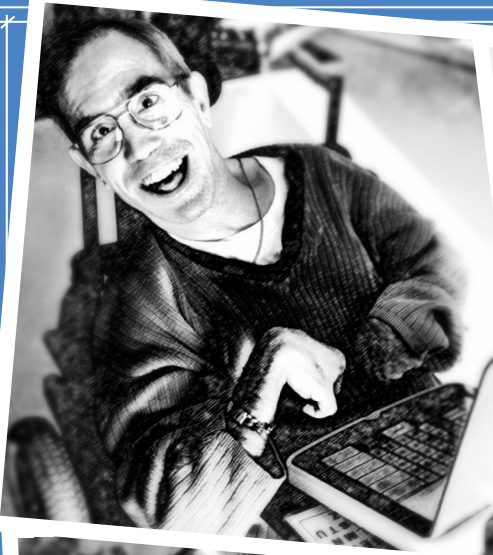


# CLOSING THE GAP:

A National Blueprint to Improve the Health of  
Persons with Mental Retardation

Goal 1: Health Promotion and Community Environments

Goal 6: Sources of Health Care



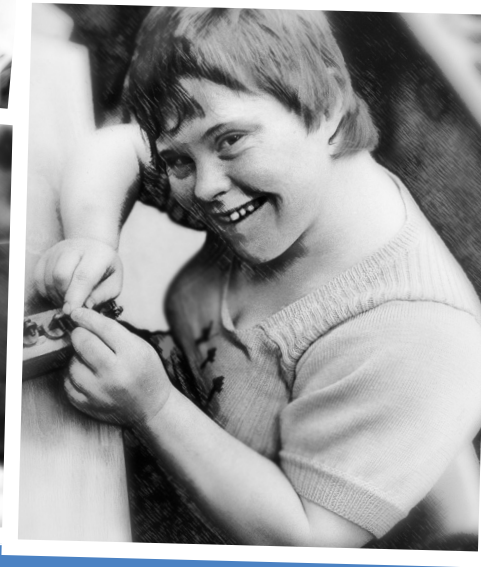
Goal 2: Knowledge and Understanding



Goal 5: Health Care Financing



Goal 3: Quality of Health Care



Goal 4: Training of Health Care Providers

Report of the Surgeon General's Conference  
on Health Disparities and Mental Retardation

U.S. Department of Health and Human Services • 2002





CLOSING THE GAP:  
*A National Blueprint to Improve the Health of  
Persons with Mental Retardation*

Report of the Surgeon General's Conference on  
Health Disparities and Mental Retardation

2002

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# Message from Tommy G. Thompson

Secretary of Health and Human Services

Good health is essential to quality of life, and the health and well-being of its people are essential to the strength of the Nation. At a recent White House dinner honoring the Special Olympics, President Bush eloquently stated that “America at its best upholds the value of every person and the possibilities of every life.” He went on to say that “the story of our country is an ever-widening circle, a society in which everyone has a place and everyone has something to give.”

Yet there is a segment of our population that too often is left behind as we work to achieve better health for our citizens. Americans with mental retardation, and their families, face enormous obstacles in seeking the kind of basic health care that many of us take for granted. Unfortunately, societal misunderstanding of mental retardation, even by many health care providers, contributes to the terrible burden. Too few providers receive adequate training in treating persons with mental retardation. Even providers with appropriate training find our current service system offers few incentives to ensure appropriate health care for children and adults with special needs. American health research, the finest in the world, has too often bypassed health and health services research questions of prime importance to persons with mental retardation.

Individuals with mental retardation are more likely to receive inappropriate and inadequate treatment, or be denied health care altogether. Children, youth, and adults with mental retardation receive fewer routine health examinations, fewer immunizations, less mental health care, less

prophylactic oral health care, and fewer opportunities for physical exercise and athletic achievement than do other Americans. Those with communication difficulties are especially at greater risk for poor nutrition, overmedication, injury, and abuse.

In issuing this Blueprint for improving the health of those with mental retardation, the Surgeon General has drawn the attention of the Nation to the longstanding health disparities experienced by a group of Americans who deserve our full attention and support in their efforts to get the health care they need. By identifying these needs and outlining concrete action steps for addressing them, this community has created an unprecedented opportunity to narrow the gap between the health needs and health services for this special group. The Surgeon General’s national Blueprint, which complements the suggestions contained in the President’s *New Freedom Initiative*, takes the essential first steps needed to bring together self-advocates with mental retardation and their families with the scientists, health care providers, professional training institutions, advocacy organizations, and policymakers who can make a difference in the lives of individuals with mental retardation.

Our national commitment to the health of every American is demonstrated most clearly in efforts to reach those whose circumstances in life are most difficult. In this important new report, the Surgeon General articulates how the health of people with mental retardation can be significantly strengthened in the years ahead.



# Foreword from the Surgeon General

As Surgeon General I have focused on identifying and addressing some of our Nation's pressing unmet health needs and disparities in health and health care. These efforts have dealt with issues such as mental health (especially children's mental health), suicide, oral health, and obesity. By learning more about these issues and focusing the country's attention on them, the process has begun to develop broad support for specific steps that can be taken to improve them.

Over the last year, we undertook an effort to examine the health of persons with mental retardation, especially the health disparities they suffer. It became apparent that as our system of care for those with mental retardation evolved, our attention to their health lessened. Even a quick glimpse at the health status of persons with mental retardation, both children and adults, reveals glaring deficiencies that must be addressed. To better understand, we sought to listen, not just to the experts in this field, but directly to individuals with mental retardation, to their family members, and to their other caregivers—those who live and struggle every day with the wide spectrum of issues that affect the health of these individuals.

This dedicated community can teach us a great deal. They can help us all to better understand and face their unmet needs, which are significant and all too common. Perhaps the greatest lesson is that as a society we have not really been listening and paying attention to them. We have been too likely to expect others, without mental retardation, to speak to their needs. We have found it too easy to ignore even their most obvious and common health conditions. Just as important, we have not found ways to empower them

to improve and protect their own health. No one who cares would suggest that this is acceptable. Nothing, however, will follow from this effort unless we help our society better understand and appreciate that these persons are an integral part of the American people, with much to give if they, too, enjoy proper health.

Each person reading this report has an opportunity to learn more about these individuals' lives and needs, and to work together to improve their health. As the Report of the Surgeon General's Conference on Health Disparities and Mental Retardation, held in December 2001, this national Blueprint identifies goals and action steps set forth by this community as its priority needs.

The goals and action steps should be considered for implementation at all levels, in all sectors of our society, from single individuals acting in their own communities to the largest national organizations or government agencies acting on state- and nation-wide issues. Each of us must accept the responsibility to do our part to improve the health of all persons with mental retardation.

Reports don't have arms and legs. Like many others, this report will just sit on shelves unless we turn it into action. It is important to listen to those affected to learn what needs to be done, but to listen and not respond with determined action will only heighten the injustice this community has too long endured. I ask everyone reading this report to do your part to achieve our noble objective of improving the health of all persons with mental retardation. If we do, together we will make a significant difference in the lives of these important individuals.

David Satcher, M.D., Ph.D.  
Surgeon General  
January 2002





# **CLOSING THE GAP: A National Blueprint to Improve the Health of Persons with Mental Retardation**

## **REPORT OF THE SURGEON GENERAL'S CONFERENCE ON HEALTH DISPARITIES AND MENTAL RETARDATION**

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# Acknowledgments

The Surgeon General expresses sincere appreciation to all who contributed their time, experience, and knowledge to support the development of this report and national Blueprint to improve the health of individuals with mental retardation. The Surgeon General would especially like to acknowledge the following:

## THE PUBLIC

Among the most valuable contributions were those from members of the public who participated in many ways:

- Approximately 8,500 comments were received at the Surgeon General's dedicated website and at the Surgeon General's Listening Session on Health Disparities and Mental Retardation, October 10, 2001.
- The participants and speakers at the five sites included in the Surgeon General's Listening Session—Civitan International Research Center at the University of Alabama, Eunice Kennedy Shriver Center at the University of Massachusetts Medical School, Oregon Institute on Disability & Development at the Oregon Health & Science University, Waisman Center at the University of Wisconsin, and the National Institutes of Health.
- The participants, speakers, and moderators at the Surgeon General's Conference on Health Disparities and Mental Retardation, especially the self-advocates and family members who shared their perspectives on the day-to-day challenges of enabling persons with mental retardation to achieve good health.

## NATIONAL ORGANIZATIONS

Many national organizations of advocates, patients, and health care professionals supported the Surgeon General's effort by sharing their expert knowledge, and by participating in the Listening Session and the Conference. In particular, the Surgeon General would like to recognize the major efforts contributed by the following organizations:

American Academy of Pediatrics  
American Association on Mental Retardation  
American Dental Association  
American Osteopathic Association  
American Psychiatric Association  
Association of University Centers on Disabilities  
Child Neurology Society  
Joseph P. Kennedy, Jr. Foundation  
Special Olympics, Inc.  
The Arc of the United States

The support and continued interest of the following national organizations also are appreciated:

American Academy of Child and Adolescent Psychiatry  
American Academy of Neurology  
American Association of Physician Assistants  
American Association on Health and Disability  
American College of Obstetricians and Gynecologists  
American Medical Association  
American Neurological Association  
American Nurses Association  
American Physical Therapy Association  
American Psychological Association  
The Council on Quality and Leadership  
Developmental Disabilities Nurses Association  
Family Voices  
Federation of Families  
Intertribal Voices for Children's Mental Health  
National Alliance for Caregiving  
National Association for the Dually Diagnosed  
National Association of Developmental Disabilities Councils  
National Association of Qualified Mental Retardation Professionals  
National Association of Protection and Advocacy Systems  
National Association of State Directors of Developmental Disabilities Services

National Dental Association  
National Down Syndrome Congress  
National Hispanic Medical Association  
National Indian Child Welfare Association  
National League for Nursing  
National Medical Association  
Oglala Sioux Tribe  
People First  
Self Advocates Becoming Empowered  
Special Care Dentistry  
TASH – The Association for Persons with  
Severe Handicaps  
Voice of the Retarded

## **GOVERNMENT AGENCIES**

The Surgeon General's Conference on Health Disparities and Mental Retardation was sponsored by the following Government agencies:

### ***Department of Health and Human Services***

Office of the Surgeon General, Office of Public Health and Science  
National Institute of Child Health and Human Development, National Institutes of Health  
National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention  
Agency for Healthcare Research and Quality  
Center for Mental Health Services, Substance Abuse and Mental Health Services Administration  
Indian Health Service  
National Institute on Aging, National Institutes of Health  
National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health  
National Institute of Dental and Craniofacial Research, National Institutes of Health  
National Institute of Mental Health, National Institutes of Health  
Office of the Assistant Secretary for Planning and Evaluation

### ***Social Security Administration***

Office of Disability

in collaboration with the following agencies:

### ***Department of Health and Human Services***

Administration for Children and Families  
Administration on Developmental Disabilities  
Centers for Medicare & Medicaid Services  
Maternal and Child Health Bureau, Health Resources and Services Administration  
National Center for Health Statistics, Centers for Disease Control and Prevention  
National Center on Minority Health and Health Disparities, National Institutes of Health  
National Institute of Environmental Health Sciences, National Institutes of Health  
National Institute of Neurological Disorders and Stroke, National Institutes of Health  
National Institute of Nursing Research, National Institutes of Health  
Office of the Director, National Institutes of Health  
Office of Public Health and Science  
President's Committee on Mental Retardation

### ***Department of Defense***

Office of the Assistant Secretary of Defense, Health Affairs, TRICARE

### ***Department of Education***

Office of Special Education and Rehabilitative Services

*The Surgeon General would especially like to recognize Duane Alexander, M.D., Director of the National Institute of Child Health and Human Development, and the staff of the Institute for their assistance in conceptualizing the effort, organizing the Listening Session, conducting the Conference, and preparing this report.*

# Introduction

*“Individuals and their families should be equal partners [with providers] in making health care decisions....”*

Conference participant\*

Like other Americans, persons with mental retardation (MR) grow up, grow old, and need good health and health care services in their communities. But people with MR, their families, and their advocates report exceptional challenges in staying healthy and getting appropriate health services when they are sick. They feel excluded from public campaigns to promote wellness. They describe shortages of health care professionals who are willing to accept them as patients and who know how to meet their specialized needs. They struggle with unwieldy payment structures that were designed decades ago when people with MR often died in childhood or lived out their lives in residential institutions (U.S. Senate Appropriations Committee, Hearing Report No. 107-92).

Today, the life expectancy of people with conditions associated with MR has lengthened into adulthood and middle age. People with MR are remaining in their communities. In ever-increasing numbers, people with MR either do not enter institutions, or they leave them to live with their families or in other community settings, and they are determined to understand and take charge of their health. But in most cases, neither the education and training of health professionals nor other elements of the Nation’s health system have been updated to reflect their progress. Especially as adolescents and adults, people with MR and their families face ever-growing challenges in finding and financing primary and specialty health care that responds both to the characteristics of MR and to the distinctive health care needs of each stage of life.

## Terms in This Report

**Environments** refers to the characteristics of residential, work, educational, and community sites that may have positive or negative impacts on the health of people with MR. “Environment” includes family members and other caregivers, employers, teachers, and others at community sites, whose attitudes and treatment may support or impede people with MR in maintaining their health.

**Family and other caregivers.** “Family” refers to parents (including foster parents), siblings, and other family members who are primary caregivers for individuals with MR. “Caregiver” refers to personal care assistants, job coaches, housing counselors, volunteer “buddies,” and others who assist individuals with MR in diverse ways.

**Persons with MR or self-advocates** refers to individuals with MR. The Surgeon General is aware that there is a controversy around the use of the term “mental retardation” and that self-advocacy groups and professional associations are currently discussing alternatives. Until a consensus is reached, with the goal of drawing attention to the great health disparities faced by people with what has been traditionally known as “mental retardation,” that term has been used in the Surgeon General’s effort on health disparities and mental retardation.

**Providers or health care providers** refers to physicians, dentists, nurses, physician assistants, dental hygienists, physical/occupational/speech-language therapists, behavioral health specialists, and all other health care providers.

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\*Statements quoted in the Blueprint were made by Conference participants.

As health needs and service systems change over a lifetime, transitions are reported to be exceptionally difficult. Medicaid recipients speak of “falling off a cliff” when they graduate from the program’s expansive pediatric coverage to more constricted adult benefits. Many may spend years on a waiting list to gain access to the more flexible service packages that are available only through Medicaid waivers to limited numbers of adults with MR.

