health system is different compared to other States. In 2004, a behavioral health collaborative was formed that includes 17 government agencies and departments. Within the collaborative, there is a behavioral health planning council with more than 80 providers, advocates, family members, and consumers who advise on block grants and other matters. In addition, local community collaboratives are the grassroots advocacy groups needed for expanding consumer-support services.

The collaborative's strategic plan priorities were developed primarily by the State with some input from consumers. The process still tends to be top-down planning, but more effort is being made to have consumers' input.

Ms. Prophet works for the Office of Consumer and Family Engagement (CAFE), which is an expansion of the Office of Consumer Affairs. CAFE has moved from working with only adults to now including mental health consumers of all ages. Currently, CAFE is engaged in collaborative actions, including creating a children's plan, which is now before the local community collaboratives for their input. The plan proposes a clinical home concept, known as "wrap around," whereby a person will have a particular place to go to get integrated services and thus lessen the difficulty of navigating a fragmented system. In addition, a community engagement toolkit has been created for the local collaboratives. It provides contact information for State mental health leadership, a resource directory, information on how to organize, and sources of available technical assistance.

Shela Silverman
President, Mental Health Association of New Mexico

Total Community Approach (TCA) is a pilot project and part of a local collaborative for three rural and frontier counties. The project offers services to deal with the serious problems of substance abuse and co-occurring disorders. TCA obtained funding from the State to addresses adult substance abuse and co-occurring disorders in a specific geographic area of high need, the Las Vegas, New Mexico area. The State hospital is located there, but it does not provide services for co-occurring disorders. The project targets prevention, education, and treatment recovery support services such as housing, jobs, and finding alternative services (e.g., churches and transportation).

Taking a total community approach includes the following activities.

- Providing training for providers, especially with Value Options, an agency that has funding to provide behavioral health services throughout New Mexico to enhance skills in working with people with co-occurring disorders
- Hiring *promotoras*, lay health workers, which is not a Medicaid-reimbursable service (in addition, funds are used to provide training in mental health and substance abuse support because these are not the areas in which *promotoras* usually work)
- Taking a community reinforcement approach to get the entire family together to do the things they enjoy (e.g., Community Reinforcement and Family Training (CRAFT), started at the University of New Mexico)
- Training peer specialists in a culturally relevant manner that is specific to New Mexico, emphasizing consumer choice and treating the whole person
- Providing supportive housing and wrap-around services for adolescents with serious mental health illnesses who were in the criminal justice system and are now in transition

Transportation is the number-one rural issue mentioned in every town in which a focus group has been conducted. Because of consumer advocacy, the State funded a pilot project to provide consumer-operated service even though the geography was not very rural. Because of the behavioral health collaborative, the project can develop partnerships with several agencies, such as transportation, aging, long-term service, and vocational rehabilitation services.

It took 4 years to develop training to obtain certified peer specialists and certified family specialists, which was necessary to become a Medicaid-eligible and reimbursable service. Native American Peer Specialist training includes a medicine wheel model: mental, spiritual, emotional, and physical. Mental Health America provided funds to do training for the Navajo nation.

Additional initiatives were described, including services to Native Americans; focus groups to develop a cultural competency plan; an anti-stigma campaign called Talk About It New Mexico; consumers' involvement in research; and research, evaluation, training, and evidence-based practices.

In a recent focus group, people said what they wanted most of all is an integrated physical and mental health treatment system. In addition they want the following:

- to close the State hospital (why should those with mental illnesses be the only group to have their own hospital?);
- jobs, housing, recreation, and education;
- universal healthcare and increased benefits; and
- improved transportation.

Comments from others in the audience from New Mexico

- We want to grandfather-in Native American counselors for alcohol and substance abuse in order to get Medicaid-eligible and reimbursable services.
- We are learning how to obtain consumer involvement in the research process. For example, one project is the evaluation of a drop-in center; we get the tools and help develop questions, and then we will go around and ask the questions.

