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## **Consumers and Social Workers in Dialogue Phoenix Park Hotel Washington, D.C. November 29-30, 1999**

### **Sponsored by:**

Center for Mental Health Services  
Substance Abuse and Mental Health Services Administration  
U.S. Department of Health and Human Services

### **Prepared by:**

KRA Corporation

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## **Background**

The Center for Mental Health Services (CMHS) within the Department of Health and Human Service's (DHHS) Substance Abuse and Mental Health Services Administration (SAMHSA) was created by Congress in 1992 to improve the prevention, treatment and support services for individuals with mental illness, their families and their communities. One of its guiding principals is to develop strategies for high quality and accessible mental health services through partnerships with a wide variety of individuals and groups such as policy makers, academicians, states and their communities, researchers, providers and consumers of mental health services. Partnerships with consumers have been particularly emphasized and are a component of the CMHS mission statement: "CMHS will promote consumer participation in the design, financing and delivery of mental health services."

In the past few years, CMHS has been very active in collecting and disseminating information through a number of knowledge exchange activities with consumers and provider groups. It was in the spring of 1996 that the idea for the first consumer/provider dialogue surfaced from a discussion between two CMHS staff: Consumer Affairs Specialist Paolo del Vecchio and Dr. Melvyn Haas, Associate Director for Medical Affairs, Office of the Director. These two individuals began to formulate ideas about the need to cultivate better relationships between consumers and the providers they interact

with. They began to refer to these relationship-building opportunities as "dialogues" which were defined as "a forum in which two or more groups of people are brought together as equals to explore their differing views, experiences and belief systems. It is structured to allow for exploration of one's own perceptions and attitudes, as well as to listen to other people explore their own."<sup>1</sup>

Since that time, the CMHS Office of External Liaison (OEL) Consumer Affairs has convened a total of three meetings between consumers and providers of mental health services. The first was held in July of 1997 and was titled: "*Consumers and Psychiatrists in Dialogue*." The second was held in August of 1998 between *Consumers and Psychologists*, and the third and most recent in July of 1999, between *Mental Health Consumers and Psychiatric-Mental Health Nurses*.

This report summarizes the dialogue between mental health consumers and social workers that took place on November 29-30, 1999, at the Phoenix Hotel in Washington, D.C.

## **Welcome and Introduction-Day 1**

The opening remarks for the "*Consumers and Social Workers in Dialogue*" meeting were made by Paolo del Vecchio, Senior Policy Analyst with the Office of Policy, Planning and Administration at CMHS. Noting that this was the fourth in a series of opportunities to engage consumer-survivors and providers in dialogue, Mr. del Vecchio provided a brief overview of the history behind the development of the CMHS dialogue and shared CMHS's goals and objectives for the two-day meeting. This discussion is summarized below.

Mr. del Vecchio recognized members of the planning committee and thanked them for their time and commitment in establishing the meeting agenda. He also acknowledged his CMHS colleagues from the Office of External Liaison's Consumer Affairs Program, Iris Hyman and Carole Schauer, who coordinated and assisted in planning the meeting.

During his introductory remarks, Mr. del Vecchio emphasized the importance of keeping the discussion focused on the relationship between consumers and social workers. He also stressed the importance of this initial interaction as a stepping-stone to ongoing individual and group discussions on ensuring respect and mutual understanding in the partnership. Mr. del Vecchio reminded the group that the dialogue process is most successful when group participants allow themselves to step out of the day-to-day mode of thinking, look at one another without using labels, and get to know one another as people.

## **Review of Meeting Objectives**

Objectives for the two-day session were outlined and explained as follows:

- To develop better mutual understanding and respect between consumers and social workers present at the meeting.
- To develop a set of recommendations regarding how consumers and social workers can prepare themselves to achieve better mutual understanding and effective partnerships.
- As a follow-up to the meeting, to prepare and distribute a monograph describing both the process and the outcomes of the meeting.