Planning health care services, allocating sufficient resources, and monitoring the health and quality of care for people with MR are major policy challenges because needed data are not sufficient for the task. For example, for a majority of people with MR, their condition is relatively mild, and once they leave school, they disappear into larger communities, untracked in major national data sets.

**Disparities and Diversity**—Compared with other populations, adults, adolescents, and children with MR experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care. These challenges are even more daunting for people with MR from minority communities with many cultures and languages and whose culture and primary language may not be reflected in available health services. As with many other disabling conditions, the multiple disorders associated with MR are found disproportionately among low-income communities that experience social and economic disparities when they seek health care. Mental retardation compounds these disparities because many health care providers and institutional sources of care avoid patients with this condition. Without direct clinical experience, health care providers may feel incapable of providing adequate care. They may not value people with MR and their potential contributions to their own health and to their communities.

**Identifying the Problems**—This report presents a national Blueprint to improve the health of persons with MR. The Blueprint identifies problems and solutions proposed by the community of people with MR and those who care about their health. It consists of multiple action steps that were developed by work groups at the Surgeon General’s National Conference on Health Disparities and Mental Retardation, December 5–6, 2001, in

Washington, DC. The action steps are organized under six broad goals that emerged from Conference discussions and analysis of work group recommendations. (Appendix A is a summary of data presentations at the Conference. Appendix B is a list of Conference participants.)

**Setting the Agenda and Realizing the Goals**—

The purpose of this Blueprint is to set forth an agenda from the community for national, State, and local action, in both public and private sectors, to improve the health of individuals with MR and to include them fully in health systems that meet their needs. Realizing the goals of this Blueprint calls for partnerships at all levels of public and private endeavor, from government agencies, legislatures, corporations, foundations, research and health care organizations, universities, and accreditation boards for health professions schools and training, to self-advocates, their families, local businesses and schools, voluntary, civic and faith-based organizations, individual clinical practices, and community-based health care services for other vulnerable populations. (Appendix C illustrates the diversity of potential partners, as suggested by participants in the December Conference.)

**Goals to Improve the Health of People with Mental Retardation**

- Health Promotion and Community Environments
- Knowledge and Understanding
- Quality of Health Care
- Training of Health Care Providers
- Health Care Financing
- Sources of Health Care

**Dual Diagnosis Research Agenda**—A separate national Workshop, held days before the Surgeon General’s Conference, developed a detailed agenda for research on emotional and behavioral disorders and mental illness in people with MR and developmental disabilities. These coexisting conditions (“dual diagnosis”) are among the most common and least understood aspects of health and MR because people with MR are commonly excluded from research on mental illness (as well as other types of disorders) on the basis of IQ rather than specific safety or other

considerations in a research protocol. This type of disparity also is seen in the organization of health care services. For example, mental health programs and providers may exclude individuals on the basis of low IQ.

The Workshop, supported by the National Institutes of Health and the Joseph P. Kennedy Foundation, developed research recommendations on epidemiology, diagnosis and assessment, and interventions in emotional and behavioral disorders of people with MR. The agenda also addressed ethical considerations, research design, and research training needs. (National Institutes of Health, *Workshop on Emotional and Behavioral Health in Persons with Mental Retardation/Developmental Disabilities: Research Challenges and Opportunities*, November 29–December 1, 2001, [http://draft.ninds.nih.gov/news\\_and\\_events/Emotional\\_Behavioral\\_Health\\_2001.htm](http://draft.ninds.nih.gov/news_and_events/Emotional_Behavioral_Health_2001.htm)).

**Federal Initiatives on Disabilities**—This report is published at a time when other Federal initiatives also are seeking to enable individuals with disabilities to live in their communities and receive appropriate services, including health care. These initiatives address some of the same problems that action steps in this report address and, in certain cases, propose the same or similar responses. For example, in a preliminary report to the President on his *New Freedom Initiative*, Federal agencies addressed structural changes in Medicaid, family support services to avert caregiver “burnout,” and better training for personal care attendants and other direct service providers (U.S. Department of Health and Human Services, *Delivering on the Promise: Preliminary*

*Report of Federal Agencies’ Actions to Remove Barriers and Promote Community Integration—New Freedom Initiative*, December 21, 2001).

Shortly after the Conference, the Health Resources and Services Administration (HRSA), in partnership with the March of Dimes, the American Academy of Pediatrics, and Family Voices, held a national conference to promote a ten-year plan for appropriate community-based services for children and youth with special health care needs (HRSA, *All Aboard the 2010 Express: A 10-Year Action Plan to Achieve Community-Based Service Systems for Children and Youth with Special Health Care Needs and Their Families*, December 2001).

In conjunction with the Surgeon General’s Conference on Health Disparities and Mental Retardation, the National Institute of Child Health and Human Development supported a national study describing diverse programs and creative strategies for providing community-based health care and supportive services for people with MR. (Appendix D is a summary of programs included in this study, which was provided to Conference participants.)

Most, if not all, of the content of this Blueprint is generally applicable for any population with disabilities. In fact, individuals with MR also may experience physically disabling conditions and disabling mental illness. The special role of this Blueprint is to set an agenda reflecting the distinctive implications of MR for health and disabilities policy and practice.





# A National Blueprint to Improve the Health of Persons with Mental Retardation

This Blueprint resulted from a multistep process designed to identify and address the health-related concerns and recommendations of the community of individuals, families, and providers who are concerned with health and MR. The first step occurred at a March 5, 2001, Senate Appropriations Subcommittee hearing, called by Senator Ted Stevens (R-AK), to receive a literature review of the health and health status of adults, adolescents, and children with MR. Authors of this study and other witnesses reported that people with MR had poorer health and far less access even to basic screening and corrective treatment for vision, hearing, and oral health problems than others and that diagnosis and treatment of mental illnesses and other serious disorders in this population were often delayed, inadequate, or not provided at all.

At the hearing, the Surgeon General announced his intention to focus the attention of the Nation on the health needs of adults, adolescents, and children with MR. Subsequently, the community of people concerned with health and MR were invited to help plan a national conference on health disparities and MR by communicating their experiences, concerns, and ideas to a dedicated website and at a national Listening Session held on October 10, 2001. The estimated 8,500 comments and suggestions sent to the website and expressed at the Listening Session formed the basis for planning the national Conference. (Appendices E and F are a summary of the Listening Session and a list of speakers at the Listening Session, respectively.)

**The National Conference**—The purpose of the national Conference, held December 5–6, 2001, in Washington, DC, was to identify important issues in health and MR and to develop action steps to address these issues. In inviting Conference participants, every effort was made to reflect the broad diversity of people with MR and others concerned with their health. Officials of Federal agencies attended the Conference as observers and as “resources,” providing information requested by participants.

Eight Conference work groups identified priority issues from those proposed during the planning process and from their own experiences. Work group topics ranged from provider attitudes and health care financing, to appropriateness of services across the lifespan and health promotion. Before the work groups began their deliberations, plenary session presentations provided background information on what was currently known about each group topic, and described examples of diverse programs providing health care and related services to adults, adolescents, and children with MR.

**Drafting the Blueprint**—To draft the Blueprint, it was necessary to consolidate nearly 50 issue areas and 200 action steps recommended by the Conference work groups. All records of the work of the groups were reviewed, including plenary session presentations of highlights of the work group decisions and written notes and audiotapes of group deliberations. An informal discussion among work group moderators as well as review of these records enabled drafters of the Blueprint to array the action steps under six broad goals that reflect priorities shared among the work groups. Action steps shown under the goals have been distilled from multiple group deliberations and reports.

“Potential strategies,” also derived from group deliberations, have been added to provide examples of activities, topics for research, and the like. These action steps and strategies should not be considered the only ways to achieve the six goals. The resulting Blueprint presents a consolidation of the problems identified and solutions proposed by participants from the website, the Listening Session, and the Conference. It is intended for multiple audiences, from the community of people who live with MR on a daily basis, to the health care providers, researchers, agencies, and others that can contribute to a more inclusive health care system. Each partner and combination of partners will bring their own priorities and ideas to the task of improving the health of people with MR.

***Core Values for All Aspects of the Blueprint—***

Throughout the Conference, certain core values permeated the deliberations of the work groups and the general Conference discussions at plenary sessions. As expressed by several Conference participants, these values include the following:

*“We ought to be about keeping people healthy...”*

*“For things to change, we must change the stigma [of MR] to understanding and respect.”*

*“[Every action must fully include]...people with MR, ...family involvement, and...people telling us what they need, as opposed to our telling them what they want.”*

*“Providers have to look beyond the disability and see the person—talk to us!”*

*“...If we do all [of the action steps], and we don’t do it in a person’s first language, and we don’t do it showing respect...for their culture, it means nothing...”*

*“[There must be] coordinated, community-based services that [are] integrated, available, and accessible. Let’s not make it all so difficult.”*

## GOALS AND ACTION STEPS

### GOAL 1: Integrate Health Promotion into Community Environments of People with Mental Retardation

*“Health promotion programs should accommodate people with MR. Examples include smoking cessation, weight control, fitness, safe sex, drugs, and alcohol.”*

As with other populations, health promotion and disease prevention are multifactorial for individuals with MR. They need to be empowered with adequate and understandable information and reinforcement to avoid health risks and maintain healthy personal habits. Their health care providers and the environments where they live, work, learn, and socialize should offer opportunities to inform, support, and reinforce healthy lifestyles. Routine preventive services, from periodic oral prophylaxis and restoration, to cancer screening, immunizations, and early intervention with emerging mental illness are critical to prevention of more serious conditions and secondary disability. Because of the potential for modeling behaviors, health-promoting knowledge and habits of personal care attendants and family members, co-workers, and others can help individuals with MR to protect and maintain their health.

#### **Action Steps:**

- **Wellness: Educate and support individuals with MR, their families, and other caregivers in self-care and wellness.**

*Potential strategies:* Adapt self-care and wellness programs designed for general populations and cultural, ethnic, and socioeconomic minorities to the needs of individuals with MR. When proven effective, replicate existing programs for individuals with MR, especially peer-designed programs for wellness, self-care, and mental health. Evaluate the use of assistive technology and different media in educating and reinforcing healthy behaviors in individuals with MR, their families, and their caregivers. Develop and disseminate models for health care provider counseling and reinforcement of wellness and healthy behaviors in individuals with MR, their families, and caregivers.

*Potential topics:* Nutrition and weight control; exercise; oral health; family planning; safe sex; strategies for protection from rape, domestic violence, and sexual abuse; maintaining treatment regimens; avoiding medication errors; recognizing and seeking care for emerging disorders; and age-related changes in, and risks to, health status.

- **Caregiver support: Develop and implement strategies for reducing care burdens for families of individuals with MR, and reducing high rates of turnover in nonfamily caregivers.**

*Potential strategies:* Identify stressors and sources of resilience in individuals with MR, their families, and their caregivers, and support strategies to enhance resilience. Support respite care, case management, advance (lifetime) planning for transitions to different stages of life and age-associated health needs. Provide assistance in caring for individuals with dual diagnosis, including family and caregiver training in behavior management and advance planning for behavioral crises. Provide technical assistance to families in information technologies, including how to use the Internet. Explore compensation, including basic health coverage, for family caregivers whose care responsibilities prevent them from working outside the home.

*Additional strategies:* Provide training in health care, including supporting healthy habits, for personal care attendants and other caregivers. Create career tracks leading to certification of caregivers with regard to health-related competencies. Support basic health care coverage and increased compensation, commensurate with demonstrated health competencies, for caregivers.

- **Workplace: Protect the health of individuals with MR from occupational hazards.**

*Potential strategies:* Develop and disseminate modules to educate and train individuals with MR, their employment counselors and job coaches, their families and caregivers, their employers and potential employers, and occupational health and safety inspectors, in recognizing and eliminating hazardous working conditions that may require special accommodations for employees with MR. Potential accommodations include ensuring that employees

with MR work in safe and healthful environments and understand how to avoid repetitive motion disorders and other occupational hazards.

- **Assessment:** Assess the effects of health promotion and wellness activities for individuals

**with MR on their morbidity, secondary disability, mortality, life satisfaction, independent living, achievement of life goals, and cultural and ethnic identity.**

## **GOAL 2: Increase Knowledge and Understanding of Health and Mental Retardation, Ensuring that Knowledge Is Made Practical and Easy to Use**

*“We’re invisible in the data. We can’t make people believe we need more services if we don’t have data to back us up.”*

Credible scientific knowledge is considered essential to all goals in this Blueprint, from establishing appropriate standards of health care, to training health care providers, to revising financing structures, and improving the capacity of individuals and their families to protect and maintain their health. For example, the lack of population-based data on prevalence of MR and the health status and service needs of this population impedes planning and allocating resources for their care. Failure to monitor the quality of their care hampers detection of prejudicial or inadequate treatment. Recent advances in neurosciences, genetics, psychopharmacology, and other fields of research could improve the diagnosis and treatment of individuals with MR and emotional, behavioral, or psychiatric disorders (dual diagnosis).

At the same time, individuals, family members, and health care providers need easily accessible, scientifically accurate, culturally relevant, and understandable information for prevention and health promotion, as well as for diagnostic and treatment decisions. All aspects of health-related research, from biomedical and epidemiologic to health services and ethics, offer multiple opportunities to increase and improve the utility of scientific knowledge on health and MR.

### **Action Steps:**

- **Participation:** Enable individuals with MR, their families, and their health care providers to partner with professional investigators in identifying health research priorities, and in designing and implementing research relating to health and MR.

*Potential strategies:* Include individuals with MR, family members, and their primary and specialty health care providers in research advisory committees and planning groups to provide input into the development of research proposals and grant

submissions. Offer training to lay advisors in identifying research questions and other technical matters. Encourage federally funded health researchers to develop partnerships in which persons with MR, their family members, and other caregivers, including health care providers, are consulted and participate in the planning and conduct of research relevant to MR.

- **Research agenda:** Develop a national research agenda that identifies gaps in existing scientific knowledge related to health and MR, including methodological challenges, priorities, feasibility, and timetables for achieving priority research.

*Potential strategies:* Develop specific agendas for basic, clinical, and translational research; for studies of the efficacy of wellness and treatment services and service models for people with MR; for legal and ethical issues, health care financing, and its relationship to outcomes; and for other matters identified by the community. Implement the December 2001 research agenda of the Workshop on Emotional and Behavioral Health in Persons with Mental Retardation/Developmental Disabilities (National Institutes of Health, Workshop on Emotional and Behavioral Health in Persons with Mental Retardation/Developmental Disabilities: Research Challenges and Opportunities, November 29–December 1, 2001). Enhance research collaborations across multiple research agendas and disciplines.