Oklahoma

Ken Gunnells
Credentialed Peer/Recovery Support Specialist
Oklahoma Mental Health Consumer Council

Specific and obvious problems include underfunding of community mental health centers, non-competitive salaries, and difficulties in recruiting psychiatrists (one hospital had to close because they couldn't hire qualified doctors). Fortunately, in Oklahoma there are Programs of Assertive Community Treatment (PACT) teams to work with people unable to come to clinics. People with severe mental illnesses often don't know services are available or don't believe they are effective. Unfortunately, the criminal justice system is the major mental health treatment provider, and people in that system are only being treated with medications and outdated treatments with little choice.

The community mental health centers and other agencies are doing the best they can with the little funding available.

At a recent meeting, consumers discussed their problems. In addition to long waits that are apparently the norm with public services, the main complaint is that physicians and nurses are not listening to their concerns. Old-school caregivers believe they know what is best for consumers. Compounding this problem is that too many consumers let go of their responsibility for their own health and the creation of their treatment plan. Some consumers are content to stand passively by and allow the providers to take over without their input about what might or might not work for them.

The State has been successful in getting consumers more involved in treatment planning, by educating administrators and other front-line providers about the importance of collaboration.

In 2000, Oklahoma created the systems of care program and the wrap-around program for youth and family to respond to the demand for person-centered, family friendly, culturally appropriate services for children. The children's system has grown and matured, and has become an example of the true wrap-around process that it is supposed to be.

Many programs, including the hardworking State innovation center, are working diligently to improve services. Consumer involvement is critical.

What we hear most often is that the client/consumer wants to be heard. This takes overcoming stigma and changing the attitudes of providers that make it difficult for them to let go of control. More and more providers realize that the consumer lives with his or her illness 24/7, and understands what works and what doesn't work for their own recovery.

Too many consumers let go of their responsibility and think that providers know best. One consumer said, "The doctor doesn't know how to be a doctor" because the doctor asked, "What do you think will work?" The consumer said, "I don't know…you are the doctor…you are supposed to know."

A recent participant in a peer-support recovery program needed individualized treatment, which was initially denied by the young woman's nurse and case manager. She was told she had to "stick with her treatment plan" and if she didn't, she could seek services elsewhere. Eventually she was given an individual appointment at the cost of part of her day treatment program.

People with mental illnesses have aspirations just like everyone else; they didn't ask for their predicament, and for the most part they are trying to get help. Most consumers really want to work and live productive lives. When people are given voices and choices, they can move forward. All of us have a need to be heard and recognized and to be a participant in our own recovery.

Cindy Row

Certified Recovery Support Specialist, Grand Lake Mental Health Center

As a mental health consumer for the past 18 years, Ms. Row stated that she is very aware that local, State, and national incentives must continue to be consumer driven and recovery oriented. Oklahoma is proud of the consumer standards being developed. Also, the Mental Health Transformation State Incentive Grant has a consumer study group that uses video and teleconferencing on many occasions so all who want to participate can participate.

Ms. Row is currently employed by a community mental health center that serves the State's largest geographic area: 5,000 square miles, with more than 200,000 people and 3,000 consumers. In recent conversations with consumers who live in rural areas, she learned of a number of issues that need attention. These issues include the following.

- Access: Transportation is the number-one concern. Some cities have a televan, but most people can not afford the fare. If people can not access services, our work is in vain.
- Employment: Consumers want to go to work. Our community mental health center worked with the vocational rehabilitation service to create a recovery through employment initiative. It is still hard to access, again due to transportation.
- Funding: We need much more funding to provide transportation for mental health, youth, and employment services.
- Housing: Consumers are learning skills (cooking, paying bills, etc.), but in a residential care home it is hard to use their skills if they are paying someone to do their cooking for them. A transitional housing situation is a place for them to practice their skills and see if they can move forward to live on their own.
- Peer-support and recovery-support services: There is only one credentialed recovery support specialist (RSS). The agency served 3,000 consumers in 1 year and the numbers are rising. We believe that there should be one RSS for every 25 consumers. More funding would make this possible.

