### Substance Abuse and Mental Health Services Administration Center for Mental Health Services National People of Color Consumer/Survivor Summit One Washington Circle Hotel Washington, DC November 9-10, 1998

### Overview/Introduction

Over the past several years, the Center for Mental Health Services (CMHS) has sponsored teleconferences for consumers/survivors of color to identify key issues and needs and to facilitate networking among this community' s leadership. Members of this community have only met informally by chance or periodically at consumer conferences, seminars and trainings (i.e. CMHS events, Alternatives, IASPRS, NARPA).

The impact of health care reform, notably through managed care initiatives, has been identified as a significant concern. This encompasses issues such as:

•Meaningful participation in the design, delivery, and evaluation of these systems;

•Access to culturally-competent, high-quality services;

• Protection of human rights;

• Peer-operated services; and

• Provision of essential community-based services, such as housing and employment.

CMHS planned an in-person invitational meeting for Consumers/Survivors of Color (e.g. African American, Native American, Hispanic/Latino & Asian/Alaskan/Pacific Islander) from across the nation to further examine these and other issues and provide recommendations on how they can be addressed. The meeting—the first of its kind ever assembled—was held in Washington, DC, on November 9-10, 1998.

This document was prepared to provide the participants of the Summit and other interested parties with a summary of the meeting.

### Day I

1.

Opening Ceremony

Gilberto Romero opened the conference with remarks about how there has

always been a POC community working on behalf of people with mental illness. He dedicated the conference to a friend who had taken his life earlier in the year.

Mr. Romero invited the conference participants to stand in a circle and join hands. He led them in breathing exercises designed to relax them and help them focus on the tasks that lay ahead for the next two days. He then opened a ceremony with an invocation to the Creator to bless the group's endeavor and guide the participants in their work as a group and as individuals. The real work, he noted, was not in Washington, DC, but at home, and he asked the Creator to guide the group as they work to alleviate suffering among their friends at home.

### II. Welcoming Remarks and Meeting Purpose

Paolo del Vecchio of the Center for Mental Health Services (CMHS) formally welcomed the conference participants. He thanked participants for traveling over long distances and through illnesses to join the conference, and expressed his gratitude to the conference planners: Ting Mintz, Jacki McKinney, Gilberto Romero, Arthur Evans, and his CMHS colleagues Iris Hyman and Carol Schauer.

Mr. del Vecchio introduced the first speaker, Dr. Deloris Hunter, the Associate Administrator for the Substance Abuse and Mental Health Services Administration (SAMHSA) Office of Minority Health.

Dr. Hunter noted that Dr. Bernie Arons, CMHS Director, was present earlier in the morning to meet the participants and attended the conference opening ceremony.

Dr. Hunter discussed SAMHSA' s past and current efforts to improve consumer services. She identified CMHS' s Consumer Affairs office as a key example of SAMHSA' s commitment to fulfill its pledge to provide consumers with quality, culturally and linguistically appropriate services. She applauded the office for its work in these fields.

Dr. Hunter acknowledged that past teleconferences have not provided enough networking opportunities for people working on diversity issues. She noted that it took a full seven years for this People of Color Conference to actually take place. She reiterated SAMHSA' s resolution that no one should suffer from a lack of services or inadequate services and hoped that this conference would provide thought-provoking and concrete ideas for SAMHSA and CMHS to use as they incorporate diversity issues within service design and delivery.

Over the past few years, SAMHSA has explored a lot of potential program ideas. One new program will spend four years to examine the effectiveness of consumer services. Dr. Hunter wants SAMHSA to move beyond the traditional walls of public health and explore ways to advance other programs. Toward this end, SAMHSA recently sponsored a series of regional meetings to identify services that consumers need most, such as jobs, peer-run services, and housing.

Dr. Hunter stressed the following:

•SAMHSA' s top priority is to ensure that consumer' s rights are always protected;

•SAMHSA is committed to changing the service delivery system so that it can meet the needs of diverse populations who require its services;

•SAMHSA wants to hear directly from consumers about how the services it develops impacts them and their families, particularly within managed care settings; and

•SAMHSA' s staff is committed to ensure that the services it provides are high-quality and culturally and linguistically appropriate.

SAMHSA' s ultimate goal for this summit is to define ways to reach and provide culturally competent and effective services for consumers of color. These consumers often receive little or no help from the present system, which tends to leave them feeling as if they are a forgotten people. Many are unable to advocate for themselves and are at-risk for a host of traumas, that some consumers present, at this summit have themselves survived.

