Summary Report
A National Call to Action:
Eliminating the Use of Seclusion and
Restraint
J.W. Marriott Hotel
Washington, D.C.
May 5, 2003

U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration Center for Mental Health Services 5600 Fishers Lane Rockville, Maryland 20857

#### Purpose, Disclaimer, and Contact for More Information

This document provides a summary of the proceedings of the May 5, 2003 National Call to Action to Eliminate Seclusion and Restraint held at the J.W. Marriott Hotel in Washington, D.C. and attended by approximately 200 mental health consumers, providers, family members, advocates, researchers, State and Federal officials, and others. The views and opinions expressed are entirely those of the participants and do not necessarily reflect the views, opinions, or policies of any Federal agency or office.

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#### Welcome/Goal of Meeting/Opening Remarks

Acting Center for Mental Health Services (CMHS) Director Gail Hutchings, M.P.A., welcomed participants on behalf of the Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Association of State Mental Health Program Directors (NASMHPD). She characterized this meeting as a "landmark occasion in the mental health field," as the issue addressed is literally one of life and death for mental health consumers. The meeting's goal was to obtain feedback on SAMHSA's draft National Action Plan to reduce and ultimately eliminate the use of seclusion and restraint in mental health settings.

NASMHPD Executive Director Robert Glover, Ph.D., reported that, in 1998, the Hartford *Courant* ran a series of 19 articles on deaths due to the use of restraints. In July 1999, NASMHPD issued a strong position statement on seclusion and restraint, stating "seclusion and restraint are safety interventions of last resort and are *not* treatment interventions."

NASMHPD also issued a series of technical reports on reducing the use of seclusion and restraint, including one report on lessons for deaf and hard-of-hearing communities. This report addressed the cultural issues that are critical to addressing the service needs of people with a mental illness who are deaf or hard of hearing, in order to reduce the use of seclusion and restraint in this population. The report recommended that when deaf or hard-of-hearing persons are restrained, they have a constant, unobstructed view of their surroundings and a staff person communicating in sign language as the intervention is implemented and monitored.

Dr. Glover also reported several statistics on the use of seclusion and restraint. Of the approximately 63,000 people in State psychiatric hospitals in February 2003, 3.35 percent, or 2,110 people, were restrained and 2.5 percent, or 1,575 people, were in seclusion. A large proportion of adult psychiatric inpatients have experienced physical and/or sexual abuse, and the use of seclusion and restraint retraumatizes these individuals.

Consumer advocate Jacki McKinney, M.S.W., related her experience of seclusion. Thirty years ago, Ms. McKinney was an inpatient in a 20-bed facility. When her medication made her ill, Ms. McKinney complained. When her complaints were ignored, Ms. McKinney refused to take the medication. Ms. McKinney was then involuntarily given medicine that made her unconscious. When she woke up, she was in a foul-smelling, padded room. She could hear a man in the next room making a great deal of noise. All night, this man moaned and said, "I'm dying!" By morning, "Mr. Somebody" had died, alone, with only Ms. McKinney in the next room to bear witness. Ms. McKinney has never recovered from the experience.

Ms. McKinney emphasized that this story demonstrates that seclusion and restraint never affect only one person. These practices are a violation of the human spirit, and Ms. McKinney hopes that some day millions of "somebodies" can be helped.

#### **Developing a National Agenda**

SAMHSA Administrator Charles G. Curie, M.A., A.C.S.W., stated that according to SAMHSA's vision, people with mental illness deserve a rewarding life in the community, enriched with a home, a meaningful relationship with family and friends, and a job. The use of seclusion and restraint clouds this vision. It is now a priority for SAMHSA to work with States, communities, consumers, families, providers, and provider organizations to ultimately eliminate the use of seclusion and restraint. At this meeting, a national call to action was launched to eliminate the use of seclusion and restraint. Individuals with mental illness should not be confined, restrained, or retraumatized by the persons and resources put in place to help them.