The Oklahoma Mental Health Consumer Council received a consumer networking grant from SAMHSA to establish a Key Leadership Institute (KLI). Many people are willing to advocate for improved services, and upon graduation from this training they will have the skills to advocate effectively.

Many consumer organizations are working together in partnership. Services are being consumer driven and recovery oriented. The medical model is history that should not be repeated.

Comments from the audience

- There is a problem with Medicare not paying for medications. Consumers need medications from both medical doctors and psychiatrists. This is a big financial burden in the State today.
- The WRAP program is well received and works well. What would it take to have the WRAP program implemented in the school system?
- We are working toward employment; however, we shouldn't expect to live in poverty. Everyone wants to own his or her own home and have real retirement benefits. For example, the speaker said, even though he is employed, these simple dreams are beyond his means and reality.
- The advocacy organizations recently revised peer-support training to include substance abuse.
- New leadership in Oklahoma will carry us into the future. It is great to see active support and participation in this meeting from the commissioner. When people see their commissioner, they know they have support and someone who is working with them.

Texas

Carli Scales
Chairman of the Board, Texas Mental Health Consumers

Ms. Scales is the Executive Director for the Amarillo Mental Health Consumers. Her part of the State is very isolated in the Texas panhandle, and she is probably the only consumer in her area who is interested and knows what is going on downstate. Consumers in her part of the State are isolated and not exposed to the rest of Texas.

Amarillo Mental Health Consumers was formed in 1993 by 13 consumers who were very angry with the mental health system when the peer-support component of the psychosocial rehabilitation was taken away. In 2001, they started the Agape Center, the only peer-support center in the panhandle. Initially funded by Texas Mental Health Consumers, they became fee-for-service providers when grant monies were no longer available. When they did not receive enough referrals, they started reverse referrals, charging for people they were already working with. This was a very effective process; however, they are now back on a State-funded grant program.

Twelve members of the Agape Center recently were asked, "What are the major problems and concerns?"

The top five issues were as follows:

- trauma counseling;
- housing;

- the need to treat all mental health problems;
- personal help with filling out forms, budgeting, food, obtaining resources, and transportation; and
- the need for an anti-stigma campaign that actually dispels myths that discredit consumers and includes caseworker sensitivity training.

Other issues that are important, but are not in the top five, include supported employment, the need for proper diagnosis, more agency support groups, transportation, better quality services, and more help getting Social Security benefits.

When asked, "What was being done well?" people mentioned the following:

- crisis care, including mobile crisis teams and hotlines;
- Assertive Community Treatment (ACT) team was helpful, although some thought it was intrusive;
- resource library at the local Mental Health/Mental Retardation Center;
- help in paying for medications;
- assessment of symptoms and crisis follow-up; and
- a TV set, and soft drink and candy vending machines in waiting rooms.

The respondents said that the mental health system was lacking in the following ways:

- lack of holistic care, such as follow-up with problems caused by the side-effects of medication;
- lack of collaboration with medical care providers;
- sensitivity to consumers is a very big problem – caseworkers and providers are overheard joking about people with mental illnesses, which perpetuates stigma;
- limited consumer education on side-effects and drug interactions – one provider at the clinic says consumers should not be concerned about side-effects, as he does not want patients to stop taking medication if they know it could cause diabetes and heart disease; and
- staff shortages and retention of good providers is a major problem – consumers tell their story to one provider, and the next week they are repeating it to another provider.

Mike Halligan, M.A.
Executive Director, Texas Mental Health Consumers

The Texas Health Institute is contracted to carry out the organizational function for Texas, which is one of the States receiving a Mental Health Transformation State Incentive Grant (MHT-SIG). As part of an initial organizational meeting, Mr. Halligan facilitated a session with a group of consumers.