SAMHSA has vowed to change these circumstances and recognizes that it must move forward and use less traditional methods to achieve this goal. SAMHSA needs to identify effective and creative ways to reach the most vulnerable people and must work with consumer advocates of color to achieve this goal. The purpose of this summit, therefore, is to:

•Establish a shared, equal partnership with Consumer/Survivor' s of color to provide SAMHSA with concrete ideas for actions to be taken which will result in Behavioral Health Care service improvements for the most under-served, under-represented and vulnerable communities in our nation.

•Establish a clear and focused common vision between SAMHSA and Consumer/Survivor advocates of color.

•Establish an action plan to achieve all goals identified.

3.

Introduction of Facilitator

Mr. del Vecchio introduced the Summit' s facilitator Arthur Evans, Ph.D. Dr. Evans was chosen to be facilitator because of his being a person of color and because of his life commitment and dedication to his community and to his being a Behavioral Health Professional. He is a licensed clinical psychologist and Director of the Office of Managed Care for the Department of Mental Health and Addiction Services in Connecticut; co-owner of a multicultural clinical training company in New Haven, Connecticut; and faculty member of the Yale University School of Medicine.

Dr. Evans thanked the planners for inviting him to facilitate the Summit. He noted that he is generally the only person of color at many of the conferences he attends on systems development, indicating that there is no strong voice from communities of color on this important issue.

### IV. Overview of Managed Care and Cultural Competency

Dr. Evans introduced the issue of cultural competency as a key item within managed care today. He noted that this provides the POC community with an opportunity to develop an effective voice within managed care settings. The POC community should identify points where they can exercise leverage within managed care and thus have an impact on services and delivery.

Dr. Evans asked participants to think about their expectations and goals for the Summit. During the participant review process the Summit coordinators found out that many shared the same or similar goals, which fell into the following overall categories:

### Personal Professional Development

•Learn about best practices used around the country.

• Strengthen networking skills and make new contacts.

• Obtain input and insights on what others are doing to better serve minority populations in their community.

•Become more knowledgeable about the issue of cultural

competency/diversity as it relates to Behavioral Health Service delivery.

### Group Development

• Help the group achieve unity in its purpose to serve consumers/survivors of color.

- •Network to find ways to immediately implement ideas.
- •Establish an atmosphere of openness, healing, and trust.
- Provide mentoring/support to new comers to the movement
- Develop an action plan that compliments the groups agenda.

• Create a strategic plan to coordinate and implement activities and initiatives.

• Create a comprehensive marketing/media campaign with CMHS.

### Managed Care/Policy Issues

•Be educated and better informed about Managed Behavioral Healthcare administration and policy.

•Establish the necessary community linkages so information can be disseminated consistently and effectively.

### Service Delivery

•Help Consumer/Survivors of Color obtain the resources to be better organized.

• Develop approaches to influence and impact critical decisions that affect communities of color.

•Assess how other states respond to issues of discrimination.

• Design processes and procedures to ensure cultural competence.

• Find out how the Federal government can implement the ideas we discuss here.

•Establish partnerships with government agencies

Dr. Evans delivered a condensed version of his presentation on managed care and identified opportunities to incorporate cultural competency within the service delivery system.

His observations include the following:

•Managed care has become a target among many patients and consumers but in reality, the old fee-for-service system was not accountable to anyone, especially patients. It also did not work for people of color for several reasons. It was more interested in delivering lots of services than in providing accountability for what was delivered. It provided little opportunity to measure quality of care, and did not consider patient satisfaction at all. Consumers had no voice in this system.

•By contrast, managed care systems emphasize accountability, most obviously in the area of cost containment but also in terms of quality. This provides an opportunity for consumers and people of color to have an impact on how they receive services.

Customer satisfaction has emerged as a key component in the credentialing

process that many employers/payors now demand from their health care providers.

For example, cultural competency is ultimately an issue of accountability to the consumer. It means that the provider is paying attention to patient needs and working to provide better services. This is an important point of leverage for POC consumers to use if they want to make an impact on the system. POC need to identify other points of leverage that they can use in dealing with the managed care industry.

Finally, managed care principles have become the norm within health care, bolstered by the fact that few employers will pay for services without demanding accountability for their health care dollars.