Research shows that physical force, mobilization, and isolation are dehumanizing. Seclusion and restraint should no longer be viewed as treatment options but rather as treatment failures because they risk lives and inflict emotional and physical trauma. Seclusion and restraint should be a safety measure of the very last resort, used only when all other options have failed.

Current and planned SAMHSA activities related to the National Action Plan for reducing the use of seclusion and restraint include the following:

- Creating a consumer-based staff-training manual that will be pilot tested and distributed widely;
- Conducting staff training to reduce the use of seclusion and restraint through a \$7.5 million effort proposed by the President. Some of these funds will be used to develop a resource center to support State grantees and others;
- Using existing technical assistance resources;
- Disseminating a compendium of evidence-based practices and guidelines; and
- Working with the Centers for Medicare and Medicaid Services (CMS) to develop standards for healthcare facilities.

SAMHSA also recognizes the need to work in other fields, such as substance abuse, justice, and education, where people with mental illnesses might be subjected to seclusion and restraint. Mr. Curie hopes that the mental health field can serve as a model for these other settings in which progress is also needed.

Eliminating the use of seclusion and restraint requires the following:

- An adequate number of qualified staff to meet patient treatment needs;
- Staff training, especially in verbal crisis management, including de-escalation techniques;
- Active treatment;
- Active risk assessment and risk-based treatment planning;
- Availability and use of second-generation antipsychotic medications;
- An environment of care that promotes patient comfort, dignity, privacy, and personal choice; and
- State-level, aggregate data about each hospital's incidents of seclusion and restraint.

Policy changes are needed to effect change in hospital and other settings. These policies must be flexible to allow for change and incorporate staff involvement. Some policy options consistent with current State or Federal rules include the following:

- Seclusion and restraint must only be used when the potential exists for imminent physical danger to the patient or others;
- Seclusion may not exceed 1 hour, and ongoing monitoring is needed so that the patient is out of seclusion as soon as possible;
- A physician must physically assess the patient within 30 minutes of the first order and each reorder;
- Physical restraint may not exceed 10 minutes;
- Persons in seclusion or restraint must be kept in constant face-to-face human observation;
- The use of chemical restraint is prohibited;
- Whenever seclusion or restraint is used, patient and staff debriefing must occur, and feedback must be included in the treatment plan to prevent the use of seclusion or restraint in the future; and
- Extensive staff orientation and education is required.

Recovery needs to be the frame of this initiative; every activity must have the goal of facilitating recovery toward a life in the community.

#### **Perspectives From the Field**

J. Rock Johnson, National Association of Protection and Advocacy Systems, Inc. (NAPAS) and National Alliance for the Mentally Ill (NAMI): Alternative measures to the "incredibly horrible practice" of seclusion and restraint, such as alternative dispute resolution, are needed to enable people with serious mental illness to live and work in, and be a full part of, the community.

<u>Trina Osher, Federation of Families for Children's Mental Health</u>: The use of seclusion and restraint with children teaches that the use of power and violence is acceptable. These practices are still widespread in schools, day treatment centers, and foster care homes in which children are placed to protect their safety.

<u>David A. Pollack, Oregon Department of Human Services</u>: The use of seclusion and restraint should be viewed broadly to include correction and community settings.

<u>Richard Hunter, American Psychological Association</u>: The next step in eliminating seclusion and restraint is to develop and implement advanced clinical training in understanding and treating the precursors to aggression, and teaching socially appropriate replacement behaviors involving client choice in the treatment planning process.

<u>Lynn C. DeLacy, American Psychiatric Nurses Association</u>: Staffing needs must be addressed to reduce the use of seclusion and restraint, which is particularly important in light of the national nursing shortage. Attention must also be paid to all settings in which seclusion and restraint are used, especially community-based treatment settings and emergency rooms.