## Results of Previous Dialogues

The first dialogue between mental health consumers and psychiatrists in July of 1997 created the framework for future dialogue objectives and agendas. Recognizing that respect, dignity, trust, communication and decision making are key elements in developing a successful consumer/provider relationship and that there are also contextual issues, i.e., external factors or systems such as managed care and regulations which often dictate how these relationships exist, the dialogue process was designed to focus on the following issues:

- Personhood and Relationships
- Contexts within Which Relationships Exist.
- Recommendations for Improving Relationships and Systems

Mr. del Vecchio expressed the importance of participant contributions and shared some of the recommendations that CMHS has embraced from other dialogues. For example:

- At the Consumers and Psychiatrists in Dialogue meeting, it was suggested that psychiatrists-in-training need education on how to be more sensitive. As a result, a 22-minute training video is in development for use by psychiatric residents and mental health providers on partnering to improve the recovery process.
- The Consumers and Psychologists in Dialogue resulted in a series of consumer-focused events on collaboration at the 1999 American Psychological Association Conference.

## Expectations and Ground Rules

Mr. del Vecchio introduced the meeting facilitator, Ms. Kathy Koontz, currently the Director of Health Programs at KRA Corporation in Silver Spring, Maryland. To ensure an effective and efficient flow of information from participants and to guide participant behavior, Ms. Koontz asked the group to create a list of dialogue ground rules. Figure 1 provides the results of this discussion.

**Figure 1**

### **Dialogue Ground Rules**

Respect one another  
Use I messages-no personal attacks  
One person speak at a time  
Appreciate other's opinion  
Maintain confidentiality  
Ask if you don't understand  
Use plain English  
Speak in specifics not generalizations  
Recognize unique communication styles  
Give examples  
Avoid tendency for tunnel vision  
Speak up so everyone can hear  
Speak the unspeakable

### **Participant Introduction and Sharing**

For the remainder of the first day's session, participants introduced themselves and shared their personal experiences in the context of the consumer/social worker relationship. Many of the social worker participants stated that at some time within the past few years, they had been consumers of mental health services or had dealt with a friend or a family member with a mental illness.

With participant sharing came insight into some of the issues that consumers and social workers each face independently and in the context of the working relationship. As each participant took the opportunity to share their background and experiences, the facilitator used flip charts to document the key message or issue coming from the experience. These flip charts were posted for review throughout the remainder of the program and served as a basis for later dialogue.

### **Social Worker/Consumer Communication**

In general, the relationships between social workers and consumers were represented fairly positively. For many consumers, the interpersonal skills, nonverbal communication and sensitivity of the social worker were the most helpful elements of a relationship leading to a successful recovery. Consumers expressed that their greatest personal frustration was not being listened to, not being believed and not being allowed choices in the recovery process. One participant noted that the social worker needs to be more forthcoming and honest about their own and other's mental health experiences in order to break down the communication barriers. This sharing gives the consumer a level of trust that puts the two on equal ground. As one social worker stated, this sharing in a relationship is unfortunately contrary to what social workers (and most other providers) are taught in professional schools. Other consumers revealed that sometimes the system

does not understand how to deal with them because there is lack of understanding of what the consumer is going through.

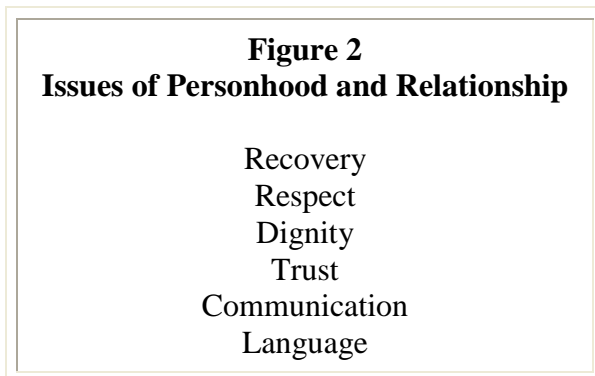
## **Self-Determination**

One social worker explained how difficult it is to support and contribute to self-determination and resolve social action issues when external forces limit effective interventions. There seem to be significant ethical dilemmas and contradictions among values in the social work code of ethics, the concept of self-determination, and other elements of empowerment. For example, "How do social workers contrast self-determination with involuntary treatment and coercion" and "How do social workers resolve issues of social action when they are being drawn into the processes of managed care? It is difficult to be a change agent in a clinical therapeutic setting." Another mentioned that in some cases, outside of the inpatient setting, consumers do not even have access to social workers and do not know what services are available to them. Many of these issues were elaborated on in the second day's discussion.

At the conclusion of the first day, there was an expressed consensus that a positive, successful relationship between the consumer and the social worker is a fundamental component of the consumer's recovery process. Mutual respect and understanding are fostered when there is open, two-way communication and each person can identify and share expectations.