•Managed care has forced providers to deliver more services with fewer resources. Providers are expected to view each patient as a whole person and not just someone with an isolated physical or mental health need. They are expected to understand various components within their patients' lives and how they impact their recovery. Providers are learning that it is beneficial for them to recognize, identify, and incorporate culturally competent services into their overall treatment objectives and plans. POCs can benefit from this because they advocate for services that are cost-effective.

Dr. Evans identified the following key points where consumers can readily influence managed care organizations (MCOs):

- Consumer satisfaction;
- Advisory groups or councils;
- · Evaluations and performance standards;
- Monitoring of services used by consumers;
- Credentialing organizations such as NCQA that can incorporate cultural competency into customer satisfaction measures;
- •Clinical guidelines and protocols;
- Provider panel composition; and
- Cultural competency certification– Temple University offers a course on offering culturally competent services.

**Conclusion**–We are now at a point where the climate is right for us to move forward and help shape managed care to meet our needs. Today' s highly competitive managed care climate offers substantial opportunity to demand culturally competent services from providers. Consumers should seize the opportunity to become a resource for MCOs as they develop services to meet diverse cultural and linguistic needs.

Ting Mintz and Jacki McKinney offered examples of how consumers can individually and as a group take advantage of the customer-oriented climate in managed care:

Advocate while you educate. Consumers and their peers have survived the kinds of experiences that MCOs cannot ignore and need to view as being relevant and valuable. The sharing of experiences and struggles with those who are in power need to be encouraged – especially by people of color.
Get to know people within managed care systems. Consumers should get on their MCO' s quality assurance committee – and ensure that there is adequate support to be educated so involvement/participation is truly effective and meaningful.

• **Understand patient rights**. Providers need to be accountable, educated and sensitized to the rights of consumers.

Mr. Mintz emphasized the importance of group cohesion—' sticking together' – to initiate change and ultimately create and sustain a movement that can change the system. He welcomed the newcomers who were present and encouraged them to embrace advocacy as a way to work with the system in order to change it.

Ms. McKinney emphasized that group must leave with the groundwork set for joint efforts to impact managed care. She echoed Mr. Mintz' s conviction that the group must stay together, be proactive, and network.

Ms. McKinney stated that she is grateful to managed care; without its services, she would not be here today. She is proof that this system can work if consumers " carve themselves in". She urged attendees to take advantage of SAMHSA' s invitation to partner with them and hoped that they would leave feeling more powerful.

### V.Break-Out Session–Discussion and Identification of Issues Relating to Health Care Reform within People of Color Communities

Participants broke into separate discussion groups that focussed on identifying cross-cutting impacts of health care reform. Groups addressed topics on resource development; access to services; networking and organizing; service delivery; and education. Each group was composed of four or five participants

| •Group 1:<br>Donald Clark<br>Alma Lee<br>Delois Scott<br>Facilitator:                            | Louis A<br>Gilberto Romero | •Group 2:<br>Billy Brown<br>Kathy Cox<br>Randy Hack<br>Travis Sandova<br>Facilitator:                      | ıl<br>Ting Mintz     | Connie A |
|--------------------------------------------------------------------------------------------------|----------------------------|------------------------------------------------------------------------------------------------------------|----------------------|----------|
| •Group 3:<br>Katsumi Kenat<br>Laureen Jackse<br>Lonnie Russell<br>Conseulo Thiel<br>Facilitator: | on<br>on                   | •Group 4: And<br>Cookie Gant<br>Pearl Johnson<br>Russell Pierce<br>Diane Stanton<br>Facilitator:<br>Walker | lrea Cooke<br>Kineke | Bermudez |

plus a designated facilitator. The following people composed the different groups:

| •Group 5:      |               | Celia |
|----------------|---------------|-------|
| Regina Duvall  |               |       |
| Ronald Gibson  |               |       |
| Janet Sheppard |               |       |
| Facilitator    | Maria Maciera |       |

Working groups were provided with suggested guidelines to follow:

•Ask for a recorder and designate someone to make a brief presentation at the conference report session.

• Review the purpose of the working group:

For each participant to discuss how people of color consumer/survivors in their particular State or region are being positively or negatively affected by health care reform developments.

• Sample questions for the working group to focus on:

–What are the barriers to recovery for people of color within managed care?

- What are the opportunities that managed care brings?

- What are the issues, as people of color and as consumers, that are faced in overcoming these barriers and in realizing opportunities?