<u>Daniel K. Powers, National Association of Consumer/Survivor Mental Health Administrators:</u> Mr. Powers experienced restraint 11 years ago and characterized it as the most terrifying experience of his adult life.

<u>Joseph Rogers, National Mental Health Consumers Self-Help Clearinghouse</u>: Consumer involvement should be specifically addressed in each of the activities proposed in SAMHSA's National Action Plan.

<u>Charles E. Riordan, American Psychiatric Association</u>: The crumbling infrastructure and funding crisis in national, State, and local mental health systems must be addressed if the use of seclusion and restraint is to be reduced. Also, the collection of data can have unexpected consequences, as hospitals may refuse to admit patients who might need seclusion and restraint if data on their use are published.

<u>Gary P. Gross, NAPAS</u>: The operations of facilities must be made transparent through adequate reporting of use of, and deaths from, seclusion and restraint. Also, rules in the Children's Health Act regarding seclusion and restraint must be enforced.

<u>Ron Honberg, J.D., NAMI</u>: The current funding climate is not conducive to progress on seclusion and restraint, as staffing and other shortages prevent facilities from averting crises.

Oscar Morgan, National Mental Health Association: The national call to action should serve as a platform to continue advocating for an end to discrimination against people with mental illness. Consumers must be asked to identify environmental factors that might precipitate an outburst, and practitioner behaviors that influence decisions to use seclusion and restraint must be understood.

Robert Bernstein, Ph.D., Judge David L. Bazelon Center for Mental Health Law: Complete, accurate, and timely reporting of every restraint and seclusion incident is needed and must involve consumer assessment of their actions and those of the facility.

<u>Curtis L. Decker, NAPAS</u>: The effort to eliminate the use of seclusion and restraint must cross disabilities and facilities. The involvement of CMS in this effort is critical, as this agency can control enforcement.

<u>Wanda Mohr, Ph.D., Rutgers University</u>: Physical restraints are not therapeutic, and their use is not monitored. More research is needed on the prevalence of this practice, as well as on prevention techniques and alternative interventions.

Michael Freedman, Advocate: Certain combinations of medications can cause permanent damage when used to treat short-term problems, and their improper use must be examined.

<u>Linn Cohen-Cole, Independent Scholar</u>: Seclusion and restraint must be characterized as "massive human rights abuses" that are perpetrated on a very vulnerable population.

<u>Andrea Stephenson, Empower Alliance</u>: Ms. Stephenson was raped while in five-point restraints and was retraumatized by readmission to the same hospital 12 years later.

<u>Judi Chamberlin, National Empowerment Center</u>: Seclusion and restraint are not just mental health issues, as they cross disabilities. People must stop being tortured in the name of treatment.

<u>Jun Fujimori, PEOPLe, Inc.</u>: Seclusion and restraint can be effective treatments, but only when used on a voluntary basis by the patient. When forced, seclusion and restraint represent an abuse of patient rights.

John Piacitelli, Older Adults Consumer Mental Health Alliance: The older adult population is subjected to greater use of restraints than any other group and should be included specifically in all five domains of SAMHSA's National Action Plan.

## **Overcoming Barriers and Protecting Consumer Rights**

Consumer and Staff Experiences

Consumer advocates Tom Lane, Gayle Bluebird, and Joyce Jorgensen read aloud stories of actual patients who experienced seclusion and restraint and of staff who witnessed or participated in such incidents.

Common Assumptions and Realities

Seclusion and restraint are "therapeutic

interventions."