## **Issues of Personhood and Relationship-Day 2**

In both facility and community-based settings, mental health consumers and social workers realize the importance of establishing and maintaining rapport as an effective means of productive communications, thereby increasing the likelihood of beneficial care outcomes. In other settings such as education and training, program planning, administration, and policy development, consumers and social workers have not always been successful at creating trusting partnerships or developing effective collaborative initiatives. Participants began a thoughtful dialogue on what constitutes a successful consumer/social worker relationship. Figure 2 outlines suggested discussion topics; however, the group spent the greatest time focusing on those highlighted under the headings below.



## **Connecting with an Individual's "Meaning System"**

The individual relationship between the consumer and the social worker is founded on trust and the ability for each participant in the relationship to listen. Social workers need to believe in what consumers say and need to dialogue with the consumer about what his or her choices and what they mean. Consumers want to be given options, i.e., a menu of choices. Even if resources limit options, social workers need to find choices and creative ways to work within those limitations. It was noted that the discharge planning process does not always allow for that kind of consumer choice. One participant suggested that consumer's treatment goals do not always reflect what the consumer needs or wants but what the social worker thinks are most relevant. A social worker responded by explaining how difficult it is to help the consumer understand that in some cases the treatments or goals that are established for the consumer have nothing to do with the mental illness but to other socioeconomic factors such as income level, education and limited external support systems. One social worker commented on the importance of connecting to the individual's meaning system. She gave the example of a consumer who would not take his medication because when off it, his internal voices spoke to him in his native language, and he felt much better.

## **Support Systems**

One of the greatest success factors to recovery is an extended support system. Whether it is family, friends or community-based organizations, having the support of one who cares is critical. Participants provided several examples of situations in which they were hospitalized, incarcerated or in outpatient treatment and friends came to their aid. Because the visitors were not immediate family members, they were turned away. One consumer described how isolated this made her feel because she had no family available to provide the support she needed.

Several social workers agreed and stated that because the social worker contact is brief, outside support typically comes from the family and community. Social workers are not encouraged to bring family and friends into the therapy process. Consumers offered that these "helpers" should be brought into the relationship as early as possible if the consumer wishes to have them involved. The dialogue ended on the need to learn from other cultures and other countries where family and friends are an integral part of the healing process.

## **Addressing Cultural Differences**

Self-identifying that you have a mental illness and also being a member of an ethnic group creates difficulties in accessing the system, explained one consumer. " There is a feeling that there are two sub-cultural barriers that you have to face." Those who are

minorities and have cultural differences often end up in a prison system or in a drug and alcohol program because they could not effectively communicate or navigate the health care system or were mis-perceived. It is for this reason that one consumer became involved in working more closely with social workers through a self-help program environment.

She also commented on how interesting it is to see that first generation immigrants who need mental health services often have a better support system through family than second or third generation minorities. She insisted that it is critical for individuals to have some type of family and friend support system.

Having language and cultural barriers creates a potential for discrimination. Coupled with a mental illness, this potential is magnified and is often the reality. Consumers want to know that their social worker understands or is like them in some way. There was also discussion on the need to ensure that communities recognize these differences by having organizational boards and school systems include individuals who represent the populations served.

**Figure 3**  
**Characteristics of Successful**  
**Relationship**

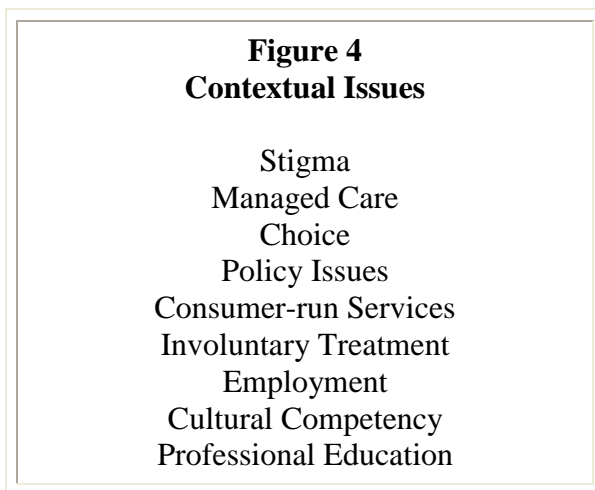
Connect with individual's meaning system  
Involve consumer in treatment goals  
Offer choices  
Listen to find out what the consumer needs  
Recognize that each side has expertise  
Address consumers' language and cultural needs  
Avoid labeling and stigmatizing  
Agree on terminology, jargon