- **Data collection:** Collect data on the health status of persons with MR in relation to the utilization, organization, and financing of their health services.

*Potential strategies:* Identify and evaluate existing data on health and MR. Add MR to population-based data collection on health status, health risks, health services utilization, and health care costs. Test methods of identifying patients with MR on Medicaid and other third-party payer claims for purposes of collecting data, while also protecting patient confidentiality. Conduct market research to determine attitudes toward MR of health care providers, and how to change negative attitudes. Survey individual practices, managed care

organizations, and localities and States to better understand the experiences of individuals with MR when they seek health care.

- **Research subject protection:** Review current ethical and legal rules for protection of human research subjects as they relate to individuals with MR. Revise these rules as necessary to facilitate the participation of persons with MR in clinical trials and other types of research, with full protection of their autonomy, health, and safety. Ensure that individuals, their families, their health care providers, and their advocates participate as partners in reviews and revisions of these rules. Ensure their participation in Institutional Review Board (IRB) reviews of research proposals relating to MR.

*Potential strategies:* Provide training in legal and ethical rules for protection of human research subjects to lay participants in review and the revision of these rules. Provide training in IRB standards and procedures.

- **Understanding and use:** Provide assistance for individuals with MR, their families, and their health care providers in finding, evaluating, and using health research findings to help in the prevention, diagnosis, and management of medical (including psychiatric), psychological, and oral health conditions, and to inform treatment decisions by individuals and their families.

*Potential strategies:* Establish, and keep current, a national clearinghouse, a website, and a list-serve to guide users in identifying and evaluating research, and to promote their exchange of information and opinions. Design science-based continuing education curricula for licensed health care providers. Translate peer-reviewed journal information, reports of

evidence-based best practices, and other findings for lay consumption, and disseminate information to provider groups, and State agencies that serve persons with MR, and provider trade journals.

- **Research capacity:** Increase the number of investigators trained in health and MR research.

*Potential strategies:* Fund undergraduate training and postdoctoral research fellowships at medical, dental, and other health professions schools and training programs targeted specifically at issues relevant to MR. Solicit proposals for multidisciplinary research. Solicit proposals from centers and programs that provide health care to individuals with MR, especially those living in their communities. Solicit joint proposals from these providers and investigators at medical, dental, and other health professions schools and programs.

- **Visibility:** Enhance the visibility of health and MR research.

*Potential strategies:* Increase and ensure appropriate use of funds to support research on health and MR, including expansion of studies on dual diagnosis and other disorders for which individuals with MR are at elevated risk. Create prizes and other awards for excellence in health and MR research. Endow chairs for health and MR research at health professions schools. Establish special interest sections in health research organizations. Support special plenary lectures on health and MR at national medical, dental, and other health professions meetings. Publish health and MR research findings in peer-reviewed medical (including psychiatric), dental, psychological, nursing, physician assistant, dental hygienist, and other health-related journals, as well as in health services research and policy journals.

### **GOAL 3: Improve the Quality of Health Care for People with Mental Retardation**

*“Encourage agencies and health care professionals to treat people with MR according to age and health needs, not just for their disability.”*

The quality of health care for individuals with MR depends on the knowledge and skills of individual providers, particularly their capacity to engage these patients in their own health care, and on systemic factors. Such factors include monitoring the utilization of health care services and outcomes for people with MR, and correcting deficiencies in the quality of their care, such as medication error, underutilization of services, and failure to interact effectively with patients and family members.

At both the individual provider and health systems levels, credible standards of health care, based on scientific evidence, are essential to improving the quality of health care for people with MR. Until an adequate science base is available, however, consensus standards that reflect the knowledge and experience of recognized experts (including the community of people concerned with health and MR), and are formulated in standardized procedures, are an important interim step. The potential for MR-specific standards to contribute to stigmatization must be balanced against the need for health care services that fully meet the needs of this population.

#### **Action Steps:**

- **Priorities: Identify priority areas of health care quality improvement for persons with MR.**

*Potential strategies:* Consult with individuals with MR, their families, and their primary and specialty health care providers and researchers to identify priority areas for ensuring and improving the quality of their health care. Identify existing best practices that may be used systemwide to improve the quality of care, and those areas in which better practices may be needed. Use these consultations, together with evaluations of existing and needed scientific knowledge, to establish priorities for improving the quality of health care for people with MR.

- **Standards of care:** Identify, adapt, and develop standards of care for use in monitoring and improving the quality of care for individuals with MR.

*Potential strategies:* Work with associations of health professionals that develop consensus and science-based standards of care for populations with disabling conditions, for people with MR, and for general populations. Identify and adapt standards developed with the support of the National Institutes of Health, the Centers for Disease Control and Prevention, the Centers for Medicare & Medicaid Services, and other Federal agencies; consult with the National Committee for Quality Assurance and with contractors that develop health care standards for quality assurance in managed care. Identify existing strategies for adapting and developing additional standards of care for use with culturally diverse populations.

*Additional strategies:* Develop science-based standards on topics for which sufficient scientific knowledge exists. Develop interim, consensus standards on topics for which scientific knowledge must be developed. Replace consensus standards, to the extent feasible, with science-based standards. Review and update standards to reflect new knowledge, as it becomes available.

*Potential priority topics for standards:* Responsiveness to distinctive cultural values of diverse communities; self-care and maintenance of health-promoting activities; diagnosis and treatment of emotional and behavioral disorders and mental illness; provider screening; and prevention and early intervention in medical, psychiatric, behavioral, and oral health conditions for which individuals with MR are at heightened risk, such as premature aging, and for coexisting conditions, such as diabetes and mental illness.

*Other potential priority topics:* Recognition and treatment of emergency conditions, including sexual, physical, and psychological abuse and their sequelae; prevention, diagnosis, and treatment of substance abuse; development of plans of care, including self-care, to achieve health goals of individuals and their families; development and revision of lifetime health plans for individuals with MR; age-appropriateness of

health services (including pediatric, adolescent, adult, geriatric, palliative, and end-of-life care); and age-related transitions, including pediatric to adult health care.

- **Use: Ensure that the practice, organization, and financing of health care services for individuals with MR promote improvement in their quality of care.**

*Potential strategies:* Determine whether and how existing standards for care of people with MR are used. Integrate standards of care for MR into the following: clinical practice guidelines; curricula for health professions training; guidance for individuals, their families, their other caregivers, and their primary and specialty care providers; organized health services (including managed care organizations, hospitals, community health centers, and others); and quality assessment and performance improvements in organized health services and individual provider practices.

*Additional strategies:* Explore methods of linking health care financing to appropriate standards of care for people with MR. Methods could include health care quality requirements in managed care contracts and oversight of such contracts by private and public purchasers, and projects to test such linkage in behavioral health, maternal and child health, family planning, oral health, and comprehensive health care services programs.

- **Recognizing excellence: Establish local, regional, and national awards that recognize excellence in providing health care to individuals with MR.**

*Potential strategies:* Work with individuals, their families and caregivers, academic institutions, medical, dental, and other health professions societies, and national associations and other interested parties and groups to recognize excellence in providing health care for individuals with MR. Recognition could include financial prizes and nonmonetary awards.



#### **GOAL 4: Train Health Care Providers in the Care of Adults and Children with Mental Retardation**

*“The number one issue is lack of training to support healthy lifestyles [for individuals with MR] across the lifespan.”*

The challenges and rewards of treating individuals with MR are rarely addressed in the training of physicians and other health care professionals. However, anecdotal evidence and limited data indicate that opportunities for clinical experiences with these patients, early in medical and other health professions training, increase the capacity of providers to value and accept these patients into their practices.

##### **Action Steps:**

- **Professional education:** Integrate didactic and clinical training in health care of individuals with MR into the basic and specialized education and training of all health care providers.

*Potential strategies:* Evaluate existing health professions training curricula that address health and MR and disseminate those found to be efficacious. Partner with families and individuals with MR to develop and implement training modules. Use providers experienced in the care of individuals with MR and family members to mentor health professions students, residents, and fellows in the care of this population. Develop and implement criteria for accreditation and certification of health professions schools and training programs, based on inclusion of mental retardation in their curricula.

*Potential curriculum topics:* Dual diagnosis; health risks and expression, in people with MR, of age-related conditions found in other populations; direct

interactions with these patients, such as history-taking, including cultural practices, diagnosis, treatment, and counseling and supporting individuals in wellness and in adherence to treatment regimens; appropriate use of medications and alternative behavior management techniques; working with individuals and their families to develop and update goal-oriented health care plans, including lifetime plans and plans for transition points; and use of augmentative communications devices and other specialized equipment.

- **Interdisciplinary education and training:** Support development and dissemination of effective training modules in interdisciplinary practice. Design modules to include social workers, family members, individuals with MR, and others, when relevant, such as teachers, personal care attendants, job counselors, and frontline office staff.
- **Provider competence:** Develop methods of evaluating and improving health provider competence in the health care of individuals with MR. These methods should be based on appropriate standards of care, including care that reflects understanding and respect for diverse cultures, and should be used to evaluate the competence of students and practicing providers, and to provide feedback and reevaluation of their performance.
- **Continuing education:** Develop, evaluate, and disseminate continuing education curricula for health care providers at all levels of practice in the care of individuals with MR. Such curricula should be based on appropriate standards of care and include training opportunities that reflect understanding and respect for diverse cultures.

## **GOAL 5: Ensure that Health Care Financing Produces Good Health Outcomes for Adults and Children with Mental Retardation**

*“Let’s develop reimbursement that is respectful of the diverse lifestyles of people with MR and their families and that is tied to outcomes they value, [but] be careful...that we don’t develop policies that will cover more people, with more flexibility, without ensuring the basic level of care that we know our people need.”*

High rates of poverty among adults and children with MR mean that a large proportion of them rely on publicly financed health care insurance, which is not always well-adapted to serving their needs. People with MR find that many providers avoid the program, citing low reimbursement rates, administrative burden, and fear of being inundated with underfinanced patients. Providers who are committed to treating individuals with MR report that restrictive Medicaid rules on which services are covered, in which settings, can limit use of innovative service models.

Families with private-sector coverage encounter gaps in coverage, unaffordable premium payments, and little flexibility in designing packages of services to meet their children’s needs. Cost-avoidance and cost-shifting by both public and private payers force families to try to mediate between special education programs and third-party payers and between long-term and acute care systems. Research and understanding of financing structures, to better accommodate service needs of individuals with MR, are hindered by lack of critical utilization and reimbursement data.

### **Action Steps:**

- **Outcomes and financing:** Determine relationships among diverse financing mechanisms, service packages, and health outcomes for individuals with MR. Use findings to ensure accountability of flexible arrangements for financing services.

*Potential strategies:* Test effects on health outcomes, for people with MR, of diverse models for providing health care services, service packages, and financing mechanisms. Identify factors in varying

combinations that affect outcomes. Determine effects of adjunct services, including respite care, transportation, child care, and case management, in combination with medical, dental, and other health services, on outcomes. Support longitudinal studies of portability of health services packages as educational, employment, and residential circumstances change. Develop methods of ensuring accountability for sufficiency and quality of health care services, including accountability for outcomes, in models for flexible health service financing.

- **Definitions:** Use appropriate definitions of “effective,” “cost-effective,” and “health outcomes” in research, organization, and financing of health care for individuals with MR.

*Potential strategies:* Explore expanding definitions of terms used in measuring the effects of health care financing and service models to include wellness, functionality, patient and family understanding of health maintenance and treatment regimens, capacity for consumer choice among services, and satisfaction and individualization of service packages. Calculate health care costs across all systems with responsibility for health care of individuals with MR, such as special education, and third-party payments for behavioral therapy. Support development of methods to determine cost-effectiveness of services over the lifespan, taking into consideration cost offsets among long-term, preventive, and acute care, and other factors.

- **Services:** Identify a package of health care services for individuals with MR that will produce good outcomes in terms of health maintenance, management of illness, functionality, and life goals across the individual’s lifespan.

*Potential strategies:* Review currently available public and private packages of health care and supportive services for cost, quality, and consumer satisfaction. Test models of comprehensive lifetime coverage to better meet the needs of persons throughout their lives and avoid age-related disruptions of financing and services. Assess the use of criteria, including acquiring and maintaining functionality for making decisions on coverage.

- **Leveraging:** Evaluate models for leveraging health dollars to maximize purchasing power by and for individuals with MR. Ensure that individuals' coverage and access to primary and specialty health care and support services are not eroded by revisions in purchasing practices and policies.

*Potential strategies:* Evaluate models for coordinated funding of pediatric, adolescent, adult, and geriatric care, including acute and long-term care, primary care, specialty services, and school-based services, through use of pooled funds, complementary financing from multiple funding streams, and other innovations. Evaluate models for tying funding mechanisms to good outcomes, as defined in the first action step. Evaluate models that enable individuals with MR and their families to choose needed health services on an individualized basis and to monitor outcomes and service utilization. Encourage third-party payers to reimburse for health care services in carefully monitored clinical trials and other studies at academic centers of excellence.

*Additional potential strategies:* Provide technical assistance to States, tribes, and health care programs and providers in using Medicaid authorities to finance innovative models for providing health care, and identify and eliminate financial disincentives for such

models. For example, payer rules limiting reimbursements to one visit per patient per day may mean that families must make multiple appointments with multiple providers to complete multidisciplinary assessments. Evaluate and replicate the use of incentives, such as enhanced Medicaid reimbursement rates, to encourage States to develop and/or replicate effective models that meet the needs of individuals typically not covered.

- **Cost offsets:** Explore strategies to offset financial costs to providers and health services programs that are associated with meeting specialized needs of patients with MR.

*Potential strategies:* Assess the relationship between different rates of Medicaid and Medicare provider reimbursement and any impact on access to health care for individuals with MR. Identify sources and amounts of costs to providers that are associated with meeting specialized needs of individuals with MR. Assess the effect of offsetting such costs on provider acceptance of individuals with MR. Assess combined and separate effects of cost-offsets and nonfinancial provider supports, described elsewhere in the Blueprint, on provider acceptance.

## **GOAL 6: Increase Sources of Health Care Services for Adults, Adolescents, and Children with Mental Retardation, Ensuring that Health Care is Easily Accessible for Them**

*“Services can be wonderful and high quality, but if there aren’t enough, or if you can’t get to them, or if you don’t know about them, [they’re of] no help to you...”*

Like other Americans, especially those who are poor and disabled, people with MR are confronted with a fragmented health care system in which primary and specialty sources of care are often poorly distributed, inadequate in number, and ill-equipped to respond to their needs.