Mental health provider Mary Ann Nihart presented several common assumptions about seclusion and restraint and also presented data challenging each assumption:

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<u>ASSUMPTION</u>	REALITY		
Restraints keep patients safe.	Each year, 50-150 deaths occur nationally due to seclusion and restraints.		
Restraints keep staff safe.	For every 100 mental health aides, 26 injuries were reported in a three-State survey in 1996.		
Restraints are used only when absolutely necessary and for safety reasons.	Patients are restrained for such trivial "offenses" as refusing to move to another dining table.		
Unit staff know how to recognize a potentially violent situation.	In a study of nurses' decisions based on clinical cues of patient agitation, self-harm, inclinations to assault others, and destruction of property, nurses agreed only 8 percent of the time, when data were analyzed for agreement due to chance alone.		
Staff know how to de-escalate potentially violent situations.	Almost half the mental health technicians interviewed in one study either believed that no good alternatives to restraints exist or could not identify good alternatives. A survey of nurses found that only 7.4 percent were aware that death was a risk factor of restraint use.		
Seclusion and restraint interventions are based on clinical knowledge.	Little evidence exists for beneficial claims regarding restraint and seclusion.		
Restraints are not used as, or meant to be, punishment.	People who have been secluded or restrained typically experience a sense of punishment.		
Seclusion and restraint are used without bias and only in response to objective behavior.	Research demonstrates the existence of cultural and social biases in the use of seclusion and restraint.		

Patients characterize the experience as dehumanizing and

humiliating and report no beneficial results.

#### Challenges to Cultural Change

Facility administrator W. Russell Hughes, Ph.D., M.B.A., discussed the cultural changes needed to reduce and eliminate the use of seclusion and restraint. The culture must change from one in which seclusion and restraint are viewed as positive and therapeutic to one in which they are regarded as violent acts that result in traumatization to patients, observers, and others. The impact of abuse and trauma on the lives of consumers and staff must be acknowledged and addressed therapeutically.

Staff are trained predominantly in the medical model of treatment, which is based on identifying illnesses and using treatments from the research literature. This model is highly effective in treating illnesses but not in promoting health. Staff also have experience working in huge hospitals, in which the only way to operate was through policies and procedures. Many staff are trauma survivors with a strong need to control their environments. The consequences of this culture include a focus on disability, rather than recovery, and the view of pain as an acceptable byproduct of treatment.

Staff are likely to treat their patients in the same way as they are treated by management. When staff are treated in a dictatorial, controlling manner, they treat their clients through extreme control and use of rules. But if staff are treated in a warm and caring way, they treat those they serve with compassion and care.

#### Legal Issues

Advocate Susan Stefan, J.D., reported that the standard of care for people with serious mental illness in this country is changing. Deaths due to restraints are no longer acceptable, and criminal charges can be brought against the staff involved. When someone with a known medical condition dies while being restrained, a State grand jury investigation may be initiated. The standard is shifting from viewing deaths and injuries as due to improperly used restraints to the problem being the restraints themselves. People are increasingly realizing that restraints are excruciatingly painful, labor intensive, injury prone, and less effective than alternatives.

#### Ms. Stefan also pointed out that:

- Although eliminating restraints from all State and private hospitals is an important start, the use of restraints must also be eliminated from departments of juvenile justice, foster care, and other settings in which troublesome young people are placed;
- To eliminate restraints, the culture of force must be addressed. Otherwise, facilities will replace seclusion and restraint with equally objectionable techniques, such as pepper spray; and
- Deaths and injuries from seclusion and restraint are not inexplicable aberrations in an otherwise outstanding system of care but indications that the system is not working.

#### Reducing Seclusion and Restraint Use -- What Works!

#### The Pennsylvania Experience

To show that elimination of seclusion and restraint is possible, State official Steven Karp, D.O., reported on the dramatic results in Pennsylvania State hospitals. The number of hours of seclusion, for example, dropped from more than 5,000 in February 1993 to just over 4 in February 2003. During this same period, the number of mechanical restraint hours dropped from almost 11,000 to slightly more than 90. Two State hospitals in Pennsylvania have not used restraints, and two others have not used seclusion, in more than 2 years.

Critical factors in Pennsylvania's success include the following:

- Adequate, well-prepared staffing;
- Abundance of active, meaningful, state-of-the-art treatment options, including evidence-based practices and free access to modern medications and therapies;
- Consumer involvement;
- Performance measurement system supporting the quality improvement process;
- Care environment that places top priority on patient dignity; and
- Patient and staff debriefing.