### **Agreeing on Terminology**

It was noted by several participants that in describing relationships, the term "clinical" denotes something other than relationship and should not be used to describe the partnership. For example, the use of clinical care or clinical services implies a one way type of communication from the provider and is not necessarily mutual. The terms consumer, survivor, recipient, client, patient and customer are all used to refer to an individual receiving mental health services. Everyone has a different perspective on what term should be used. The characteristics of a successful consumer/social worker relationship are summarized in Figure 3.

## Contextual Issues

The therapeutic partnership between the consumer and the social worker does not occur in a vacuum. Often times there are external factors beyond the control of either group that may effect the direction the relationship may take. Managed care, Federal and State policy development, the educational system, resource availability and public perception are but a few. A list of issues, which affect the context in which the relationship exists, was reviewed with the group and is presented in Figure 4. As the group began dialoguing, many admitted that it was difficult to separate the relationship issues from the contextual ones. Of those discussed, the following were unique from the earlier relationship discussion.



## Stigma/Prejudice/Discrimination

Considerable time was spent on addressing stigma, its meaning and implications to consumers and the mental health movement. A participant who provided a definition of the term initiated the group discussion. The word stigma originates from the term "stigmata" meaning an identifying body mark or pain resembling the wounds of the crucified, i.e., a mark of shame or discredit. Its implication is that it is on "you" and belongs to "you," so therefore it is about "you." Many agreed that the term is in itself prejudicial and leads to discrimination. A question was then posed, "What is this discrimination and how do you define it?" Responses included the following:

- There seems to be uniqueness about the way in which individuals with mental illness are discriminated against.
- People who are identified as having a mental illness can lose their civil rights on a moment's notice. Involuntary commitment, involuntary hospitalization, and involuntary treatment are all covered under civil rights.
- The key to resolving stigma is through the process of awareness.

- People are always put into categories. People are still people no matter what the disability, minority or cultural difference. One participant noted that a number, not a name, historically marked the grave sites of those with a mental illness. Even in death, these individuals were discriminated against.
- It is not viewed as a strength for an individual with mental illness to come forward for help. In fact, it is often viewed as a weakness. This perception needs to change, that seeking help is ok.
- People often think that you are dumb, wild, or acting out when you are trying to communicate your needs. There is a reluctance to let anyone know that you even take medication for fear of being labeled.

Ms. Hyman shared work efforts for reducing stigma between CMHS and a Maryland consumer agency called On Our Own of Maryland. As a result of several workshops, a video was produced called "Stigma in Our Work and in Our Lives." This video is currently being used to increase awareness about issues of stigma.

## **Abuse and Trauma**

In conjunction with the discussion of stigma, group members addressed the issues of abuse and trauma, especially in relation to the use of restraints. A participant discussed a recent story publicized on "60 Minutes" about a social worker having gone undercover to report on a facility where the inappropriate use of restraints led to an individual's death. It was not until the story received media attention that the problem of death-associated restraint use became public.

Many shared their views on how the use of restraints contributes to trauma and is also a loss of civil rights. One individual noted that there is a huge disconnect between abuse and trauma and its relationship to understanding and treatment of persons with mental illness. Herself a victim of sexual abuse, she recounted an experience where during an acute crisis situation she was restrained and secluded. No consideration was given to her history of abuse and this particular intervention made the situation worse. Individuals need to be asked about a history of abuse.

The final comment came from a consumer who was surveying the use of restraints at a local inpatient facility. Knowing that she had been a past patient and restrained at this same location, she asked what the current restraint procedure was. She was told that the facility had reduced its use of patient restraints resulting in decreased employee injury and reduced workers' compensation claims. She summarized by saying that decreased restraint use will not only reduce discrimination, but will reduce the amount and severity of injuries to health care workers. She added that sometimes it is important for consumers to draw out the economic implication to get someone to hear about the problem. In conclusion, one participant called for elimination of the use of restraints and seclusion and suggested that staff be provided the necessary training by consumers including appropriate communication skills and use of advanced directives.