When asked, "What are the most important consumer needs and concerns?" consumers responded:

- consumers lack education about the mental health system and how it works;

- training bureaucrats to listen, not just hear consumers;
- implementation of "no wrong door," an initiative to help people served by several different programs, is still not operational;
- need for standardized curriculum for peer certification (what is the standard curriculum?);
- need for true, informed consent and accountability. Consumers are still being told, "here's your treatment plan…sign it" (how do you hold providers accountable?);
- we want to unite membership but can't get lists of consumers to contact; and
- workforce training is inadequate, and university training is based on old information.

When asked, "What is the mental health system doing right?" consumers mentioned the following:

- faith-based initiatives on suicide prevention and non-profit organizations are effective;
- there is a movement to self-directed care in San Antonio;
- there is a peer-run drop-in center in Waco;
- more centers are hiring consumers as peer specialists;
- collaboration among consumer groups; there are more than 200 consumer groups in Texas; and there are beginnings of a statewide network of consumer advocacy organizations;
- extending outreach to youth is occurring;
- public/private partnerships are occurring in mentoring; and
- businesses are becoming involved with a center in San Antonio.

When asked, "What is lacking?" responses included:

- funding for peer services;
- training;
- consistent funding (48th in funding for mental health care in the United States);
- prioritization for consumer-run services;
- recovery as a focus of treatment;
- clarity about what services exist;
- trauma-informed services;
- united consumer voice;
- service continuity; and
- courage on the part of administrative personnel, who generally operate out of fear; they want to help, but they are afraid of retaliation and afraid of losing their jobs.

When asked about solutions, consumers proposed:

- leadership training;
- advocacy training;
- more involvement with legislators;
- more unity;
- emphasis on employment and basic needs (e.g., housing, food, transportation);
- use of advanced directives to inform care;
- self-directed care;
- consumer as a full partner in treatment decisions; and
- consumer choice of providers.

Comments from the audience from Texas

- In Dallas, the system is different; there is no mental health/mental retardation (MHMR) center and though not perfect, people are happy with our Medicaid managed care system. Features of this system include: both mental health and substance abuse treatment; open access and no waiting list for services or medications, including new generation medications; peer support that is funded and staffed; and an administrative authority function that is separate from the provider function, which allows dissatisfied consumers to go to a different provider.
- Consumers in Dallas have been very active and have improved the system with the police department. Every police officer in Dallas receives a required 40 hours of mental health training that includes 2 days of mental health information, and 2 days of scenario training; on the fifth day, consumers attend and tell their stories of recovery and experiences with the criminal justice system, which gives officers a different view from what they are accustomed to seeing. Recently there was a mental health conference in Dallas for officers and their spouses that included consumers telling their stories of recovery. Peer-to-peer services are being developed for police officers who are experiencing depression and stress. Mental Health America does training on medication management and adherence. There is a program that includes peer-to-peer assistance for veterans that will allow vouchers for private care if they do not want to go to the VA.
- Prosumers, an organization in San Antonio, is an empowerment group that focuses on wellness, not on pathology and illness. While funding is helpful, they don't wait to receive funding before they do anything; they hold fundraisers. When people see consumers doing well, it results in changes in public perspective. The organization's focus is on wellness, which is different from the typical consumer perspective; it's a different mindset. We have consumer-to-consumer teaching of wellness and consumers helping consumers (e.g., in the aftermath of Katrina).

  Prosumers use a model called salutogenesis, the study of health and building on strengths and assets, focusing on wellness with three major parts:

  - realizing you have choices and you can make a choice on how you handle your situation and problems (e.g., when getting angry);

- finding the resources that you need; and
- having something meaningful to do in your life (e.g., we encourage volunteering).

Special Presentations

Serenity House Players of Red Rock West

This group of 18 performed a musical skit with no spoken words and included audience involvement that portrayed the journey of recovery. The audience was moved and inspired by the truth and authenticity of this heartfelt and moving performance. Recovery is possible!