### **Action Steps:**

- **Diversity:** Increase the number of physicians, dentists, clinical psychologists, and allied health care professionals who have appropriate training and experience in treating adults, adolescents, and children with MR, including those from socioeconomically and linguistically diverse communities.

*Potential strategies:* Recruit students, residents and fellows, and practicing providers from diverse communities, and train them in providing health care to individuals with MR. Establish health professions curricula and continuing education modules in cultural competence in relating to patients with MR. Work with spiritual and other leaders who know the cultural and ethnic beliefs, values, and primary languages of individuals and families in diverse communities to plan and provide health care services, develop health professions training curricula, and otherwise ensure responsiveness to diverse ethnic, cultural, and linguistic needs in all aspects of health care for individuals with MR and their families.

- **Easier access:** Make access to health care services less complicated for individuals with MR and their families and caregivers, whether in urban, rural, or remote communities.

*Potential strategies:* Ensure that independent service coordinators who work on behalf of clients to locate and ensure access to and coordination of services are available for individuals with MR who wish such assistance. Co-locate primary and specialty medical, psychiatric/psychological, and dental

services. Support multidisciplinary teams, including mobile teams to bring services to individuals’ homes, schools, and other nonclinical sites. Ensure that individuals with MR receive assistance in care coordination and transportation to health care services. Ensure that individuals and families in various community settings receive usable information about available health care in their communities.

*Additional strategies:* Review eligibility to reduce the need for multiple applications and multiple determinations of eligibility for services. Promote the use of presumptive eligibility, once initial eligibility is established, for services through Medicare or Supplemental Security Insurance (SSI)/Medicaid.

- **Community-based care:** Integrate health care services for individuals with MR into diverse community programs.

*Potential strategies:* Incorporate preventive health education and interventions into early intervention and special education plans. Support development of protocols and dissemination, for care of individuals with MR and coexisting conditions, at community and migrant health centers, community mental health services, addiction disorder services, family planning programs, rape/sexual abuse and family violence services, public health clinics, and other publicly funded, community-based health services and programs. Prohibit such programs and services from excluding individuals solely on the basis of IQ.

- **Health professionals:** Expand the types of health professionals used in providing health care to individuals with MR, including geriatric, pediatric, and other nurse practitioners and nurses, physician assistants, dental hygienists, and behavioral therapists.

*Potential strategies:* Identify and remove disincentives and barriers in Medicaid, Medicare, and private third-party payer reimbursements to expand the use of a wide variety of health professionals to care for persons with MR.

- **Supporting providers:** Support supplementary services to help physicians, dentists, psychologists, and other providers and organized health services in providing care to individuals with MR.

*Potential strategies:* Work with providers to identify nonfinancial “costs” in including individuals with MR in their practices and programs. Support needed services that could offset such “costs.” Such services could include technical assistance with Medicaid and other types of claiming, case managers, preliminary health screening and referrals, completing informed consent procedures, and assembling complete and current medical and dental histories (including family histories) of individuals with MR. Explore the use of “health passports” (copies of up-to-date health histories, including family history) that “travel” to health services with individuals with MR.

- ***Special equipment:*** Ensure that adaptive equipment and assistive technologies are available in urban, rural, and remote communities for use at clinical sites where individuals with MR receive health care.

*Potential strategies:* Provide support to health care providers to finance the costs of purchasing and

installing special equipment and modifications to practice sites, such as installation of automatic doors, specialized examining tables and chairs, and wheelchair-accessible bathrooms. Evaluate and support the use of overhead allowances, direct subsidies, cost- and time-sharing among providers, and other mechanisms for offsetting costs of acquiring (and, as necessary, training in the use of) specialized equipment.

- ***Lifetime health:*** Ensure continuity of health care services throughout the life of an individual with MR.

*Potential strategies:* Develop and implement State plans for providing age-appropriate, comprehensive, and continuous health services for individuals throughout their lives. Develop and disseminate models for individual lifetime health care plans, with periodic review and updates.



# **Appendix A: Surgeon General's Conference on Health Disparities and Mental Retardation**

## **Summary of the Plenary Session of December 5, 2001: Background Presentations**

The plenary session on the first day of the Surgeon General's Conference on Health Disparities and Mental Retardation provided important background information for the work groups held later that day. Starting with the opening remarks, the presentations set the tone and provided the foundation for the eight separate work group discussions.

For each work group, a moderator introduced the key issues to be addressed, and another expert presented the current state of knowledge. To complement the facts, an individual representing a service program that creatively addressed the issues discussed the program, challenges, and achievements. Brief summaries of the opening remarks and presentations follow.

### **OPENING REMARKS**

#### ***Duane Alexander, M.D., Director, National Institute of Child Health and Human Development (NICHD)***

Dr. Alexander noted that because the NICHD was established by President John Kennedy to lead the Nation's research effort to improve the health of individuals with mental retardation (MR), he welcomed the Surgeon General's request to convene the conference. He expressed appreciation to all who would help develop recommendations and to the many Government agencies that supported the effort. Dr. Alexander introduced Dr. Satcher as the moving force behind the Nation's efforts to address the many health disparities faced by different population groups across the country.

#### ***David Satcher, M.D., Ph.D., Surgeon General of the United States***

Dr. Satcher described the conference and its outcome as an important example of efforts to move forward in the best interests of the American people

following the tragedies of September 11. After recognizing the NICHD and other agencies involved, he pointed out that Surgeon Generals' reports have enjoyed great credibility with the American public because they are based not on opinion, politics, or religion, but on the best public health science.

This conference complements several top priorities of the Surgeon General's Office, including health disparities and meeting the health needs of our most vulnerable, the role of the community health system in the struggle for access to care, and identifying and addressing common problems and experiences within our global health community.

The genesis of this conference was the March 2000 field hearing of the Senate Appropriations Subcommittee on access to care for individuals with MR, at which families and self-advocates testified convincingly about the problems they face. The Conference and the Blueprint for action reflect the Surgeon General's efforts to not only listen but respond with effective programs. The Conference report and its implementation are key to achieving this goal. Noting the caveat with the use of the term "mental retardation," he asked all participants to judge each other not by the words used to describe the condition but rather by the actions taken to help improve the lives of those with the condition.

#### ***Loretta Claiborne, Athlete and Self-Advocate***

Ms. Claiborne thanked the Surgeon General for listening to individuals with MR, and expressed her hope that her experiences seeking health care as a child would not happen to others. She credited the Special Olympics with recognizing the urgent health needs of many of their athletes, and pointed out that this conference, with its high rate of involvement by people who have never been listened to before, was different and important.

## PRESENTATIONS

### ***Bonnie Kerker, Ph.D., Overview Presentation on the Prevalence of Mental Retardation***

Dr. Kerker noted that accurate and consistent prevalence data on MR are essential for developing health policies and health care services, and for allocating public funds to address the needs of children and adults with MR.

Current data show that approximately 0.3 to 3.1 percent of the general population, and about 1.1 percent of all children, have MR. Of these individuals, most are classified as having mild MR. Other developed countries report a lower and narrower range of MR than the U.S. Some of the discrepancy in prevalence estimates is due to differences in the way MR is defined and in the types of data used. For instance, MR is commonly defined in three basic ways—on the basis of intellectual functioning alone, intellectual functioning with adaptive behaviors, or intellectual functioning with an identifiable etiology of MR. Likewise, prevalence data may be population-based, including counts of people with MR in an overall population, or the data may be drawn from clinical or administrative sources, meaning that it is based on individuals who access services. Most U.S. prevalence data come from the latter sources; however, such data usually provide less accurate counts because many adults and children with MR may be unable to access care.

Another difficulty lies in the timing and ease of identifying individuals with MR. For example, because of naturally occurring but subtle differences in early developmental patterns, children may not be diagnosed early in life. Those children diagnosed later through the school system, especially those with mild MR, are often lost in followup as adults.

In summary, despite wide ranges in prevalence data, many people in the U.S. and abroad must confront the challenge of MR. The challenge for our Nation begins with more accurately estimating the prevalence of these conditions. This requires using a standardized definition of MR, increasing the use of population-based data that emphasize participation of individuals with MR, and encouraging and helping health care providers to identify both adults and children with MR.

### **Work Group One: Attitudes of Health Care Professionals**

#### ***David Coulter, M.D., Moderator***

Referring to comments made at the Surgeon General's Listening Session on Health Disparities and Mental Retardation, Dr. Coulter noted that many family members and self-advocates continue to encounter poor attitudes among health care providers.

Our society assumes health care professionals should provide accessible, comprehensive, family-centered care that is also coordinated, continuous, culturally competent, and respectful of a patient's choices. Meeting the needs of individuals with MR, however, also requires developing new ways to incorporate the concept of self-determination and patients' own goals for a healthy life into their care. This requires better training for providers to improve their attitudes and their knowledge of the needs of those with MR.

Listening Session participants also noted that health care providers may reluctantly accept Medicaid recipients or individuals with MR as patients. Provider attitudes also may influence the quality of care delivered to people with MR and reduce direct communication with these patients. For patients who come from different ethnic and cultural groups, provider attitudes may lead to misunderstandings concerning the values and perceptions of health or concerning MR itself.

#### ***K. Charlie Lakin, Ph.D., Scientific Presentation***

Dr. Lakin discussed the wide range of intellectual ability and health needs of children and adults with intellectual disabilities. Poverty is a key issue for those with intellectual disabilities: adults with these disabilities are three times more likely to live in poverty than other adults in the U.S. Similarly, children with intellectual disabilities are twice as likely to live in poverty as other children. In addition, people with intellectual disabilities are less likely to be insured than the general population.

Despite these facts, data from the National Health Interview Survey show that a majority of people with intellectual disabilities, or their proxies, report their doctor's thoroughness, respect and



attention to privacy, interest in them and their condition, and availability in an emergency to be either “good” or “excellent.”

However, other literature shows that if health care providers lack the experience or specific knowledge, they are reluctant to treat people with intellectual disabilities. Likewise, providers may hesitate to treat patients with intellectual disabilities because of poor experiences in past encounters or because providers are inadequately compensated for the additional time that may be required to care for these patients.

Provider training is key to influencing these attitudes. Research shows providers (or other professionals working directly with patients in a clinical setting) who took a structured training course concerning the health care of individuals with intellectual disabilities had an increased desire or willingness to treat these patients. The attitudes of providers who were trained with only reading or course work did not change.

In summary, the literature reveals that provider attitudes influence access to services. A provider’s willingness to treat people with intellectual disabilities is influenced by public, private, and advocacy groups; access to technical support and professional allies; and evidence that it is financially viable to treat people with intellectual disabilities. In addition, transportation, communication, and other problems commonly experienced by persons with disabilities only increase the challenges faced by providers.

### ***Sharon L. Ramey, Ph.D., Creative Program Presentation***

Dr. Ramey shared findings about a unique research program at the Alabama Mother and Family Specialty Center in Birmingham, Alabama. Originally developed to determine whether providing good prenatal care could decrease the rates of low-birthweight and premature babies, the program faced the challenge of caring for many women with intellectual disabilities. In a previous study, about one-third of the mothers with low-birthweight or premature babies had low IQs themselves.

The researchers carefully documented the amount and quality of care each of the 600 women enrolled in the program received during her pregnancy. Mothers received highly tailored prenatal care provided by the same nurse over the course of the program. Instructional videotapes, educational materials, flexible clinic hours, transportation to the clinic, child care during office visits, and participation in a talk show to discuss common questions during pregnancy complemented the care the mothers received.

An evaluation revealed that the tailored program of prenatal care failed to reduce significantly the incidence of low-birthweight or premature babies; however, the program improved the health of the mothers and their knowledge of their bodies, promoting healthy lifestyles and healthy behaviors. In the end, the program and its many components helped to prepare these women, many with low IQs, for the challenging task of motherhood.

## **Work Group Two: Quality of Health Services**

### ***Roxanne Dryden-Edwards, M.D., Moderator***

Dr. Dryden-Edwards noted that individuals with intellectual disabilities need specific approaches to health care treatment. Most importantly, to give quality care, providers will need to spend more time with these patients and take advantage of opportunities to learn about a broad range of their needs. Current and future health care professionals will need to be better trained. It will be important that they learn how to provide comprehensive care respectfully, prevent the inappropriate use of medications, and ensure that children receive appropriate followup care as they make their transition into adolescence and adulthood.

### ***K. Charlie Lakin, Ph.D., Scientific Presentation***

In reviewing the literature, Dr. Lakin noted that much research concerning the quality of care for individuals with intellectual disabilities targets those living in institutions. In these settings, a wide range of health needs are generally met in a satisfactory manner. However, as the needs of this population become more complex, the need for additional professional training increases.

Interesting data from the National Health Interview Survey also show that children with intellectual disabilities were just as likely to see a doctor within the past year as children without these disabilities. In fact, adults with intellectual disabilities were more likely to see a doctor within the past year than those without such disabilities. One fact also was clear—people with intellectual disabilities have a greater need for specialized health care.

Despite these promising findings, anecdotal evidence suggests that many people with intellectual disabilities fail to have their basic health needs met. Unfortunately, no comprehensive study documents this fact or the technical quality of health services provided. Such studies, with outcome-oriented approaches, must be conducted. These studies, in turn, will provide the foundation for developing quality-of-care guidelines for people with intellectual disabilities. These guidelines should address access to health professionals, health promotion and nutrition, routine monitoring of health care, dental and oral health, and commonly associated health problems. The role and training of support staff also must be addressed.

### ***Nancy N. Cain, M.D., Creative Program Presentation***

Dr. Cain discussed Rochester Community-Based Crisis Intervention Services, a program to increase access to psychiatric care for people with intellectual disabilities. The Rochester program has two main components, including a crisis intervention team and a specialized psychiatry clinic. During a crisis, the intervention team works with families and group homes on a short-term basis to help find appropriate care for the adult or child with intellectual disabilities. Program staff are on call for emergency room consultations 24 hours a day, and may be asked to evaluate an individual in the emergency room to determine whether the problem is psychiatric in nature. If so, the team member facilitates a psychiatric admission.

Although the crisis intervention team evaluates both children and adults, currently, only adults are seen in the specialized psychiatry clinic. Adults with intellectual disabilities may be followed on a long-

term basis in the clinic. Both medical students and psychiatry residents may train with either the crisis intervention team or in the specialized psychiatry clinic.