### VI. Reports–Group Discussions and Identification of Cross-Cutting Impacts of Health Care Reform

All the discussion groups concluded that consumer POC present unique issues that make them more vulnerable to mistreatment from MCOs. One group commented that consumers carry too much ' patient baggage' for MCOs to handle while another noted that many MCOs are just too rigid to handle the multiple issues and needs presented by consumer POC.

Other criticisms of the managed care system include:

•Service Reduction– Some MCOs that have won Medicaid contacts have drastically reduced behavioral health service hours and staff, including access to case management staff. Others have reduced the hours of drop-in centers that many consumers consider key to their treatment.

• Competition with Other Consumers/Patients – Some MCOs will reduce behavioral health benefits to compensate for rising costs of primary care. This also underscores the issue of stigma.

• Lack of Provider Choices– MCOs tend to limit provider choices. Consumers are losing access to providers with whom they have built a relationship and trust.

•Capitated mental health benefits usually translates into strict limits on office visits regardless of the need for more services. Mental illness benefits are usually capped at a much lower rate than physical illnesses.

• Language Difficulties – Consumer POC who are not fluent in English face additional access problems. Moreover, English-speaking consumers are confounded by overly technical, jargon-laden language used by many MCO staff.

Participants also offered solutions to these problems:

•MCOs can encourage the self-help movement and sponsor peer-run services. This would increase consumer satisfaction, which is an important factor for MCOs seeking accreditation from outside organizations.

•Get involved with MCO committees. Many MCOs are required to have patient representation on their committees. Work to ensure that cultural competency is a real factor considered by quality assurance committees and link it to client satisfaction, which plays a major role in an MCO' s success. Proper care should be mandated and MCOs are willing to be held accountable for this.

•SAMHSA can build up consumer POC influence by hiring and promoting them for their personal experience as much as they would for their formal educational background. •Establish a POC Leadership Institute that will focus on POC issues and treatment alternatives so that MCOs are not left as the only treatment option for consumers.

• Carry voter registration cards and encourage other consumers and consumer POC to register to vote. Provide transportation so they can reach polling sites. This can counter the legal and political trends that are harming people with mental illness and possibly influencing managed care decision-making.

• Consider keeping a fee-for-service option. Mandating managed care ultimately reduces consumers' choices and does not take each individual person' s best interest into consideration.

Participants also identified other things which need to be considered by MCO's and state agencies.

•More MCO' s need to accept Medicaid and Medicare recipients.

• Ensure that MCO sites are in a place accessible by public transportation.

- •MCO' s should be encouraged to hire consumers/survivors.
- •Need to incorporate alternatives to traditional treatment in their service arrays.

Participants also identified other problems not directly related to managed care but seem to be influenced by it.

### VII. Prioritized Findings of Cross-Cutting Issues

Participants discussed the various issues identified by each Break-out group.

### A. Resource Development

Certain resources are required to accomplish our common goals:

- Political contacts
- Technical assistance
- •Grant writing and funding support
- •Training

#### B. Access to Services

SAMHSA/Center for Mental Health Services

General Service Issues:

•Lack of user-friendly services

- •Capitation/service limitations
- •Case management tracking and monitoring systems
- •Choice of services/providers
- Language barriers
- •Responsive Grievance and Appeal process
- •More flexibility in hours that services can be accessed

Clinical Issues:

- Misdiagnosis
- Overmedication
- Medical necessity

Legal/Criminal Justice Issues:

•Ensure provider accountability to Patients Bill of Rights

- •Train police to properly assist and work proactively in crisis situations
- •Improve and strengthen linkages to and within the criminal justice system
- •Increase access to appropriate legal assistance

### C. Networking and Organizing

- •Create a Newsletter
- •Establish connections to other Behavioral Health periodicals/publications

•Create a national database of Consumer/Survivors of Color who are active in their communities

- •Establish protocols for the dissemination of information
- •Implement organizational development activities

•Establish relationships and partnerships with family members, providers and community leaders of color.

### D. Service Delivery

- •Inadequate discharge planning
- •Continuity of care
- •Spiritually-oriented care options and other non-traditional or holistic services
- •Other basic services necessary to ensure successful recovery
- •Housing
- Education

•Rehab/Voc.