CMHS National Advisory Council, Subcommittee on Consumer/Survivor Issues

Gilberto Romero, Member since November 2007
De Sol A Sol, Santa Cruz, NM

Mr. Romero is a member of the CMHS National Advisory Committee's Subcommittee on Consumer/Survivor Issues; he shared his thoughts on wellness and recovery. He is a strong advocate for improving the social aspect of health. The six aspects of wellness are social, intellectual, emotional, spiritual, physical, and occupational.

Mr. Romero says that he stopped looking for a job when he became career-oriented; attitude is critical. Knowledge, age, and experience are not as important as attitude. Now he works in media and addresses wellness and attitudes in a daily 3-minute radio show. One of the greatest compliments he got was when someone said to him, "Thanks for making mental illness groovy." What he does is help demystify mental illness by dialogue and talking about mental illness; it is no longer a taboo. He emphasizes the following issues.

- What does it mean to be consumer and family driven?
- Governance: Who are my representatives? How do I access my representatives?
- Balance between medical health and mental health; some of the best help I've received has been from my medical doctor.
- Social structure: we have to look at the social frustrations, and the difficulties and inadequacies in the helping systems.

2008 CMHS National GAINS Center Impact Award

Kay Rote, the Executive Director of the Oklahoma Mental Health Council, proudly announced that last week her organization received this award, the first national award that they have received.

Common Themes Expressed Throughout the Meeting

Common themes expressed throughout the meeting were identified and discussed by participants. They include the following topics.

Concerns

Recovery Support Services

- For some, it is difficult to obtain transportation to services, especially in rural areas.
- There is a great need for safe and affordable housing.
- Destitution and poverty can occur as a result of having a mental illness.
- There are employment ceilings – only a certain level can be attained due to various factors.

Funding of Programs

- Overall, there is inadequate funding of mental health programs.
- Not all available or needed services are funded by Medicaid.
- Fundraising is important, but how can we do more fundraising when other sources are not available?

Health Care

- There is a general lack of affordable and accessible medical care.
- In health care, there is little integration of substance abuse treatment and mental health services.
- In the VA, more problems are being identified related to traumatic brain injury, post traumatic stress disorder (PTSD), and history of earlier trauma that needs to be addressed.
- The use of the medical model in personal care is outdated; there needs to be more of a focus on wellness.
- The criminal justice system is a major provider of mental health services – are mental health services in the criminal justice system adequate?
- More training is needed for providers in terms of cultural competency.
- Better diagnostic services are needed; often times a consumer is given an improper diagnosis.

Communication

- Providers are not listening to what consumers are saying.
- Peer input is needed in the planning that occurs at the State level.
- In general, there is poor communication between providers and consumers; how can this be improved?
- The mental health system demonstrates a lack of understanding of mental health consumers; we need to incorporate consumers into policy and discussion.

Peer Support and Peer Run Services

- There is a lack of peer involvement at all levels.
- Peer support services are being co-opted; there needs to be more accountability and responsibility in these situations.
- Peers face the challenge of advocating within the roles and boundaries of the organization in which we work.
- There is a lack of diverse training opportunities and of standards in training.
- There is a lack of provider involvement - notably in the peer-to-peer support (e.g., in disaster response, or in creating accessibility to services).

Outreach

- There must be attention paid to reaching all consumers, including rural areas and desolate parts of a State.
- Media messages about mental illness must be addressed, especially messages about people with mental illnesses being violent.
- There are difficulties and disparities in the lesbian, gay, bisexual, transgendered, and questioning communities, including stigma and discrimination.
- Veterans are having difficulty with suicide – special attention is needed in reaching out to the veteran community with suicide prevention resources.