A program review revealed that the crisis intervention team and specialized psychiatry clinic have prevented unnecessary hospitalizations, enhanced appropriate community placements, maintained behavioral health, enhanced the expertise of providers working in the community, and increased collaboration between the developmental disability and mental health systems.

### **Work Group Three: Finding and Getting to Health Care Services**

#### ***Sheryl White-Scott, M.D., Moderator***

Dr. White-Scott discussed what was learned about finding and getting to health care services at the Surgeon General's Listening Session on Health Disparities and Mental Retardation. Participants highlighted a lack of information concerning the types and location of services, and a definite shortage of appropriately trained health providers. Transportation and access problems exist in both urban and rural settings. Often people face cultural and language barriers, and patient education materials are not geared to individuals with cognitive impairments. Complicating matters, few formal health care standards exist for treating these individuals. Multidisciplinary experts, working across systems, must develop these standards.

#### ***Deborah Spitalnik, Ph.D., Scientific Presentation***

Dr. Spitalnik discussed key factors influencing an individual's ability to obtain needed health services. These factors include "access, affordability, availability, and acceptability." Research in this area is complicated by difficulties in collecting data, lack of comparability across studies, lack of good measures of access, and imprecise definitions of MR.

Unfortunately, poverty is an access issue for many people with MR, who often depend on public support for health care. A recent study of children on Supplemental Security Income (SSI) showed that they frequently received care from a general practitioner without pediatric experience. In

addition, children with MR often failed to receive subspecialty care. Additional disparities are related to race, geographic location, and SSI status.

Another problem is that individuals' health needs are frequently interpreted only in reference to their MR and not in regards to broader issues. Beyond negative perceptions and issues involving stigma, this "diagnostic overshadowing" continues to limit access to appropriate and quality care. Ironically, adults with mild MR may have trouble accessing care because they often have a normal appearance but may have difficulty with compliance, authority, behavioral challenges, and abstract thinking. Together, these characteristics pose significant barriers to care.

Transportation and financing also pose access problems for many individuals with MR. In particular, Medicaid fee-for-service programs may provide financial disincentives for treating individuals with a disability, based on the inherent health care needs of these patients. Medicaid's managed care programs, however, may offer more protections than these and commercial managed care programs. Many States are moving towards such Medicaid systems.

### ***Ronald Lindsay, M.D., Creative Program Presentation***

Dr. Lindsay presented the Ohio Rural Developmental and Behavioral Clinic Initiative. The program was developed in 1995 in response to a needs assessment completed by the Ohio Department of Health. The study identified gaps in coverage, lack of service coordination, lack of information, and unmanageable systems as constraints for individuals with MR to access comprehensive care. Urban counties were also found to have more resources to care for children than rural counties. In response, the State created a new rural initiative. Although the program started with two rural health clinics in two separate counties, the program currently has 37 clinics in eight counties and receives evaluations of children living in 18 other counties.

A key goal is to decrease health disparities for children with suspected MR and developmental disabilities. To accomplish this, two evaluation teams were created: a developmental team for children up to age six and a behavioral team for school-age children. The interdisciplinary teams conduct

comprehensive evaluations; both teams have local public health nurses who serve as liaisons between the teams and local communities. The nurses receive referrals from parents and providers, obtain appropriate records, conduct home visits after a child is evaluated, and help to implement the teams' recommendations. Families play an important role in both the child's evaluation and treatment.

A program evaluation assessed the first two years of activities, during which 120 children were seen. Children's clinical charts were reviewed, and parents were interviewed. The evaluators assessed how diagnoses were formed, team recommendations, and the outcome of these recommendations, including whether services were obtained or pursued. The study found that few system barriers exist for families once children are evaluated. In addition, a family's refusal to pursue services is the chief reason for not obtaining care. Of families that did pursue services, 98 percent successfully obtained the needed care.

While the evaluation showed that the program improved access to diagnostic evaluations, identified previously undiagnosed conditions, aided access to followup care, and met family needs, it also highlighted the need for more outcome and population-based data and ways to improve the acceptance of social recommendations by families.

Finally, the program's primary challenge remains sustaining a program that is community-based and integrated, providing a seamless system of care. This challenge entails collaborating with local agencies that must share a vision, work together, and integrate their services. The primary challenge is to integrate service delivery, training, technical assistance, consultation, and research.

### **Work Group Four: Paying for Health Care Services**

#### ***Daniel Bier, M.P.A., M.S.W., Moderator***

Mr. Bier discussed how health care services work in a marketplace, and how reimbursement can promote the best value. The work group would address the relevant themes developed at the Surgeon General's Listening Session. These include (1) what services should be covered by insurance, (2) the

preauthorization process and the definition of medical necessity, (3) co-insurance, and (4) the cost of premiums.

### ***Deborah Spitalnik, Ph.D., Scientific Presentation***

Dr. Spitalnik discussed how methodological issues can influence research concerning the financing of care for individuals with MR. These issues include the lack of precise diagnoses and the failure to record diagnoses, as well as the instability of diagnoses within the billing systems and clinical claims data.

For example, Medicaid files were not designed to identify populations with special health needs; however, most people with MR pay for health care through public insurance, whereas only 7.1 percent of adults with MR have insurance through their employer. The inadequate design of Medicaid files means that Medicaid datasets often lack important utilization and reimbursement data concerning the services provided to individuals with MR. These deficiencies hinder research and our understanding of the financing and use of services by this population.

Although children with MR may be insured through their parents' coverage, commercial insurance often has coverage gaps, high premiums, and no mandate to provide benefit packages to meet their needs. Nonetheless, given the scarcity of good coverage, parents of children with MR frequently will not move or change jobs for fear of losing their health insurance coverage.

Medicare covers 480,000 people with MR, but these beneficiaries differ from the average elderly beneficiary because they are poorer and less likely to be connected to health care providers. Approximately 70 percent of Medicare beneficiaries with MR are also enrolled in Medicaid, which has become the largest financial funding source for health care for people with disabilities. Medicaid covers 1.5 million noninstitutionalized adults with MR and 246,000 institutionalized ones. It provides acute and some long-term care benefits. Although individuals with MR make up only 4.9 percent of the beneficiaries, they use 15.7 percent of Medicaid's dollars. To reduce health costs, States have a keen interest in switching beneficiaries to Medicaid managed care programs.

Complicating matters, Medicaid has two parts, including mandatory and optional services. Unfortunately, many services deemed optional are critical for people with disabilities and include items such as dental coverage, prescription drug coverage, and long-term care services. States also vary as to whether they mandate that Medicaid beneficiaries enroll in managed care programs. Many Medicaid managed care programs lack claims data and diagnostic information concerning people with MR.

### ***Theodore Kastner, M.D., M.S., Creative Program Presentation***

Dr. Kastner presented some general issues related to the provision of primary care and mental health services in Medicaid managed care, and discussed the creation of Developmental Disabilities Health Alliance, Inc., a company providing health care services to persons with developmental disabilities under contract with several health maintenance organizations (HMOs) in New Jersey's Medicaid managed care system.

Premised on providing high-quality, comprehensive health care to individuals with MR, the program seeks to overcome the limitations of scale by creating a statewide integrated system of care. Several key business assumptions also are built into the program, starting with the notion that the use of capitation helps to better predict future cash flow. In addition, a successful for-profit program will increase choices and competition, improve accountability, and align the business goals with the clinical needs of the patients.

To market the package of services to private HMOs, program officials used familiar business terminology and discussed ways that the new system could better manage disease by providing comprehensive care. Several HMOs were enlisted to broaden the range of payers and to help establish market-based reimbursement for their unique managed care systems. Although obtaining capital was a hurdle, capitation payments proved to be very helpful.

Although relatively young, the company represents an effective way to provide an array of managed care services to individuals with MR, relying on Medicaid reimbursements. Success also is related

to developing the talents of staff and being flexible in the face of market changes. Compromise is also essential as is the need to be opportunistic, to add value to the services provided, to leverage funds effectively, to use capitation effectively, and to develop a good business plan.

## **Work Group Five: Age-Appropriate Health Services**

### ***Timothy Kowalski, D.O., Moderator***

Dr. Kowalski highlighted the transition points all individuals encounter as they advance through the developmental stages of life. The work group was asked to focus on the transition points and how they may interact with the special needs of individuals with MR.

### ***Marsha M. Seltzer, Ph.D., Scientific Presentation***

Dr. Seltzer noted that the health of approximately one-third of individuals with MR is reported to be fair or poor. About 60 percent of people with MR and developmental disabilities live with their families, who often serve as their brokers for health services; however, as children and adults with MR live longer, the role of their parents and siblings in brokering health care services changes.

To plan for care, it is important to merge the life course perspective with the special needs of individuals with specific diagnoses related to MR. For instance, individuals with Down syndrome often experience the early onset of aging. Similarly, individuals with MR versus those with developmental disabilities must be treated differently because they have such heterogeneous needs. At the same time, each stage of life, such as adolescence, early adulthood, and advanced age, offers unique challenges that must be considered in relation to factors such as gender, poverty, barriers to health services, and lack of trained providers.

### ***Paul Glassman, D.D.S., M.A., M.B.A., Creative Program Presentation***

Dr. Glassman discussed the Center for Oral Health for People with Special Needs at the University of the Pacific (UOP) School of Dentistry. Historically, as individuals with MR moved from

institutions to community settings, their untreated dental problems worsened in response to the lack of community resources. This situation had significant implications for the well-being of this population; research shows that oral health strongly correlates with systemic disease as well as nutrition.

Established to create the “ideal” community-based system for dental care, the Center is a coalition of dental professionals, faculty from the UOP School of Dentistry, regional centers, hospitals, agencies, and individuals, linked by a dental services coordinator. The coordinator, who is usually a dental hygienist, serves as a liaison between the individual and people in the community, often working with general dentists to help them become more comfortable treating individuals with MR. In addition, the Center has a triage and referral system and training programs for all personnel levels. Prevention programs and treatment resources also have been developed. Among others, these include educational materials for dental hygienists, an online resource directory, and a hands-on training program for dentists.

The increased awareness of the importance of oral health and the new coalitions that have been formed highlight the Center’s success. For example, a statewide task force on oral health for people with special needs was formed, in addition to a new effort, the California Endowment for Oral Health Care Program. Going beyond local and State impact, a national forum, Special Care Dentistry, has been established to bring together dental professionals for training, advocacy, and coalition-building to work on common problems.

## **Work Group Six: Continuity of Health Services Throughout Life**

### ***George Jesien, Ph.D., Moderator***

Dr. Jesien noted that as individuals move from one health care system to another throughout life, continuity of care is often disrupted. Each system tends to operate under different rules and various eligibility requirements that hinder efforts to obtain needed care. Starting with children, school and the health care systems fail to communicate well with each other, and many services are dropped for various reasons as the child becomes an adult. The goal is to

provide systems of care that are easier to navigate, with agencies and key stakeholders coordinating services more efficiently.

### ***Marsha M. Seltzer, Ph.D., Scientific Presentation***

Dr. Seltzer suggested that participants consider an interesting paradox—that as communities develop more “age-specialized health care services for individuals with MR,” the specialized care may “become a barrier to continuity of services across the life course.”

The barriers start with health care specialists. If individuals with MR must seek the care of numerous specialists to meet a broad range of health needs, this situation automatically increases discontinuities in care. The specialty needs may change as a patient gets older (e.g., geriatrics) and may require specialty care based on gender (e.g., women’s health services). In this situation, family practice physicians, or having a particular point of service, may play a special role in the care of people with MR.

Fragmentation of the service system also poses barriers to receiving continuous care. Most often, this fragmentation occurs as individuals move from early interventions into public education and then into adult services. Changes in policies and services also pose unexpected barriers. For example, changing the definition of MR and the terminology used can easily affect eligibility requirements. In addition, significant State-to-State variability exists in the availability of services.

Finally, another barrier often arises depending on whether individuals with MR choose to live in family situations. Nearly 60 percent of individuals with MR live with their parents throughout their life course, but disruptions in care can occur when parents die. By contrast, individuals living in nonfamily licensed settings have greater access to health care. This situation occurs because many settings are affiliated with larger efforts to provide at least minimal access to care.

### ***Joel Levy, D.S.W., Creative Program Presentation***

Dr. Levy discussed the Young Adult Institute (YAI) Premier Health Care Program, which provides comprehensive health care to individuals with MR and developmental disabilities. Specially trained medical professionals provide both acute and chronic medical, dental, psychiatric, and in-home nursing care services to children and adults. With more than 50 percent of clients being minorities, cultural competency is essential to the program’s success.

Other Program goals include providing continuous care and offering a wide range of services. The Program’s philosophy is that treatments should be integrated, provided in the least restrictive manner possible, and based on the individual and family’s unique needs. To achieve this goal, the Program coordinates its services with those offered by local agencies. This coordination allows individuals with MR to receive care in their communities. At the same time, the Program has contracts with academic hospitals around the State to provide any services that are unavailable locally.

### ***Work Group Seven: Promoting Health: Providers***

#### ***Sanford Fenton, D.D.S, M.D.S., Moderator***

Dr. Fenton introduced several issues raised at the Surgeon General’s Listening Session. These issues included providers not screening individuals with MR for dietary and nutritional status, tobacco or alcohol use, cancer, or domestic violence. Participants in the Listening Session also mentioned that some health care providers have little or no specialized training or equipment needed to care for individuals with MR. Specialized providers also may miss opportunities to ensure that needed immunizations are obtained and to educate clients and their families concerning a range of primary care and prevention topics. These problems are exacerbated by the high turnover rate of personal care attendants and by frequent gaps in the medical record.

On the basis of these trends, recommendations could be devised to help improve preventive screening, provider training, provider coordination, the rate of turnover in personal care attendants, and the use of health promotion techniques.

### **David Braddock, Ph.D., Scientific Presentation**

Dr. Braddock discussed the history of institutionalization of people with MR. Today, States vary in the range of services they offer to individuals, particularly to those in community-based settings. Any effort to develop new health promotion programs must be tailored to this reality. Although the number of small residential homes serving six or fewer clients has increased, health promotion in these settings poses problems. A British study comparing health promotion for individuals with MR in community versus residential settings found inadequacies particularly in community settings. This situation must be corrected, given the importance of health promotion and the number of individuals with MR living in a community setting. Activities could include developing recreation and fitness programs in the community, providing counseling for individuals in the community, working with mental health centers to address the behavioral and mental health needs, collaborating with special education programs to teach children healthy habits, training health professionals about health promotion, training and supporting staff members in residential settings, collaborating with provider and parent organizations to make health promotion a national priority, and working with new technology to promote health.