## **Social Work Code of Ethics and Education**

As the discussion continued, one social worker reminded the group that "the mission of social work is the achievement of human rights and social and economic justice; the practice of social work should be about this." Despite this statement, many social workers present agreed that the Social Work Code of Ethics is antiquated. It encourages promotion of self-determination but has not been modified to evolve with the times. It speaks of addressing self and individuals instead of community. A social worker cannot work in isolation. "The code of ethics needs to be rewritten for all social workers to include that there is a partnership. The current code addresses us as individuals." Social work education needs to ensure that the focus is on the importance of a helping relationship and how to build such a relationship. Another concern was expressed about the use of the term "social worker." The group discussed the many different levels of training for individuals who refer to themselves as "social workers." "Consumers don't have a clue whether the person they are dealing with is licensed, or what kind of training they have had."

## **Recommendations**

During the lunch break, participants were asked to vote on their top five priority issues emanating from the discussions on relationship and context. Issues were then prioritized in order of importance, which formed the basis for the recommendations made.

Ms. Schauer outlined the process that the summary recommendations would go through. First, a monologue of the dialogue process and outcomes will be summarized and reviewed by CMHS. The document will be disseminated by CMHS to the group participants for comment, and the draft document will be discussed via conference call with the planning committee where final edits will be made. Distribution of the document will follow the group's recommended dissemination strategy.

Recommendations for Improving the Relationship Between Social Workers and Consumers

### **For the Center for Mental Health Services Create a National Mental Health Awareness Campaign**

- Create an ad-hoc task force to develop a strategy for refuting the negative image portrayed of mental health.
- Implement a national mental health promotion campaign with emphasis on the following:
  - Normalize mental health.
  - Stop de-evolution. Endorse the Universal Declaration of Human Rights.
  - Consider individuals as people first.
  - Treat the individual holistically.
  - Promote the idea of "it's more than taking a pill"

- Highlight positive not negative mental health events in the media.
- Model campaigns after other successful outreach initiatives, e.g.,
- HIV/AIDS, individuals with physical and developmental disabilities, gay rights, children's health insurance.
- Identify a spokesperson.
- Teach children about their mental health.
- Encourage mental health checkups.
- Promote the value of peer-supported services and self-help groups.
- Include the Surgeon General's talking points in all outreach materials.
- Develop local media kits.
- Implement more mental health dialogues with community members-at-large and other helping professions.
- Conduct outreach to improve public awareness through partnerships with groups familiar with discrimination issues, e.g., individuals with disabilities.
- Collaborate with mental health and social work associations.
- Recruit staff who meet the ethnic and language needs of the at-large population.

#### Research and Evaluation of Mental Health Services

- Impact the National Institute of Mental Health 15 percent set-aside for research.
- Investigate effective strategies for evaluating mental health services.
- Develop a quality improvement program with standard measurement tools and outcome-based measures.
- Involve consumers in the evaluation process —they are the foundation for quality.

### **For Schools of Social Work**

#### Encourage Consumer Participation

- Encourage consumer participation in program planning, implementation and evaluation of social worker training, practice and research.
- Involve consumers in social work curriculum development.
- Involve consumers in development of social worker research agendas.
- Encourage consumers to sit on boards of licensing organizations.
- Recruit consumers of mental health services as students and provide them scholarships.

#### Offer Students Consumer-Focused Experiential Learning

- Partner social work students with consumer-survivors as part of the academic process.
- Ensure that the curriculum addresses geographic, cultural, gender, and ethnic differences in consumer wants and needs.
- Ensure that course content reflects mental health prevention and treatment as part of a holistic approach and not as a separate course content.
- Ensure that anyone using the designation of "social worker," receive a minimal set of education standards.

### **For Consumer Advocacy Organizations**

- Educate consumers on how to participate in the political process, including how to successfully advocate.
- Develop educational materials that will assist consumers in navigating the multiple entry points into the health care system.

### **For Community-Based Provider Organizations**

- Ensure that community mental health boards represent populations served, especially for ethnicity and language diversity.
- Ensure that the hiring practices of Social Work employers consider the community population that the social worker will serve.
- Ensure mental health is part of the holistic approach to treatment of the individual.
- Identify and educate health professionals on methods for identifying and treating somatic complaints with individuals who have a mental illness.
- Educate hospital staffs on appropriate methods for addressing patients with mental illness.
- Educate community-based providers on how to assess for placement options other than prison or detoxification units.