Successes

- Services are becoming more recovery oriented, trauma informed, and consumer driven.
- More peer support is occurring in the Department of Veterans Affairs.
- Peer support works, including in times of disasters and when there is little to no funding.
- Values-based practices are helpful and rivaling evidence-based practices; there is more emphasis on self-help, empowerment, and consumer choice.
- In general, there is more collaboration among stakeholders leading to the sharing of resources and a better understanding of each other. This is true amongst consumer groups as well, despite times when we do not get along or get competitive with each other.
- There is a greater focus on wellness and addressing the whole person.
- Psychosocial rehabilitation (PSR) programs within psychiatric facilities have been helpful, including in veteran programs and in community mental health centers.
- Personhood rather than patienthood is being emphasized.
- The public's view of consumers has improved; consumers are now viewed as citizens having equal rights and having a right to "sit at the table."
- The Wellness Recovery Action Plans (WRAPs) have increased in use, and are being used in schools.

- Stories of recovery, our personal stories and narratives, are being heard, helping people begin to understand us better and to demonstrate that our successes and recovery are real.
- The increased use of telehealth by consumers is helping increase access to care.
- Consumer participation in research is not just the consumer being studied, but includes consumers who participate in deciding what research should be done and promoting research that shows the benefits of consumer involvement.
- Consumer involvement standards are being developed in Oklahoma. They will address the following questions: What does it look like to have true consumer involvement? What are the standards that would assure accountability and responsibility?
- Self-direction and shared-decision making are gaining momentum.
- Cultural competency planning is being integrated into services.
- The use of faith-based services has added more choices of locations where a consumer may receive services.

Small Group Reports

Participants broke out into small groups to discuss four goals of the President's New Freedom Commission on Mental Health report. The following presents the findings and recommendations.

Goal 1: Americans understand that mental health is essential to overall health.

What is working?

- Being a friend
- Using people-first language
- Consumer responsibility
  Example - consumers can carry a list of medicines to all doctors' appointments, as well as keep a list on the refrigerator. Keep the list updated. Take personal responsibility not to have conflicting medications. Make emergency numbers well visible. Wear a panic alert bracelet with all medications, therapist numbers, and who to call in case of emergency.
- Shared responsibility - making sure *all* providers know what medications patients are taking
- Speaking to the public or legislators
  Example - ask the audience, "Do you know anyone who has mental illness or who has attempted or died by suicide?" Most hands will go up and you will find out that the person will be someone who is a very close relative/friend. Presume that most people do know someone; this gives them an opening to talk about mental illness.
- Sensitivity training
  Some jurisdictions require sensitivity training for law enforcement; they all have family members who have been affected by mental illness, so they can relate.
- Prosumers organization
- Grassroot efforts by consumers

Where is help needed?

- Disparity in health insurance and limited coverage for mental health
- Some consumers cannot get life insurance
- Integrating mental health and physical health, and the creation of a health home
- Fragmented education and information from the mental health system
- Dealing with the side-effects of medications
- Improved medications with less severe side-effects
- Labels, stigma, and self-stigma
- Consumers seem invisible to the general public

Recommendations

- Promote insurance parity
- Consumers should release information to all of their doctors to avoid problematic medication interactions and to ensure a continuity of care
- Work on public policy; pursue the Healthy People 2010 initiative and get involved
- Provide loan forgiveness for those who are in debt and financial difficulty as a result of major illnesses
- Promote disclaimers in movies that inaccurately depict mental illnesses, "This does not accurately portray people with mental illnesses."
- Consumers need to speak with one voice and model recovery

Goal 2: Mental health care is consumer and family driven.

What is working?

Discussants found that this goal is not anywhere close to being achieved; however, such approaches are found in some places, including the following:

- community mental health courts;
- Prosumers, a consumer-run organization;
- WRAP plans that are peer-driven rather than professional-driven;
- advanced directives for psychiatric care;
- education of peers, family, and public about mental health;
- support groups, such as In Our Own Voice, Peer to Peer, Depression and Bipolar Support Alliance (DBSA), National Alliance for Mental Illness (NAMI), and the Federation of Families for Children's Mental Health;
- consumer councils; and
- innovations in mental health, especially those created by peers.