### **Jill Morrow, M.D., Creative Program Presentation**

Dr. Morrow discussed the Pennsylvania Health Care Quality Units (HCQU) Program and the specific health care issues affecting people with MR in the State. Most notably, health care professionals and others working with this population lack indepth knowledge about specific health care needs. Health promotion is also an issue.

The HCQU Program was created to respond to these problems and to help people with MR become better consumers of health care, to expand their choice of health care providers, and to help deliver a higher quality of care to people with MR. The

Program targets individuals with MR and their families, providers of MR services, community medical providers, and county staff (including “support coordinators” who served as case managers). The emphasis is on providing support but not direct care services.

The Office of the Medical Director in the State’s Office of Mental Retardation coordinates the Program’s activities. The activities are implemented by a consortium of counties and are staffed by different clinicians and data personnel. To reach its goals, staff members identify gaps in health care services and health care knowledge and then develop professional training and technical assistance programs to address these needs. Staff members also identify systemic problems and work closely with other offices and agencies to address these issues.

The Program has been effective at the individual and community levels. For example, recently Program staff worked with a young diabetic man who was interested in learning more about his diabetes and how to give himself insulin injections. To meet the man’s needs, HCQU staff contacted a local nurse educator and shared specific educational techniques for working with individuals with MR. The local nurse then was able to teach the young man about his diabetes and show him how he could take better care of his own diabetic needs.

### **Work Group Eight: Health Promotion: Individuals and Caregivers**

#### **Jackie Golden, Moderator**

Ms. Golden identified key issues raised at the Surgeon General’s Listening Session. Self-advocates reported that people often talk about them and not to them. Similarly, society often tries to “do for them,” instead of teaching them how to do for themselves. In addition, neither caregivers nor individuals are valued for the potential role they can play in health promotion. Adding to this complexity is that direct care staff in group homes are often impoverished and lack health care themselves. Therefore, enhancing health promotion for individuals with MR requires training and provider support for direct caregivers, families, and children and adults with MR.

### **David Braddock, Ph.D., Scientific Presentation**

Dr. Braddock discussed some of the difficulties associated with promoting health for individuals with MR in community settings. Self-advocacy organizations can play an important role in launching new health promotion projects, working closely with family members who significantly influence the adoption of healthy lifestyles. To encourage such activities, Developmental Disability Councils should be encouraged to use their authority to give grants within the State for health promotion projects.

### **Gloria Krahn, Ph.D., Creative Program Presentation**

Dr. Krahn discussed the Oregon Healthy Lifestyles for Persons with Developmental Disabilities Program. The Program was developed to address the fact that persons with disabilities (1) often experience poorer health status and narrower margins of health, (2) may be more susceptible to illness, (3) have limited access to treatments, and (4) may be excluded from health promotion opportunities.

The Program is currently developing two new intervention efforts. The first project is the Healthy Lifestyles Workshop for adults with developmental disabilities. The two-and-a-half-day workshop uses a peer training model that emphasizes empowerment training. This training includes understanding the

importance of assessing one's own health and establishing personal health goals. The workshop also targets self-determination and motivation and describes wellness as a lifelong journey that encompasses balance across life activities. To ensure continued success, each participant is paired with a mentor who works with the individual for up to six months following the workshop.

In the past, the workshops were presented in six locations across Oregon, and have included 33 participants with cognitive limitations. Feedback on the project shows that followup is very difficult, but participants report increased awareness of healthy lifestyle choices and of self-empowerment.

Another project, called "Health and Wellness for Teens with Disabilities: Getting Sensitized," targets health care providers who are in training. This newly developed effort is trying to increase awareness of the special problems that teens with disabilities encounter and to improve provider skills in meeting these needs and in supporting the teens' overall health and wellness. The project consists of three two-hour modules, and includes didactic teaching, video presentations, and hands-on exercises. The modules, which will soon be field-tested, cover general wellness, relationships and sexuality, and mental health and substance use.



# Appendix B: Participants List

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December 5–6, 2001

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# Appendix C: Potential Partners in Realizing the Blueprint

Conference participants were asked to identify potential partners that may help to diminish the health disparities for people with MR. The names that appear below should not be interpreted in any way as a commitment by a specific agency or organization. Instead, this list is intended to illustrate the potential partnerships on many levels. Furthermore, this list is not exhaustive but includes some of the specific examples that were offered during the Conference.

## Academic Institutions and Organizations

- Accrediting Bodies
  - Residency Review Committees
- American Dental Educators Association
- Association of American Medical Colleges
- Association of University Centers on Disabilities
- Deans of Medical, Dental, Nursing, and other Allied Health Schools

## Civil Rights, Minority Health, and Health Disparities Organizations

- NAACP

## Employers and Other Purchasers of Health Care

## Families

## Federal and State Regulatory Agencies

- State Insurance Commissioners

## Federal Government Agencies

- Department of Education
  - Office of Special Education and Rehabilitative Services
- Department of Health and Human Services
  - Administration for Children and Families
    - Administration on Developmental Disabilities
  - Agency for Healthcare Research and Quality
  - Centers for Disease Control and Prevention
    - National Center for Birth Defects and Developmental Disabilities
    - National Center for Health Statistics
  - Centers for Medicare & Medicaid Services (formerly HCFA)
  - Health Resources and Services Administration

- Bureau of Maternal and Child Health
- Bureau of Primary Health Care
- Indian Health Service
- National Institutes of Health
  - National Center on Minority Health and Health Disparities
  - National Institute of Child Health and Human Development
  - National Institute of Dental and Craniofacial Research
  - National Institute of Mental Health
  - National Institute on Aging
  - National Institute on Alcohol Abuse and Alcoholism
- Office of Minority Health
- Office of Public Health and Science
  - Office of the Surgeon General
- Office of the Assistant Secretary for Planning and Evaluation
- Substance Abuse and Mental Health Services Administration
  - Center for Mental Health Services
- Department of Labor
- Social Security Administration
  - Office of Disability

## Federal, State, and Local Government Groups

- National Association of Counties
- National Governors Association
- State Developmental Disabilities Councils
- State Medicaid Directors
- State Protection and Advocacy Agencies

**Federal, State, and Local Policymakers**

State Legislatures

U.S. Congress

**National, State, and Local Professional Health and Allied Health Organizations**

American Academy of Pediatrics

American Dental Association

American Medical Association

**Pharmaceutical Companies**

**Philanthropic Groups and Foundations**

Joseph P. Kennedy, Jr. Foundation

Kaiser Foundation

Robert Wood Johnson Foundation

**Public and Private Third-Party Payers**

Insurance Companies

Medicaid

Medicare

**Self-Advocate, Parent, and Other Advocacy Groups**

American Association on Mental Retardation

National Committee for Quality Assurance

Self Advocates Becoming Empowered

Special Olympics, Inc.

The Arc of the United States

**State and Local Public Health Departments**

**Tribal Community and Health Organizations**

# Appendix D: Health Disparities and Mental Retardation: Programs and Creative Strategies to Close the Gap

Kathleen Braden, M.D.<sup>1</sup>

## I. INTRODUCTION

Individuals with mental retardation<sup>2</sup> experience poorer health, shorter lifespans, and less access to professional health care than people without this condition (Horowitz et al.). Many factors are thought to contribute to these disparities. Physicians and other providers often lack training and experience in treating individuals with mental retardation and are reluctant to assume clinical responsibility for them. Cultural sensitivity may be lacking. Financing for health care services is often inadequate, and scientific knowledge about the efficacy of care for this population is far from complete. Services may be poorer in quality because of societal assumptions that people with mental retardation cannot participate appropriately in their own health care (Surgeon General's Listening Session and Senate Appropriations Committee Report). For years, families, providers, and these individuals have sought, with varying degrees of success, to improve their health and health care.

This report is designed to provide information about service programs that have developed creative strategies to provide health care to people with mental retardation living in their communities. The report is not a comprehensive catalogue of all health care programs that use creative strategies to serve this population. There is no attempt to evaluate individual programs or to assess the merits of one

program over another. Instead, the report illustrates a variety of responses to the distinctive challenges of providing primary and specialty medical, dental, psychiatric, and wellness services to children, adolescents, and adults with mental retardation. The programs described vary in scale, geographic location, populations served, services offered, service models, and funding. Some programs are inclusive, offering services to a broader population and making special accommodations for individuals with mental retardation. Other programs specialize in care for this population.

Following a review of the origins of this report and the author's method, individual program descriptions are presented, with contact information for readers wishing to learn more about their activities. The programs are grouped in four major sections that reflect reported disparities in health care for individuals with mental retardation: medical services, mental health services, oral and dental health care services, and health and wellness programs. Within these sections, programs are shown in subcategories that relate to different strategies in program design. This scheme is flexible because certain programs could fit into more than one category.

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<sup>1</sup> Associate Clinical Professor of Pediatrics, Eunice Kennedy Shriver Center for Developmental Disabilities, University of Massachusetts Medical School, Worcester, MA. The programs and strategies summarized in this paper are described in more detail in a forthcoming report by the author. The author would like to thank the many people who helped her understand their programs and strategies for providing health care for people with mental retardation. For the most part, these people are identified as "contacts" in the summary program descriptions. The author particularly thanks Ms. Joan Beasley, formerly with the Robert D. Sovner Behavioral Health Research Center, for her help in understanding the history and scope of the Center's START Program.

<sup>2</sup> The author is aware that there is a controversy around the use of the term "mental retardation" and that self-advocacy groups and professional associations are currently discussing alternatives. In preparing her report, she has sought to retain the terminology used by the programs she describes. In the title, however, she has adopted the usage of the Surgeon General's effort on health disparities and mental retardation. Until a consensus is reached, with the goal of drawing attention to the great health disparities faced by people with what has been traditionally known as "mental retardation," that term is used in official information on the other elements of the Surgeon General's effort on health disparities and mental retardation.

in the report were presented at the Surgeon General's Conference on Health Disparities and Mental Retardation, December 5–6, 2001, in Washington, DC.

## II. ORIGINS OF THE REPORT

This report is part of recent national initiatives to highlight and improve the health and health care of individuals with mental retardation who live in their communities. Until deinstitutionalization began in the 1970s, large numbers of children and adults with mental retardation lived in residential institutions. Although the institutions were identifiable entities responsible for the health of their residents, they were typically underfunded and understaffed.

Deinstitutionalization brought important benefits. These benefits included newly established rights for individuals with disabilities, for example, the right to public education in the least restrictive environment, and for low-income individuals, the right to publicly financed health care coverage. Supported living and other types of programs were created to help individuals living in their communities. Staff-to-resident ratios in group homes typically improved compared with ratios in the older institutional care sites.

With the inclusion of people with mental retardation in local communities, public attitudes have started to change—but slowly. Severe shortages in financial and human resources that characterized institutional care have not been resolved. In addition, when individuals move into community settings, responsibility for their health care often remains diffused. This situation means that individuals, their families, and their caregivers continue to face difficult challenges finding adequate sources of health care, getting to them, and paying for the service.

Many of these challenges were addressed at a March 2001 special hearing of the U.S. Senate Appropriations Subcommittee on Labor, Health and Human Resources. U.S. Senator Ted Stevens (R-AK) convened the hearing to take testimony from self-advocates, researchers, and Federal officials on the health and health care needs of individuals with mental retardation (Senate Appropriations Committee Report). The focus of the hearing was a report prepared by a research team at the Yale

University School of Medicine for Special Olympics, Inc. (Horowitz et al.). On the basis of its literature review, the team reported critical deficiencies in physical, mental, vision, and dental health of people with mental retardation. But the team also reported that health data on this population are “scarce,” and that public resources for persons with mental retardation have been devoted primarily to their deinstitutionalization, housing, education, and employment.

At the Senate Appropriations Subcommittee hearing, Surgeon General David Satcher called for better health-related surveillance, community-based health systems, targeted research, and other steps to improve the health status of individuals with mental retardation. The Surgeon General subsequently launched a national effort on health disparities and mental retardation, beginning with an invitation to individuals with mental retardation and others concerned with their health to help him plan a national conference the following December.

More than 600 comments and suggestions sent to a special website helped to structure a Surgeon General's national Listening Session on October 10, 2001. Self-advocates, family members, and other participants in the Session spoke to the Surgeon General in person and by live, interactive video from five sites around the country. E-mail messages and written comment cards were also submitted. Participants reported multiple challenges, from dismissive and inexpert health care providers, to shortfalls in services, insurance coverage (Medicaid and private), transportation, coordination among multiple service systems, and a lack of programs promoting healthy lifestyles and disease prevention. Providers described the poor fit between their clinical training and the distinctive needs of patients with mental retardation. Family members said that their ongoing responsibility for children and adults with mental retardation meant that they were often unable to hold paying jobs and to carry health insurance for themselves. Poverty was reported to be high in this population (Surgeon General's Listening Session).

Finally, family and provider advocates for people with mental retardation urged the Surgeon General to promote research into the prevalence of mental retardation and the efficacy of care for this condition.

Some individuals said that people with mental retardation were “lost” in larger studies of people with disabilities, and they urged collection of data that could provide the basis for documenting the need for improved funding and better allocation of health care resources to serve this population. Others sought research that could be used to establish evidence-based clinical standards and provide training curricula. Researchers wrote to the Surgeon General noting that their task was complicated by the current use of three different diagnostic criteria for mental retardation.

The issues and concerns described to the Surgeon General formed the agenda for the December conference to develop a national action plan on health disparities and mental retardation. This report was prepared to provide conference attendees with examples of local and State programs that address some of their concerns.

### III. METHODOLOGY

To identify programs using creative strategies to address health disparities in people with mental retardation, the author queried key informants, including self-advocates and families, health care and social service providers, schools of dentistry and medicine, national organizations (medical, social service, and advocacy), and researchers and other experts in the health care needs of people with mental retardation. To collect information about the programs, the author conducted semistructured telephone and e-mail interviews with individuals who had established and who currently administer the programs. Respondents were asked to describe their programs generally and to identify populations served, services provided, and sources of funding. Respondents also were queried about providing training and evaluations or research associated with a program. Finally, respondents were asked to reflect on challenges encountered in creating and maintaining their programs, and to provide advice to others who may consider replicating their strategies.