- •Choice of therapist
- •Services located at a single site/' one-stop shopping'
- •Peer-run services
- •Develop recovery based models
- •Continuous Quality Improvement (CQI) Standards
- •Increased flexibility and responsiveness to individual service needs

# E. Education

- •Education about managed care services and principles
- •Leadership development
- Peer education
- •Training specific to issues impacting " Communities of Color"
- •Outreach to religious communities and other provider communities/options
- •Combating stigma/prevention efforts
- •Understanding the state and local mental health systems
- •Career development, including for careers outside the system
- •Public and consumer awareness/education campaigns and marketing about "Co-occuring Disorders (dual diagnosis)"
- •Information on new pharmacological & ethno-pharmacological activities/studies

# Day II

# VIII. Review of Day I Findings

Dr. Evans opened the second day of the conference by reporting on a morning meeting held by the Summit coordinators. The planners discussed how to re-organize the day to better meet the needs identified by summit participants to better serve the people in their home communities. They decided to focus on responding to these needs and suggested that the conference devote the first hour after the lunch break to address two specific issues. The first would help participants gain an understanding of managed care and how it can be impacted, and the second would identify their rights as consumers in terms of grievances and appeals. Additional workgroups would be formed to address these issues, and there would be time set aside to identify other areas where participants would like technical assistance.

# IX. Presentations by Supportive Organizations

The conference planners asked representatives from several organizations involved in providing services to people with mental illness to make

presentations to the conference about their efforts relative to people of color within their agency, and explain how they could act as resources or partners for the conference group. Each representative was asked to limit his or her presentation to five minutes.

Several public and private organizations were invited to present to the conference and discuss their work in providing and improving services to people of color. A summary of their presentations follows.

• Department of Health and Human Services, Office of Minority Health (OMH)– Guadalupe Pacheco discussed the Hispanic Agenda for Action established in 1995 and formally adopted in 1996 by DHHS Secretary Donna Shalala. The agenda includes a nine-point plan to incorporate Hispanic-oriented services throughout the agency, including: increasing Hispanic representation within DHHS at all levels; collecting specific data on Hispanics and various Hispanic subgroups; including Hispanics in research and clinical trials; and addressing language barriers to ensure compliance with the Civil Rights Act. A strong monitoring and evaluation component is included.

•Office of Minority Health, SAMHSA–Angelia Hill and Dr. Cecilia Casale discussed SAMHSA' s own OMH office and its agenda. Examples include initiatives with tribal colleges; its work on the Hispanic Agenda; an Asian/Pacific Islander initiative; and interagency agreements emphasizing education and internships for minority students. Moreover, SAMHSA' s OMH is paying particular attention to minority consumer concerns and has framed cultural competency as an essential vehicle to use in service delivery.

•CMHS, SAMHSA– Harriet McCombs discussed the goals she established for her own work within SAMHSA: (1) setting up cultural competency standards and guidelines to be reviewed by consumers and reported in a consumer report card; and (2) gather data on how people of color are responding to managed care by hosting focus groups and examining responsiveness to POC consumer needs, especially those enrolled in Medicare or Medicaid. Carole Schauer briefly reviewed the Consumer Bill of Rights. Both stressed the high-level interest in health care reform–including that of the President–and the fact that the President has endorsed the Consumer Bill of Rights.

•CMHS Community Action Grant Program– Santo (Buddy) Ruiz reviewed the grant program, which focuses on knowledge, development, and application of model practices that can be replicated in certain communities. He noted that 11 of 31 awards made in 1998 went to Hispanic organizations. Two of these groups held the highest scores of the 80 applicants. CMHS also offers grants for new conferences.

•National Mental Health Association– David Nelson discussed NMHA' s work on the state level, which includes developing leadership programs for consumer POC, health care reform efforts and how they impact consumers, and NMHA' s resource center. The latter offers a clearinghouse; technical assistance resources, including materials in Spanish; and grants to support efforts to create coalitions for community groups focusing on specific care topics.

•National Empowerment Center (NEC)– Laurie Ahern explained that NEC is a technical assistance center funded by CMHS and is made up of ex-patients and survivors who want to help others in the recovery process. NEC provides videos, books, and information packets that address issues ranging from clinical topics to user-oriented services. They develop curricula and work with behavioral health professionals to identify which services help consumers or are counter-productive. They also sponsor conferences on topics such as treatment alternatives, and recently cosponsored a conference on recovery with Boston University' s Center for Psychiatric Rehabilitation. They produce a newsletter for some 30,000 subscribers.