#### National Executive Training Institutes

NASMHPD's Office of Technical Assistance Director Kevin Ann Huckshorn, R.N., M.S.N., C.A.P., reported on a major training initiative concerning the reduction of seclusion and restraint. The focus is not on how to do these more safely but rather on how to prevent their use. The training program, which is funded by SAMHSA's Center for Mental Health Services (CMHS), is based on tools that are easily replicable and inexpensive.

NASMHPD national executive training institutes are held in four different regions. Five State delegations attend each institute and must include State commissioners or their deputies, State medical directors, representatives of the State consumer/survivor/ex-patient office, and other key leaders. The delegation also includes staff from the facility selected by the State for launching the project. The training lasts 2.5 days and includes the creation of a facility plan for the State and a database to monitor progress.

The training is module based, so that it can be replicated easily and shared with staff in each participating State. The theoretical framework includes recovery research and literature from the emerging science of trauma-informed care. Participants address their assumptions about seclusion and restraint use and the experiences of both consumers and staff, and they study the theoretical foundation and literature supporting the project. The delegations also learn about actual State reduction experiences and the critical components of those successes.

To date, 11 State delegations have completed the training, and all have developed a comprehensive training plan. The NASMHPD Research Institute will review data over time on

these programs to assess seclusion and restraint use in these States, the interventions that are the most helpful, and patient and staff satisfaction.

#### Best Practices in Behavior Management

Family advocate Trina Osher described a partnership, funded by SAMHSA, between the Child Welfare League of America and the Federation of Families for Children's Mental Health. The goal of this project in five demonstration sites is to reduce the use of restraint and seclusion for children through training that improves practice.

In the program's first year, best practices were identified through focus groups and measurement of the impact of the training and organizational climate in the five sites. Now in its second year, the program will conduct family advocacy training, develop and test a supervisory training curriculum, convene a national task force to produce guidelines for evaluating behavior management training programs, and develop a manager's desk reference and a plan for dissemination of findings. In its third year, the program will focus on findings dissemination, a national conference, and programs to train trainers.

Participants in this training learn to perceive their relationships with the children they are serving differently and to change their behaviors accordingly. The model is changing from one of supervising and controlling to one of educating, guiding, and supporting. Mandates, monitoring, and standards also play an important role in reducing the use of seclusion and restraint in children. Facilities need to provide children with positive behavioral interventions that help them understand how to communicate their feelings and needs more effectively and improve their ability to control their own behavior.

#### **Workgroup Reports**

Meeting participants separated into five workgroups to offer the following suggestions for SAMHSA's consideration for the National Action Plan on Seclusion and Restraint.

Promising Practices and Guidelines

Wusa Jibril of the Washington, DC, Department of Mental Health listed the recommendations of this workgroup:

- 1. National registry of programs:
  - Move toward recovery model instead of medical model; and
  - Centralized resource, including a hotline that consumers can call to report incidents of seclusion and restraint.
- 2. Emphasis on consumer education, including facility-wide wellness programs.
- 3. Acknowledgement that this model is not risk free, as not all of the risk factors involved have been eliminated. For example, although the Pennsylvania experience is a good model, most of those involved are long-term care patients, so this model may not apply to shorter-term patients, such as those with substance abuse.
- 4. Listing of what works. Facilities need to know what works for them, what they can change, and what does not need to be changed.
- 5. Use of consumers in recovery as consultants to staff. Former patients can be brought back to the facility as staff members. These advocates can show patients that there is a "light at the end of the tunnel."

Organizational Leadership and Partnership Development

Daryl Kade of SAMHSA reported that this workgroup focused on the action plan developed by SAMHSA's seclusion and restraint workgroup.