Several factors determined the selection of programs included in the report. The first factor was whether one or more key informants viewed a program as a thoughtful response to one or more health care gaps that commonly affect individuals with mental retardation. A second factor was the willingness of administrators to have their programs included in the report and to provide the author with requested information. A third factor was selection of programs that illustrate many different types of service models and strategies, populations served (urban, rural, ethnic, and cultural and racial minorities), financing mechanisms, geographic distribution, and other characteristics.

The following descriptions are based on information provided by program administrators.

## IV. PROGRAMS AND CREATIVE STRATEGIES (SUMMARY DESCRIPTIONS)

### A. MEDICAL SERVICES

#### 1. Comprehensive Health Care Integrated with Social Services

*\*a. New York City Premier Health Care Program, New York, NY*—Citywide program providing primary and subspecialty care and dental and mental health services to culturally and socially diverse population of individuals with developmental disabilities, including mental retardation. Provides case management and family care services; maintains outreach to schools, residences, day programs, and homes.

Funding: Fee-for-service from insurers of all types (Medicaid, Medicare, private insurance). State pays a special rate for recipients with developmental disabilities.

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\* Denotes programs presented at the Surgeon General’s Conference on Health Disparities and Mental Retardation, December 5–6, 2001, Washington, DC.

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**\*b. Developmental Disabilities Health Alliance, Inc., (DDHA), Bloomfield, NJ**—Statewide health care company providing primary and mental health care, interdisciplinary assessments, health promotion and disease prevention, and other services for two groups of Medicaid managed care enrollees: children and adults who qualify for services of the State Division of Developmental Disabilities (DDD), and individuals who qualify for Medicaid and Medicare. DDD arranges needed consultations with local “safety-net” providers. Providers are trained in the company’s service model. A five-year planning process including all stakeholders preceded establishment of the company.

Funding: Medicaid, under DDHA contracts with Medicaid managed care plans.

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**c. Northern Virginia Training Center’s Regional Community Support Center, Fairfax, VA**—Regional Center of Excellence providing specialized medical, behavioral, dental, and respite services for individuals with mental retardation and complex medical and behavioral needs. Program evolved from residential training center and includes inpatient services. Provides training for staff of community residential services and vocational providers, also to university students in health and other professions. Evaluates consumer satisfaction.

Funding: Primarily State and Federal funds for Intermediate Care Facilities for Mental Retardation (ICF/MR). Additional revenue sources, primarily Medicaid and private insurance, are being explored.

Steering committee includes facility and community stakeholders. State is expanding service model to other State training centers and to geriopsychiatric centers.

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## 2. Inclusive Health Services

**a. Vermont Rural Medical Home, Northfield, VT**—A program based in a primary care physician’s office, for children with developmental disabilities and their families. A steering committee composed of the physician, head nurse, and three families of the children designed special office procedures based on a survey of the parents. Procedures include a script for the receptionist to identify patients with special needs, parking and other special accommodations for office visits, and queries during visits about nonmedical needs. Other elements are a resource parent/care coordinator position and a family network that advocates on medical and educational concerns. Currently exploring expansion to other physicians’ offices.

Funding: Initial Robert Wood Johnson Foundation grant; additional grant and Medicaid funding for care coordinator position.

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**\*b. Alabama Mother and Family Specialty Center, Birmingham, AL**—Demonstration project at university research clinic providing prenatal care to multirisk, African American, inner-city clients. Estimated 30 percent of women were mildly to moderately cognitively impaired. Provided prenatal care (medical, nursing, social work, nutrition, education) using evidence-based practices. Clinic

nurse-practitioners trained to recognize potential problems in patient comprehension, communication, and understanding. Videotape and other client supports developed; transportation and onsite child care offered. Study results indicated positive effects, including participants' knowledge of risk conditions and perceived mastery in their lives.

**Funding:** Grant from Federal Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality). Research demonstrated that costs could be funded through Medicaid.

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### 3. Specialty Outreach Services

**\*a. Ohio Rural Developmental and Behavioral Clinic Initiative, Columbus, OH**—Regional outreach clinic serving children with mental retardation and developmental disabilities in Appalachian counties in southeastern Ohio. Provides onsite, multidisciplinary evaluations for infants and children up to age six with developmental delays and for school-age children with developmental disabilities and mental health/behavioral disorders. Assessment teams are clinic staff and the local public health nurse; teams also may include local school personnel, primary care and mental health providers, and county juvenile justice systems. Program also provides referrals, coordination by a local public health nurse, and health professions training in clinics. Program is evolving from one that provides direct services to one that trains local program personnel to evaluate and care for the children.

**Funding:** Primary funder is State Department of Health (Title V agency); other support includes Healthy Tomorrows and Leadership Education in Neurodevelopmental Disabilities (LEND) grants (Federal Maternal and Child Health Bureau, Health Resources and Services Administration), also private foundations and financial and in-kind support from participating agencies and local programs, such as early intervention, county health departments, schools, Head Start, county mental retardation/developmental disability boards, and physicians.

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**b. South Dakota Rosebud Developmental Clinic, Sioux Falls, SD**—Interagency program providing developmental screening at reservation WIC clinics for infants and children up to age five; also screening followup, referral for evaluations at reservation clinic for children, and linkages to services for families of children with health and/or developmental concerns. Trains local providers and university graduate students. "Uses best available practices."

**Funding:** Three-year startup funding from the Federal Bureau of Indian Affairs and State Office of Special Education; currently supported by the tribe.

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**c. Rose F. Kennedy Children’s Evaluation and Rehabilitation Center Mobile Team, Bronx, NY—**

Mobile team providing multidisciplinary evaluations to children of clients at a methadone maintenance clinic. Transportation to and medication at the evaluation site were offered to clients of other methadone clinics. Team services on site included family counseling, short-term speech therapy, nutritional counseling, and behavior management training; referrals provided for educational, therapeutic, and medical services. Training in child development, for substance abuse clinic staff, provided.

Funding: Medicaid; but reimbursement is limited to one clinician visit per client per day; limited ability of program to finance multiple clinician services needed to complete evaluations during a client’s visit.

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**4. Specialized Provider Training**

**a. New Mexico Continuum of Care Project, Albuquerque, NM—**Statewide program that trains health care professionals in care of deinstitutionalized individuals and trains direct care staff and case managers to provide medical support for clients. Program also includes specialty consultation clinics; specialized clinics at several primary care clinics; consultations for physicians, nurses, caregivers, case managers, interdisciplinary teams, and families; and consultations on policy for State agencies. Mediation provided for team or agency conflicts affecting delivery of services. Program maintains a website (<http://star.nm.org/coc>).

Funding: State Department of Health, also some Medicaid and Federal Maternal and Child Health Bureau funds.

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**\*b. Pennsylvania Health Care Quality Units (HCQU) Program, Harrisburg, PA—**Data collection, training, and technical assistance organizations working with health care and residential services providers in multicounty areas. HCQUs housed in parent organizations, such as nursing schools and mental health services, but administered independently. No direct services; program focus is on improving communication between residential care and medical systems and on increasing capacity of both systems. Future goals include collecting and analyzing data related to management of health care incidents to aid counties providing services, and expanding data collection to include individuals living outside a residential system to assess their quality of care.

Funding: Medicaid (Medicaid waiver administrative funds and funds for individuals other than those eligible for waiver funding).

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**B. MENTAL HEALTH SERVICES**

**1. Tertiary Care Psychiatric Outpatient Clinic/Training Strategies**

**\*a. Rochester Mental Retardation/Developmental Disabilities Psychiatric Disorders Outpatient Clinic, Rochester, NY—**University-based outpatient clinic offering therapy for individuals aged 18 and older, diagnosed with mental retardation and



mental illness (dual diagnosis). Provides training for psychiatry residents, providing therapy for caregivers as well as for individual clients. Housed in university psychiatry department; works with pediatric department's developmental disabilities center and its crisis intervention team. Mission includes providing a service model for professional training (all disciplines, all levels) and research to increase knowledge of dual diagnosis.

Funding: State Funding for first eight years of clinic; current funding from third-party payers.

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**b. Nebraska Neuro-Developmental Psychiatry, Omaha, NE**—University-based program providing psychiatric outpatient care for older adolescents and adults with developmental disabilities and mental health needs, living in State and in parts of Iowa. Program also trains psychiatry residents. Services include testing and evaluations, psychotherapy, behavioral interventions, medication management, and consultations. Clients are primarily from rural communities.

Funding: University Department of Psychiatry in College of Medicine and third-party payers.

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## 2. Specialty Care and Service Linkages

**a. START Program at Robert D. Sovner Behavioral Health Resource Center, Danvers, MA**—The Systemic, Therapeutic, Assessment, Respite and Treatment (START) program for individuals with developmental disabilities and behavioral/mental health care needs (dually diagnosed) in region, links developmental disabilities agencies and mental health providers serving the general population. Program also provides crisis intervention services, and specialized outpatient psychiatric services for dually diagnosed individuals. Services include a mobile emergency crisis team, emergency meetings involving inpatient units or an emergency respite facility, emergency and “planned” respite services, and short-term psychiatric inpatient care (community mental health and general hospitals). Program focus is planning and coordination by mental health crisis and developmental disabilities service teams, working with individuals, families, and caregivers. Specialty interventions provided as needed.

Funding: State Department of Mental Retardation; also insurance.

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**\*b. Rochester Community-Based Crisis Intervention Services, Rochester, NY**—University-based crisis intervention program aids communication and cooperation between community providers serving individuals with mental retardation and challenging behaviors. Services include establishing formal and informal communications and agreements among various providers, educating families and agency staff (e.g., psychiatric emergency room social worker and psychiatric residents), conducting skilled behavior assessments, and employing management techniques.

Funding: State Office of Mental Retardation and Developmental Disabilities.

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### **C. ORAL HEALTH CARE AND DENTAL SERVICES**

#### **1. Health Care and Training in Academic Settings**

a. **Dental Education in Care of Persons with Disabilities (DECOD) Program, Seattle, WA**—Clinical service and training clinic at the University of Washington dental school, providing care for adults with special health care needs resulting from developmental, physical, medical, and emotionally disabling conditions. Services include diagnostic assessments, preventive care, primary dental care, emergency services, and rehabilitation for individuals with complex oral problems. Services provided in clinic and at affiliated clinics in a residential school, at other sites, and in individual residences for those who are homebound. Emphasis is on use of patient management techniques and avoiding use of sedation whenever possible. Clinic trains dental school students in care of individuals with special needs. Patient surveys indicate a high degree of satisfaction with quality of care.

Funding: Startup funding from the Robert Wood Johnson Foundation; currently supported by dental school Department of Oral Medicine with additional support from State Department of Health and Social Services, which pays a special rate to cover specific dental services and costs from increased treatment time.

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#### **2. Linkages Between Developmental Disabilities Service Systems and Dental and Oral Health Providers**

a. **Butler County Dental Care Program, Hamilton, OH**—Countywide program coordinating care, through case management, for adults participating in the State mental retardation/developmental disabilities system. Program developed network of providers, hospitals, case managers, caregivers, and guardian agencies. Dental hygienist serves as care coordinator; provides comprehensive assessments of individuals' oral health and extent of disability, obtains medical and dental histories, and accompanies clients to participating dentists' offices. Dentists are offered professional education credits in care of this population. Program also arranges transportation to dental appointments and counsels caregivers and providers on potential sources of payment for services. Consumers are visited periodically to ensure that the health promotion plan is understood and followed.

Funding: Support from the Health Foundation of Greater Cincinnati and county Board of Mental Retardation and Developmental Disabilities. Some startup funds came from ARC.

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**\*b. The University of the Pacific School of Dentistry California Center for Oral Health for People With Special Needs, San Francisco, CA—** County-based program providing a dental coordinator for individuals with developmental disabilities in local social service agencies in rural communities. Services include community assessments of existing oral health resources, triage and referrals by a coordinator, prevention training and materials for caregivers and parent groups, recruitment of dentists and provision of in-office social supports, continuing education courses for oral health professionals, hands-on training, and educational materials. Program established a statewide task force that developed a State action plan and continues to have input on legislation. Program working with State Department of Developmental Services to integrate oral health training into health and other professional education programs.

Funding: Initial grant funding; social service agencies now fund a dental coordinator. Program expected to be replicated in eight communities with foundation support.

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### **3. Dental Care Provided by an Inpatient Intermediate Care Facility (ICF/MR)**

**a. Hazelwood Center ICF/MR Dental Services Clinic, Louisville, KY—**Program at an intermediate care facility providing dental care to individuals with severe to profound mental retardation residing at the facility and to clients from three outlying community homes. Services include general dentistry, periodontal and oral surgery, endodontics, biopsy, and emergency dental care. Conducts research on

improving quality of care (protocols reviewed by University of Louisville Institutional Review Board). Reports very low rate of referrals to inpatient operating room for treatment under general anesthesia. Program developed procedures for low-dose digital radiography and reduction of gingival hyperplasia with maintenance of seizure control.

Funding: State mental retardation/developmental disability agency; expected new State funding will permit treatment of individuals with mental retardation living in group homes or with their families.

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**b. Tufts Dental Facilities (TDF) Serving Persons with Special Needs, Waltham, MA—** Statewide, university-based program providing comprehensive oral health care for individuals with developmental disabilities. Multipart program includes a Special Needs Community Dental Health Program, which is a partnership of individuals with developmental disabilities, special education personnel, parents, social workers, and service coordinators. Provides oral health evaluations and referrals for treatment by dental hygienists, also case management and oral health education in classrooms, adult day activity centers, sheltered workshops, and community residences. Other program components include dental clinics at developmental disability centers and elsewhere, and postgraduate training for general dentists concerning care for individuals with developmental disabilities and for other special populations.

Funding: State departments of health and mental retardation and revenues from third-party payers. Dental clinic clients funded through the State's managed care plan for low-income residents. Additional funds are needed to continue the program.

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## **D. HEALTH AND WELLNESS PROGRAMS**

### **1. Wellness Training for Individuals with Mental Retardation**

**\*a. Healthy Lifestyles for Persons With Developmental Disabilities Program, Portland, OR**—Program provides workshops in health promotion, with peer trainers, for individuals with developmental disabilities. Curriculum reflects needs identified in six geographic and culturally diverse focus groups of individuals with developmental disabilities and discussions with care providers. It also teaches principles of self-determination, development of individual support systems, and healthy lifestyles. Programs include recruitment of mentors from participants' communities and collection of followup data to monitor and determine the impact of training.

Funding: Federal Administration on Developmental Disabilities grant (Project of National Significance) and partnership with State Office on Disability and Health.