Where is help needed?

- There is professional ignorance that consumers should and can be at the table when discussing care. Additionally, sometimes ideas/programs are co-opted and watered down.
- Public education is needed on mental health.
- Provide a better way for people to find needed services.
- More consumer-oriented funding is needed.
- Provide grant writing training for consumers.
- It is a challenge to find enough peers to run peer-support services; a vast army of peers is needed to run peer-run services; referrals from providers will help to find peers who can provide these services.

Recommendations

- More education and information to those who come in for services; this will be empowering and consumers will become more active and involved
- More family-to-family services
- More programs such as Hope for Tomorrow, Incorporated (which is committed to the belief that incorporating a holistic approach to the treatment of all addictive disorders) and Visions for Tomorrow (a series of workshops for direct primary caregivers of children and adolescents with brain disorders, funded by NAMI in Texas)
- Funding, funding, funding

Goal 3: Disparities in mental health services are eliminated.

What is working?

- Focus on alternatives for treatment, promote choice and healthy living; be sensitive of cultural differences and become familiar with alternatives that are valued in other cultures (e.g., *curanderas*, medicine men, and traditional healers)
- Promote a holistic approach; treating the person as a whole (mind/body/spirit), not just the symptoms or a diagnosis
- Value consumer organizations
- Money, money, money
- Use current technologies to share medical information among a person's various providers
- Focus on personal empowerment as advocates and to teach others
- More peer support and education
- Cultural competency training
  There are language barriers as well as cultural barriers; solutions involve extensive training in cultural competency. People in Oklahoma are being trained by the Federal government in cultural competency and coming back to train others, a training-of-trainers model.

- Research on ethnic minorities
  There are very few numbers of minorities in case studies in evidence-based practices. See research protocols and who was studied; different ethnic/cultural groups have different sensitivities to medications.
- Move to values-based over evidence-based practices
  Values-based practices offer hope, encourage self-determination; consumers learn how to value themselves; values-based practices are more person-centered and provide for individualized care.
- Recovery- and consumer-driven care plans
- Standardized protocols
  There is standardized care in the medical care field (e.g., protocols for treatment following a heart attack); in mental illness, it's all over the place; need more standardized protocols for crisis care.
- Person-first language
  For example, people don't say, "there's the 'broken leg'" but do say "there's the schizophrenic." Instead we should say "there's a person who is dealing with schizophrenia."
- Look at the person as an individual, even within ethnic/cultural groups.

Goal 6: Technology is used to access mental health care and information.

What is needed?

- Find out through research if online training is effective.
- In the recording of data in reporting systems, remember that information can be misreported and data can be misused; information on medical care and illnesses can be distorted or skewed. There is a need for ethics behind the process. Consumers must be able to access, review, and if necessary, contest the data about themselves. There should be different levels of access for different people. It can be used effectively, for example, if it keeps someone with mental illness out of jail because the information was readily available to an officer. On the other hand, medical insurance/life insurance can find out about consumers and use the information to deny coverage.
- Telemedicine - it is possible to hook someone up to a machine that can take vital signs; operations can be done under the guidance of a physician who is miles away. Does distance medicine help when people can't get face-to-face time with a provider? Maybe it can help if someone can get medication right away instead of having to wait. How effective is an interactive session with a counselor online? Some consumers like the distance, but no one can see what else is going on in the room.
- Can peer support be done at a distance?
- By using distance technologies, we can include people who are at a distance. Video teleconferencing is interactive and available in more places.
- Online chat lines exist. Providers can talk with large numbers of people at a time.
- Webinars are occurring more often; there may be more learning, but will we leave out those who don't have access or don't have access to the newer, faster computers?
- Many Web sites have great information for consumers. For example, there is one that provides information on how to access Medicare/Medicaid, wellness, and how to take care of yourself.