In the area of partnership, the workgroup recommended increasing types of partners, such as the following:

- Health Resources and Services Administration to address what happens to target populations when they enter the primary healthcare system with respect to seclusion and restraint;
- The National Institute of Mental Health (NIMH) to address effective practices;
- Those who manage emergency rooms;
- Private sector;
- Academia;

- Consumers and families for joint decisionmaking and accountability;
- Professional associations;
- Unions:
- Provider organizations;
- Congress;
- State Government;
- Police/corrections:
- Agencies within the Department of Health and Human Services, including CMS; and
- Direct care staff.

Leadership and vision are needed not only to stop seclusion and restraint but also to address what causes staff to feel that these practices are needed. The workgroup's recommendations in the scope/vision area are to address the following:

- Issues beyond mental health facilities;
- Crosscutting with other areas in the SAMHSA matrix;
- Other target populations, such as persons with traumatic brain injury;
- Root causes of mental health and other system failures;
- Staffing issues, such as number and quality of staff;
- Definition of seclusion and restraint to include, for example, chemical restraint; and
- The changing nature of public hospitals.

In the area of reporting, the workgroup believes that leaders at all levels must be able to both foster transparency and prepare the audience for the message. People need to be ready to use information as a management tool without penalty. A great deal of leadership is required to ensure that staff generate, analyze, report, and use data, and participate in this vision. In this area, the workgroup identified the following recommendations:

- Foster transparency;
- Develop a standard reporting/uniform format;
- Use data as management tool, without penalties; and
- Define who reports (State hospitals, private sector).

Leaders must take responsibility for ensuring that the environment is ready for change by showing that the change is needed to make everyone safer and improve everyone's lives. Trust is needed to use data and make the environment safer. Many partners must play a role in creating this trust by the following:

- Building an environment of trust (providers, consumers, family, administrators, public);
- Making people feel safe; and
- Preparing the public to discuss data and make management changes.

#### Training and Technical Assistance

Jun Fujimori of PEOPLe, Inc., explained that the Training and Technical Assistance Workgroup identified two gaps.

The workgroup recommended experiential training for all staff, including administrators, in which they experience seclusion and restraint for the maximum time allowed. This would help staff learn what it feels like to be unable to leave the room. To change the philosophy requires buy-in from leaders, who should undergo the training first. Institutional staff should participate in the training during new employee orientation and thereafter on an annual basis, so that they can experience the most up-to-date restraint and seclusion techniques available. Resources required include a training budget and staff time.

The workgroup also recommended moving what is learned in the classroom into *in vivo* training, especially for professionals, such as psychiatrists, psychologists, social workers, and nurses. Technicians and housekeeping staff should also undergo training, as they often have the most contact with patients. This training should be annual and ongoing and requires funds, possibly from SAMHSA. Many consumer agencies would probably be willing to develop a curriculum.

#### Advocacy and Rights Protection

Judi Chamberlin of the National Empowerment Center listed the workgroup's recommendations:

- 1. Gather data:
  - Enforce the Children's Health Act:
  - Create a "rogue State" list;
  - Gather data across a broad spectrum of institutions and facilities (not just State hospitals);
  - Enforce the 1-hour rule; and
  - Use advocates to collect and share their own data.
- 2. Define "restraints" to include physical and chemical restraints.
- 3. Define "institutions" to include the following:
  - State hospitals;
  - Private hospitals;
  - Mental retardation facilities;
  - Nursing homes;
  - Congregate facilities; and
  - Schools.
- 4. Chemical restraint needs to be defined as the involuntary emergency use of medication (generally but not always injectable). Lesser definitions (such as "inappropriate use") are inadequate.