### **Recommendations for Improving the System**

#### **For Social Work Associations**

##### Anti-Stigma Activities

- Hold a series of discussions for social workers on mental health issues. Place the findings from these discussions in the newsletter for the National Association of Social Workers (NASW).
- Encourage the NASW to pass a resolution to Fight Stigma.
- Support social workers who disclose having a mental illness.

#### Support a Consumer Self-Help/Peer-Support Model

- Explore options for recognizing, validating and compensating consumer experience in the service delivery system.
- Create and distribute a list of best practice models for consumer-run programs.
- Develop a bibliography of consumer-related mental health prevention, treatment and research information and submit to schools of social work. Place this on the relevant web-sites.
- Appropriately reimburse consumer-survivors who work as peer counselors or in other capacities within self-help groups for their expertise.
- Provide consumer-survivors with educational credits, certification and/or other recognition for their work in communities.

### **Dissemination Strategies**

The group addressed a variety of methods for disseminating information on this report to promote successful consumer/social worker relationships. These include forwarding reports to the following:

#### **State and Local Government**

- State and local mental health authorities with a request to route to all staff
- State Chapters of NASW
- Clinical federation and state chapters
- State Mental Health Planning Councils
- Licensing Boards

#### **Schools of Social Work and Other Providers**

- Correspond directly with Deans, chairs of curriculum and recruitment committees
- National School Psychologists

#### **Associations/Conferences**

- NASW newsletter and convention

- Council of Social Work Educators conference dialogue and dissemination
- National Mental Health Association
- National Association of State Mental Health Program Directors
- Managed Care Behavioral Health Providers

## **Media-Print and Electronic**

Develop a time line for a media campaign with consideration given to the following:

- March is social work month.
- Tie into other Department of Health and Human Services activities such as the Surgeon General's Report.
- Send information to consumer groups via the Internet.
- Communicate to providers and consumers via e-mail.
- Continue to identify personal contacts.

## **Importance of Clear and Consistent Messages**

The importance of disseminating a clear and consistent message about the mental health recovery process was expressed in closing by one of the participants. "What I would like to see happen is to incorporate by reference, several key points that were written for the Surgeon General's Report on Mental Health. The intent of these points is for the Surgeon General to include the same message in all press releases, executive summaries, talking points, or other materials that are developed as part of his efforts to communicate to the mental health community and the public about mental health." The key points are as follows.

- There should be active participation of mental health care recipients in all aspects of policy development, planning, delivery and evaluation of services.
- Self-help groups support people with mental illness to overcome feelings of isolation and powerlessness while providing an environment for mutual hope and recovery.
- Stigma is prejudice and discrimination.
- Based upon the lack of information on education, people are denied opportunities for housing, employment, insurance and full participation in our society.
- Recovery is a process of learning to approach each day's challenges, overcome our handicaps, live independently, learn skills, and contribute to society. It is supported by those who believe in us and give us hope.
- Consumer-operated mental health services are planned, delivered, and evaluated by consumers, and are a significant outcome of the self-help movement, as well as an important component of the system of services for people with mental illnesses.

- Cultural competence is a cornerstone of the development of an effective, responsive and sensitive mental health system where all our cultural differences are respected and valued.
- Childhood sexual abuse contributes significantly to the incidences of mental illness. It necessitates specific abuse-specific treatment modalities and constitutes a serious societal problem.
- Poverty among people with mental illness is a huge barrier to community integration, improved health and consumer self-respect.
- Employment opportunities for people with mental illness are key to the development of a system that promotes independence, productivity and recovery.

## **Conclusion**

At the conclusion of the meeting, each participant was given an opportunity to share his or her thoughts about the dialogue process and outcomes. The majority of participants provided feedback and expressed a newfound energy and enthusiasm with the discussion and noted the value of the process in learning about each other's perspective. Some addressed concerns at what the next steps would be. "This is such a big challenge . . . to think about making these kinds of changes." Others noted the degree of safety that was felt with this kind of forum, and encouraged CMHS to have more of these types of dialogues. "I think it would be great to do this with an interdisciplinary group."

Final closing remarks were made by Mr. del Vecchio, Ms. Schauer and Ms. Hyman, who thanked each participant for participating, for the openness and honesty in the dialogue, and for generating such a comprehensive list of recommendations.