But do people apply what they learn? How effective are these technologies? Is information enough?

- Peer services should be part of technology.
- Health care technologies should be readily available for providers and consumers for training and for information.
- Develop videos and public service announcements (PSAs). Peer organizations can localize SAMHSA PSAs related to the "What a difference a friend makes" campaign. Make PSAs more plentiful and shown at all times of day.

Meeting Summary

At the end of the meeting, attendees were asked if a 1-day regional meeting was sufficient time and what other activities should be undertaken at future meetings. Participants generally agreed that a 2-day meeting would be useful. A longer meeting would provide opportunities for the following.

- More groups would be able to travel and participate; there would be more time to tell each other what they are doing, what is working, continue networking, and have more displays.
- Take more of a lifespan approach-focus on youth, elderly, and other different types of programs.
- There would be time to showcase many more programs about which people are not aware.
- There would be time for more "how-to" sessions. For example, many participants said they would like a session on how to write grants.

At the conclusion of the meeting, each of the State presenters was asked to offer a comment on what they learned or their impressions. They reported the following.

- I'm always encouraged by those who are willing to share and help others who are working on the same things.
- We are all empowered to go out to help other consumers and work together jointly.
- We heard wonderful ideas…more aware of technologies that I can use. In small-group session, many wonderful ideas and topics were shared.
- I was amazed about how much we know about the issues and have the answers within ourselves; we need to make use of the knowledge we have ourselves. For example, I would like to learn more about addressing the reductionist mindset.
- In a 2-day meeting, you can use technology to include others.
- The underlying theme is that we need more consumer-driven programs with family involvement.
- I like the networking; I like being with other consumers; we hear the good, sad, real…that's the strength of these meetings. I want to see real change, big change for people who have been left out of life – more advocacy on how we make these things happen now.
- I like to hear what is going on in the different States. I'm so isolated in my rural area. There's a bigger world out there.

- We have heard what it has been like to be a leader in consumer mental health; it is so frustrating and sad, yet rewarding. I can't imagine doing anything else in my life; I wouldn't be doing anything else. That's what peer support can do.

Closing Remarks

Ms. Schauer thanked the State representatives for their presentations, sharing effective strategies that have worked in their particular States, and identifying further work that can be done. She thanked attendees for sharing their personal stories and speaking out on issues about which they care deeply. She encouraged them to go back to their States heartened and inspired, and ready to motivate those in the consumer communities at home. Additionally, Ms. Schauer earnestly encouraged those in attendance to contact her with their concerns.

APPENDIX

SPEAKERS

Debra Bradley
Peer Support Specialist/Consumer Liaison
Mental Health Planning Council
Shreveport, LA

Linda Donovan
Director, Network of Arkansans for Rights, Recovery and Self-Determination
Little Rock, AR

Carole Glover
President, Meaningful Minds of Louisiana
Lafayette, LA

Ken Gunnells
Credentialed Peer/Recovery Support Specialist, Oklahoma Mental Health Consumer Council
Tulsa, OK

Mike Halligan
Executive Director, Texas Mental Health Consumers
Dallas, TX

Marcia Prophet
Consumer Specialist, Behavioral Health Collaborative
Santa Fe, NM

Cindy Row
Credentialed Recovery Support Specialist, Grand Lake Mental Health Center
Claremore, OK

Carli Scales
Chairman of the Board, Texas Mental Health Consumers
Amarillo, TX

Shela Silverman
President, Mental Health Association of New Mexico
Las Vegas, NM

Eddie Smith
Peer Support Specialist, Veterans Administration Medical Center
North Little Rock, AR

Terri White
Commissioner, Oklahoma Department of Mental Health and Substance Abuse Services
Oklahoma City, OK

FACILITATOR

Kathy Muscari
Director, Consumer Organization and Networking Technical Assistance Program (CONTAC)
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