- 5. Consumers and peer support staff must be educated about their rights. Protection and advocacy (P&A) systems must be involved in monitoring and investigations. Agencies in States that conduct abuse and neglect investigations must consider seclusion and restraint to be a form of abuse and neglect.
- 6. When someone dies while in seclusion or restraint, the death must be investigated as a possible homicide, and an autopsy should always be performed. Coroners and medical examiners need to be educated about this, as they tend to characterize these deaths in ways that do not reflect the impact of seclusion or restraint.
- 7. Seclusion and restraint are not just a mental health issue, and broad coalitions must be developed across ages, disabilities, and programs to stop the use of seclusion and restraint across the board. Seclusion and restraint should be viewed as human rights violations, and agencies that protect human rights should be involved in ending their use. These practices must also be viewed as a form of assault and battery.
- 8. The use of seclusion and restraint in schools and residential facilities must be examined. Existing rules designed to protect children are inadequate to stop the use of seclusion and restraint.
- 9. Linkages must be developed among ombudsmen, long-term care facilities, and P&A systems to investigate and challenge the use of seclusion and restraint in the elderly. Additional resources are needed, as are reporting requirements. A categorical system could be developed in P&A agencies for elderly and long-term care populations.
- 10. To prevent the use of seclusion and restraint, programs and facilities need to help people withdraw from psychiatric medications.
- 11. People in emotional distress need calm, caring, positive programs where they can heal.
- 12. The use of seclusion and restraint in ambulances, emergency rooms, and immediately on admission must be examined.
- 13. Violence in our culture leads to institutionalization and the experience of seclusion and restraint. Therefore, violence in the culture must be addressed, including abuse, incest, and rape. How these types of violence in our culture lead to the use of seclusion and restraint must be understood.
- 14. Advocates need to be available on site 24 hours a day, just like nurses. They should be employed by an independent agency.
- 15. Every patient needs to be meaningfully involved in developing an individual treatment plan.

- 16. Peer advocacy positions should be mandated from the point of the request for proposals, and should be an essential part of every program.
- 17. Advocacy needs to be culturally aware, sensitive, and competent.
- 18. A centralized federal reporting system is needed.
- 19. Mandates, not goals, are needed -- the time to end seclusion and restraint is now!
- 20. SAMHSA should establish a specific deadline for ending seclusion and restraint and should issue a press release announcing this deadline.
- 21. The current SAMHSA plan is not strong enough. Tracking deaths is not an adequate measure. Instead, a commitment is needed to end seclusion and restraint with timelines and deadlines, and this meeting needs to be followed with more opportunities for input and action.

#### Data Collection

Dr. Jean Campbell of the Missouri Institute of Mental Health stated that data collection will be important in the process of change. Data are considered value free, hold people accountable, contribute to quality of care, inform decisionmaking, and promote change. Data are a very powerful tool for advocates and others who want to understand particular processes.

The type of data to collect on seclusion and restraint may differ, depending on whether the data are collected for policy, practice, quality improvement, knowledge, regulation, or accreditation. Different levels of data are collected, including national, State, and institutional. Some core indicators on which data should be collected include the following:

- Deaths:
- Injuries, including coma, broken bones, stitches;
- Incidents, including duration;
- Demographics;
- Outcomes; and
- Consumer/staff satisfaction.

How to collect and disseminate these data must be decided.

- 1. The Data Collection Workgroup argued that a battle plan, not a call to action, is needed. Specific recommendations were as follows: Develop a standardized dataset with core indicators and uniform definitions for comparison and collection at the broadest level. Core indicators, uniform definitions, and, if appropriate, instruments should be developed, although no consensus exists on how to do this. Different approaches are possible:
  - Incremental approach, through which existing data are gathered from different sources and built over time;

- Data mining project ("casting the widest net") to determine where data on seclusion and restraint can be captured; and
- Spot surveys, instead of a census effort to count every incident of seclusion and restraint.

Data sources include the following:

- The CMHS Performance Indicator Project, which might be important for collecting data on seclusion and restraint. Participation is voluntary in the first year, and required indicators are collected for all States thereafter;
- Information on its system voluntarily reported by each State to the NASMHPD profiling system;
- P&A data on allegations and investigations; and
- CMS data.