•CONTAC- Kathy Muscari provided an overview of CONTAC, a consumer-run organization in West Virginia that also received a CMHS grant to become a technical assistance (TA) center. CONTAC organized advisory groups focusing on a range of topics, including cultural competency. They provide four levels of TA: (1) training for consumers to learn to train others on empowerment, planning, and peer support issues; (2) outcome orientation, including how to develop instruments and measure outcomes; (3) technological assistance on how to use tools that will foster national efforts, including web page development and videoconferencing; and (4) grants and scholarships for a Leadership Academy.

•Health Care Financing Administration (HCFA)– David Clarke' s overview of HCFA included an admission that the medical community lags behind the behavioral health community in terms of cultural competency. However, the medical community is beginning to recognize the value of providing culturally competent services and has addressed the issue in mainstream publications such as the *Annals of Internal Medicine*. Today' s health care systems are following corporate models in terms of addressing quality improvement and examining cultural competency issues. HCFA is taking advantage of this and has incorporated cultural competency standards within quality improvement measures it now requires from providers. The 1999 budget act includes a Quality Improvement System for Managed Care that Medicare and Medicaid providers must meet. It includes a requirement for providers to demonstrate and document cultural competency practices.

•Center for Beneficiary Services, HCFA–Michael Katz discussed the role of HCFA' s new consumer protection office. HCFA created the office because changes in the health care environment required it to move beyond its former role as a payor and focus on quality as well. The Center will ensure that all HCFA contractors–providers, facilities, MCOs–are in full compliance with the

Consumer Bill of Rights by the end of 1999. This will benefit consumers in areas such as specialist access and choice and emergency services, and reflects many of the changes in health care that President Clinton has worked toward since his first-term effort to overhaul the system. HCFA' s challenge now is to move from compliance on paper toward implementing activities that will make compliance a reality and meet the goal to provide services to those most in need. Providing culturally competent services is recognized as a key factor in achieving this goal.

 International Association of Psycho-Social **Rehabilitation** Services (IAPSRS) – Ruth Hughes explained that IAPSRS represents a range of service providers who work with people with serious mental illnesses. It is composed of 500 member agencies and several thousand individual members. IAPSRS has been very involved in developing and delivering culturally competent services for the past several years. It created a cultural diversity committee that has trained IAPSRS' s Board of Directors on cultural competency issues to ensure understanding of the importance of this component from the top of the organization. The committee developed a list of principles and standards of care and distributed them to the membership and chapters. They are providing training so that their chapters can meet and implement them. IAPSRS also has a credentialing program for psychiatric rehabilitation practitioners that includes cultural competency requirements. They work with five other credentialing organizations-including the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) – to strengthen their cultural competency standards as well.

•Bazelon Center for Mental Health Law– Bob Bernstein provided an overview and history of the Bazelon Center, a legal advocacy organization that works to advance the rights of people with mental illness. The Bazelon Center is concerned about MCOs because they feel that their outcome goals for consumers with mental illness are vague. They are also addressing trends that tend to criminalize people with mental illness, such as arresting them for ' survival crimes' such as urinating in public. Previously, people picked up for these kinds of violations would be sent to a state hospital; today they end up in jail. The Center sees people arrested for these crimes as victims of neglect by the state. They hope to use this defense in court on behalf of a client.

•National Association for Protection and Advocacy Systems (NAPAS) – Debbie Hu described NAPAS as a national association for Federally-mandated protection programs that advocate on behalf of people with mental illnesses who are presently or have been institutionalized. NAPAS has established a multi-cultural committee that developed a national training program for affiliate staff. These staff are trained to become regional trainers who will in turn train others on how to develop culturally competent programs, ensure cultural compliance in all conference and training events, and data collection methods. •American Managed Behavioral Health Association (AMBHA) – Pam Greenburg provided an overview of AMBHA, which represents 11 managed behavioral health organizations (MBHOs) that serve more than 100 million people. AMBHA established a client Bill of Rights two years ago and has long recognized the importance of consumer satisfaction. They promote quality performance measures among their membership; require non-discriminatory coverage practices; and have worked to integrate behavioral health care with primary care. They work with their members to examine their clients' demographics and develop services that meet their diversity needs. For example, they assemble focus groups to determine language needs and preferred providers and regularly review complaints received by members to identify service gaps. They establish cultural advisory groups to participate in this function as well. Some of their members have also designated spaces for consumers within their boards of directors.