This will require facility buy-in, infrastructure, and compliance with the Health Insurance Portability and Accountability Act (HIPAA).

- 2. Create a research agenda and examine medication offsets, the nature of seclusion and restraint, and its prevalence. This should be accomplished through a science-to-service collaboration between SAMHSA and NIMH. Resources needed are expertise, administrative support, and funds for evaluation and services research.
- 3. Once the data are available, identify best practices for publishing data for different stakeholders, including staff, consumers, and administrators.
- 4. Disseminate the data through journals, Web sites, and reports. Partners include SAMSHA, NASMHPD, and universities. This should be a multistakeholder effort involving consumers and others, not only experts.

## **Launching the Call to Action**

Consumer advocate Laura Prescott suggested that in spite of many barriers, many reasons exist to persist in the vision of a better future, where seclusion and restraint are things of the past and nonviolence is embraced. Each step that is taken collectively widens the path for others to follow. So much has been achieved over the last few years, but more is needed to succeed in the commitment to end seclusion and restraint. The existence of seclusion and restraint sends an important message to staff, the public, and that people with mental illness are dangerous, and it is time to deliver a new message.

The words used to describe the use of force in facilities are similar to those used to describe a war. Seclusion and restraint are practices of aggression and force, implying that psychiatric facilities are dangerous places where clinical staff are soldiers battling an enemy. As long as the myth of danger persists, people will continue to justify the use of force and aggression in the interest of public safety.

The challenge continues to be a culture in which people believe that restraint helps maintain control and that seclusion provides an opportunity to destimulate. The assumption of therapeutic benefit persists, but many other ways exist to achieve these ends. Restraint and seclusion are interventions of control and treatment failure.

A different future can be created, but this will require leadership commitment. It is time to shift the focus from deficit-based models to a strength-based orientation to improve the overall quality of care. Psychiatric, criminal, and other systems have accomplished dramatic reductions in the use of seclusion and restraint when administrators, staff, consumers, and advocates work together.

The opportunity exists to embrace a new history and to become leaders. Those in the mental health field must begin to insist that the business of mental health protects and defends human dignity and autonomy, because each life lost diminishes everyone.

## Appendix A List of Presenters

- Gayle Bluebird, R.N., Independent Consultant
- Charles G. Curie, M.A., A.C.S.W., Administrator, Substance Abuse and Mental Health Services Administration (SAMHSA)
- Robert W. Glover, Ph.D., Executive Director, National Association of State Mental Health Program Directors (NASMHPD)
- Kevin Ann Huckshorn, R.N., M.S.N., C.A.P., Director, Office of Technical Assistance, NASMHPD
- William R. Hughes, Ph.D., Chief Executive Officer, Bryan Psychiatric Hospital
- Gail P. Hutchings, M.P.A., Acting Director, Center for Mental Health Services (CMHS), SAMHSA
- Joyce Jorgenson, Project Director, National Association of Consumer/Survivor Mental Health Administrators
- Steven J. Karp, D.O., Chief Psychiatric Officer, Office of Mental Health and Substance Abuse Services, Pennsylvania Department of Public Welfare
- Tom Lane, Director, Office of Consumer Affairs, National Alliance for the Mentally Ill (NAMI)
- Jacki McKinney, M.S.W., Advocate, National Association of People of Color Consumers
- Mary Ann Nihart, M.A., A.P.R.N., C.S., B.C., Clinical Faculty, University of California, Davis
- Trina W. Osher, Director, Policy and Research, Federation of Families for Children's Mental Health
- Laura A. Prescott, Executive Director, Sister Witness International, Inc.
- Susan Stefan, J.D., Senior Staff Attorney, Center for Public Representation

# Appendix B List of Participants

# Appendix C Meeting Agenda

# Appendix D Revised SAMHSA National Action Plan on Seclusion and Restraint