•Montgomery County, Maryland, chapter of the National Alliance for the Mentally III (NAMI)—Carolyn Sanger discussed local NAMI efforts to broaden its membership base. NAMI supports education and advocacy for people with mental illness and their families and has 18 million members around the nation. The Montgomery County chapter determined that minority persons were under-represented in their local membership and began an outreach effort to organizations that serve Hispanic patients, such as the County mental health services. The chapter, however, is severely limited by its budget, which can only support part-time staff.

### Conclusion:

Dr. Evans reminded everyone that inclusion would be a key factor in how the group evolves. He suggested that despite negative reactions to some of the presenters, the group needed to be open and willing to establish relationships with some of these agencies and organizations. Dr. Evans re-emphasized the importance of the entire cultural competence/diversity issue. He acknowledged the high level of skills that all of the attendees brought to the table. He also suggested that the group could ask follow-up questions in the thank-you letters they send to the organizations.

### X. Strategies to Address Cross-Cutting Issues

Participants expressed the desire to immediately implement some of the ideas discussed during the summit. They were enthusiastic about putting mechanisms in place to to facilitate post-summit activities.

Four topical re-surfaced throughout the summit and it was suggested this be the foundation for establishing working groups.

•Education and Training

### Communication

### Resource Development

### Coordination/Oversight

# Jacki McKinney suggested that Research is a critical element and a work group on Research should be developed as well.

Conference participants volunteered to serve on the four work groups identified in the areas mentioned above. Following is a list of each committee and its members. People whose names are marked with an asterisk are designated chairs<sup>1</sup>; people whose names are marked by a checkmark will serve on a Research Committee to be formally established at a later date.

### **Communications Committee**

Billy Brown Celia Brown Randolph Hack Katsumi Kenaton

Gilberto Romero\* Diane Stanton Consuelo Thiel

### **Coordination Committee**

Ishmel Beard Billy Brown Celia Brown( Andrea Cooke( Regina Duvall( Ronald Gibson Maria Maciera( Jacki McKinney( Ting Mintz( Gilberto Romero( Consuelo Thiel( Kinnike Bermudez-Walker(

### **Resource Development Committee**

<sup>&</sup>lt;sup>1</sup> No chair was designated for the Coordination Committee.

Cecilia Brown Andrea Cooke\* Regina Duvall\* Ronald Gibson Alma Lee Maria Maciera Jacki McKinney Consuelo Thiel\*

### Education and Training Committee

Louis Andrews Ishmel Beard Celia Brown\* Cookie Gant Maria Hernandez Laureen Jackson Pearl Johnson Maria Maciera\* Jacki McKinney **Delois Scott** Janet Sheppard Diane Stanton **Consuelo Thiel** Kinnike Bermudez-Walker\*

Several members are skilled speakers and trainers. At least one member is a lawyer, and others have mastered technologies essential to information dissemination. Many are extremely knowledgeable about specific topics such as disability, patients' rights, consumer operate programs, grant writing, and other skills that are valuable assests to the group. Future tasks include:

Developing an organization mission statement and formal name;

- Establishing a mentoring function so that people who are new to the consumer movement are not intimidated by more seasoned colleagues; and
- Identifying a source for Communications training so that all members can understand and appreciate the different communication styles among group members.

### XI. Next Steps for the POC Group

Dr. Evans opened the floor to get ideas about what should be the next step for the conference participants. The following is a list of suggestions that were offered:

•Develop an Institute on Alternatives Consumer/Survivor and host a conference for the fall of 1999.

•Create a POC participant Resource Inventory List - (*Ting Mintz is developing a list that will detail various skills among POC group members.*)

•Create a web-site for the group and its activities

•Each working group or committee should develop a mission statement and the chair should be responsible for seeing that the work it undertakes is completed.

•Committees should have a mentoring arm for newcomers to the consumer/survivor movement; newcomers might be intimidated by the ' old timers.'

•Obtain training on communications techniques, especially sensitivity training, for committee members.

•Designate a name for the conference participants as a group that identified it as a coalition with a national mandate but avoid a label. Dr. Evans suggested that one of the committees take on the task of identifying an appropriate name to be ratified by the rest of the group.

### XII. Final Observations and Closing Ceremony

Paolo del Vecchio thanked his colleagues at CMHS and the conference planners for helping make this conference come together.

Travis Sandoval asked the group to stand in a circle and join hands as he offered a prayer to the Great Spirit to formally bring the Summit to a close.