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**\*b. Rehabilitation Research and Training Center (RRTC) on Health and Wellness for Persons With Long-Term Disabilities, Portland, OR**—Program trains students who will become care providers for children and adolescents with neurodevelopmental and related disabilities. The center has developed a pilot-tested professional training curriculum in health promotion and wellness for adolescents with neurodevelopmental and related disabilities. Curriculum developed for use by master's level and predoctoral students and by individuals in medical fellowship programs who will provide care to children and adolescents with neurodevelopmental and related disabilities. Curriculum is adapted from materials for persons without developmental disabilities and reflects data from focus groups of adolescents with developmental disabilities, consultations with adolescents with physical and learning limitations, consultations with other LEND programs, and the literature. Curriculum modules address general concepts of wellness and disability, sexuality and mental health, and substance abuse. Data collected to monitor and to determine impact of training; field-testing planned at three other LEND programs, with further data collection to assess overall program impact.

Funding: Federal Administration on Developmental Disabilities grant (Project of National Significance); National Institute on Disability and Rehabilitation Research, Maternal and Child Health Bureau (LEND), and partnership with State Office on Disability and Health.

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107th Congress, United States Senate Committee on Appropriations, Report on Special Hearing, March 5, 2001, S. Hearing Report No. 107-92. (Includes a reprint of paper by Horowitz et al.) Link to website: [http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=107\\_senate\\_hearings&docid=f:71288.wais.pdf](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=107_senate_hearings&docid=f:71288.wais.pdf)



# **Appendix E: Summary of the Surgeon General's Listening Session on Health Disparities and Mental Retardation**

**October 10, 2001**

**National Institutes of Health  
Bethesda, MD**

**Civitan International Research Center, University of Alabama  
Birmingham, AL**

**Eunice Kennedy Shriver Center, University of Massachusetts Medical School  
Worcester, MA**

**Oregon Institute on Disability & Development, Oregon Health & Science University  
Portland, OR**

**Waisman Center, University of Wisconsin  
Madison, WI**

## **INTRODUCTION**

On October 10, 2001, Surgeon General David Satcher, M.D., Ph.D., held the first-ever Surgeon General's Listening Session on Health Disparities and Mental Retardation. The Listening Session was a major component of the Surgeon General's effort on health disparities and mental retardation, a national dialogue to better understand and address the many severe and often unmet health needs of people with mental retardation. The keystone of the effort is reaching out to individuals with mental retardation,\* their families and providers, advocacy groups, and community-based organizations that are on the front lines daily, trying to protect and promote the health and well-being of people with mental retardation.

This summary provides an overview of comments to the Surgeon General during the Listening Session. It also reflects written comment cards collected during the Session and e-mail messages to a special Surgeon General's website received before, during, and one week following the Listening Session.

The purpose of the Listening Session was to learn directly of health-related concerns and experiences of individuals with mental retardation and others concerned with their health. Participants were invited to share their thoughts regarding the unmet health needs of people with mental retardation, and to suggest possible solutions.

The major themes that emerged from the Listening Session were used to develop the agenda for the Surgeon General's Conference on Health Disparities and Mental Retardation on December 5–6, 2001. At that Conference, individuals and families will work with leading experts, researchers, and representatives of professional and other health care organizations to develop a national action plan addressing health disparities and mental retardation. This grassroots approach reflected the Surgeon General's commitment to an action plan addressing the issues of most importance to individuals with mental retardation and others concerned with their health. Conference participants will discuss what is currently known concerning the science, practice, and

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\* In this summary, "individual" refers to an individual with mental retardation. The Surgeon General is aware that there is a controversy around the use of the term "mental retardation" and that self-advocacy groups and professional associations are currently discussing alternatives. Until a consensus is reached, with the goal of drawing attention to the great health disparities faced by people with what has been traditionally known as "mental retardation," that term will be used in official information on the Conference and other elements of the Surgeon General's effort on health disparities and mental retardation.

other aspects of health care services for individuals with mental retardation, identify priority issues, and draft recommendations for action.

This summary of the Listening Session reflects comments presented by more than 40 individuals during the Session as well as comments of an additional 800 individuals, including nearly 600 who had sent comments to the Surgeon General's website before the Listening Session. Analysis of the issues described in these comments indicated that they cluster under four themes, which formed the agenda of the Listening Session. The themes were as follows:

*Understanding special health care needs.* Examples of issues were attitudes of health professionals towards individuals with mental retardation, and provider knowledge and understanding of special health care needs of these individuals.

*Getting health care services.* Examples of issues were finding and getting to appropriate health care, and paying for needed services.

*Growing up and living with disabilities.* Examples of issues were age-appropriateness of health care services, and transitions as individuals' health care needs change with their age.

*Healthy lifestyles.* Examples of issues included roles of health professionals, individuals with mental retardation, and their caregivers in maintaining health and preventing illness and secondary disability.

During the three-hour Listening Session, speakers at five sites described their concerns and ideas for improvement to Dr. Satcher, Dr. Duane Alexander, Director of the National Institute of Child Health and Human Development, other participants at the sites, and a national audience viewing a live videocast of the Session. The archived videocast can be viewed at <http://videocast.nih.gov/PastEvents.asp?c=4&s=11>. Representatives of 29 different Federal agencies and more than 70 nongovernment organizations participated in the planning and implementation of the Listening Session.

The summary begins with a discussion of several themes that recurred throughout the Session in many different comments, both verbal and written. The many specific issues described for the Surgeon

General are summarized in bulleted lists under eight topical headings (two for each of the four Listening Session themes). To convey the tone of the Listening Session, selected remarks of participants are shown in italics.

## COMMON THEMES

Throughout the Listening Session and in written comments, providers, caregivers, and especially self-advocates spoke of their determination to be treated by health care providers as "real people," with the same interest in good health and functioning as people without mental retardation. As one self-advocate told the Listening Session:

*"I am who I am, and I can be the best of who I am. All I'm trying to do is make a living, and the only way I can do that is to have good health care."*

At the same time, speakers described distinctive characteristics that indicated the need for specialized approaches to health care. One health care provider wrote:

*"...Disability impacts the way people experience medical, social, and psychological problems. Learning ability and health may be affected by medication, complicated by challenging behaviors, or impacted by anxiety or fear..."*

A second common theme was the individualized nature of the health care needs of individuals with mental retardation. The types and intensity of services an individual may need vary with the individual's age, the coexisting conditions, the etiology of his or her mental retardation, and the environment in which the individual lives. Some participants spoke primarily of the same types of preventive, acute, and chronic health care needs that people without mental retardation experience. Others reported the challenges of managing exceptionally complex coexisting conditions. One family member, describing a child with Down syndrome, said:

*"...The medical issues are more paramount. [The child] has had open heart surgery, two pacemakers, asthma, [tracheomalacia], four sets of ear tubes, four eye surgeries, ...RSV [respiratory syncytial virus], Candida albicans infection, reflux, Sjogren's syndrome, JRA*



*[juvenile rheumatoid arthritis], scoliosis, 47 pneumonias, upper right lobe lung damage (resulted in 14 months of supplemental [oxygen]), dental health issues, strabismus, and nystagmus.”*

A third common theme was the need for more information—both science-based knowledge that could improve the health of individuals with mental retardation, the quality of their care, and their access to services, and also specific information on how to understand a family member’s condition and how to find and pay for health care. In particular, difficulties in recognizing and treating behavior disorders, depression, and other mental illness were often described. Family members wanted to understand what behavior in a child is developmentally appropriate and what may be a behavior disorder that would benefit from early diagnosis and treatment. A health care professional wrote:

*“Many academic physicians/dentists are bewildered by the health problems of mentally retarded people [sic] with severe complex disabilities and will acknowledge that clinical research-based medical data necessary for optimal treatment of frequently occurring medical/dental conditions in this population is lacking....”*

A family member said she felt both overwhelmed by information available on the Internet, yet underinformed about day-to-day issues in the health of a family member with mental retardation. Another told the Listening Session:

*“No one seemed to be able to help us find what we wanted or needed.”*

Finally, certain participants described personal strategies that they considered helpful, as well as existing services and programs that seemed successful. One-self advocate said:

*“People advocated for me and helped me learn advocacy skills so that I could personally help medical professionals know my needs.”*

Among existing programs that individuals described as helpful were health promotion activities that focused on obesity in a special education setting; a Medicaid-financed waiver program that trained

minority personal assistance staff to work with adolescents with disabilities; medical curricula that included parents of individuals with disabilities as teachers of medical students; and a one-stop diagnostic, treatment, and resource center for families.

Some participants also suggested changes that could reduce health disparities experienced by individuals with mental retardation. For example, they urged priority attention to research and care for individuals with mental retardation and mental illness (dual diagnosis). Collaborations between academic medical and dental centers and physicians and other providers with experience in institutional care of people with mental retardation were suggested as a means of improving both care and the quality and use of research.

Other suggestions included development of standards of clinical practice and standards for evaluation of services for individuals with mental retardation; professionalization of personal care attendants; changes in the organization and financing of health care; and addressing public misperceptions of mental retardation. One of the most common suggestions was revisions in curricula of health professions schools and training programs. One family member said:

*“As [my daughter] gets older, [the] doctor’s appointment becomes even more challenging. Since she is nonverbal and not able to express herself in meaningful ways, finding out what has been bothering her has been the job of my instinct....I really think the medical schools should somehow incorporate curriculum on dealing with or treating persons with disabilities, particularly with mental retardation, into their existing course of study. Being a member of an immigrant community, I think there has to be more diverse medical personnel to effectively treat patients whose English proficiency is limited....”*

Many participants summed up their concerns as lack of access to the type of care they needed, when they needed it. In grouping examples of these concerns under the topical headings below, an effort was made to highlight underlying factors that could be addressed in a national action plan.

## SUMMARY EXAMPLES OF LISTENING SESSION TOPICS

### Understanding Special Health Care Needs

#### **Attitudes of Health Care Professionals**

*“Whenever I go into the doctor’s office, . . . they talk to the people that bring me. But it’s my life and it’s my illness. . . . Can you respect me enough to talk to me?”*  
(Self-advocate)

*“Doctors need to be educated by families. . . .”*  
(Health care educator)

- A physician or other health care provider may be reluctant to accept an individual as a patient.
- A provider may not accept Medicaid recipients as patients.
- A provider may provide or recommend a lower level of care for an individual with mental retardation than would be recommended for a person without this condition.
- A provider may not interact directly with the individual with mental retardation but may instead talk only with a family member or other person with the individual.

A provider may not respond to or understand values and perceptions of health and mental retardation of African Americans, Native Americans, Alaska Natives, Hispanics, Southeast Asians, and other distinctive ethnic and cultural groups; a provider may not speak the primary language of an individual with mental retardation and his or her family.

#### **The Quality of Health Services**

*“ . . . [Individuals with these disabilities] may need increased time, different treatment methods, and more frequent learning opportunities. . . .”* (Health care professional)

*“Where is research currently conducted and/or compiled that addresses (a) epidemiology of health statistics of persons with MR, (b) access to health care, (c) effectiveness of training programs for providers,*

*families, and self-advocates, and (d) impact of Federal and State funding policies in health care access and health statutes?”* (Listening Session comment card)

- Multiple gaps in the scientific knowledge base impede improvements in the health care of individuals with mental retardation. Data collection and analyses typically fail to specifically identify individuals with mental retardation.
- More translation of the existing science base into forms usable by individuals, caregivers, and health care providers is needed.
- Clinical practice guidelines and methods of measuring quality of care for individuals with mental retardation are needed. The experience of individuals with mental retardation in using a health care service should be considered when that service is being evaluated.
- Health providers often lack specialized knowledge and training in treating individuals with mental retardation.
- Health care providers may not be knowledgeable about specific clinical issues, such as diagnosis and treatment of mental illness and recognition of abuse and neglect.
- A provider may use medication inappropriately to control challenging behaviors, instead of using therapies to assist the individual and caregiver with managing such behaviors.
- Health care providers may be more likely to extract teeth than to provide ongoing preventive oral health care for individuals with mental retardation.
- An individual’s medical history, diagnosis, and treatment may be substandard because the provider does not communicate effectively with the individual. For instance, diagnostic and treatment procedures that are inadequately explained may be refused. A provider may be reluctant to accept clinical responsibility when an individual refuses recommended procedures.

## Getting Health Care Services

### ***Finding and Getting To Health Care Services***

*“We drive 200 miles to get specialized health care because doctors here have no understanding of [our daughter’s] needs, mostly because she has Down syndrome, besides other conditions many ‘normal’ people get.” (Family member)*

- Individuals, families, and providers lack information about the types, locations, and availability of health care services.
- There are shortages of appropriately trained and experienced providers at all points of contact in the health care system: primary care and specialist physicians, including psychiatrists, dentists, nurses, psychologists, ancillary health care professionals such as radiograph technicians, emergency department providers, and administrative staff of health care providers and services. Shortages are particularly acute in rural and low-income urban areas.
- Clinical sites may not be physically accessible, such as not being accessible for individuals with visual and/or hearing impairments.
- Professional equipment, from scales to dental chairs to diagnostic and treatment equipment, may not be appropriate for individuals with disabling conditions, including mental retardation.
- Shortages of appropriate health care services exist across community settings, including in homes of individuals, in schools, and in supported living arrangements.
- Mental health programs lack models of care that are appropriate for individuals with mental retardation.
- A provider may not be knowledgeable about working cooperatively with families, special education programs, community living arrangements, or other systems providing health and other types of care for an individual. This lack of knowledge concerning existing,

appropriate health and related services makes these resources less accessible to individuals who require them.

### ***Paying for Health Services***

*“...I needed to navigate a very complex medical assistance system and even find loopholes so that my dentures would be replaced sooner than the allocated time for replacement due to early breakage (from seizures).” (Self-advocate)*

- Needed services may be excluded from insurance coverage (Medicaid or private, including managed care). For example, Medicaid typically does not cover routine adult dental, vision, or hearing services or preventive care. Private insurers typically exclude long-term therapies, developmental assessments, nutritional products, and customized durable medical equipment.
- Mental retardation may be characterized as a mental illness, excluded from medical coverage, or as a neurologic condition, excluded from psychiatric coverage.
- An insurer may refuse to provide coverage for an individual with mental retardation.
- Insurance premiums may be exceptionally costly; out-of-pocket costs of services not covered by an insurer may be unaffordable for middle-class families.
- An insurer (including Medicaid) and school system may each refuse coverage for occupational, speech-language, or physical therapies, and other services provided in the educational setting. Each may consider the other program to be financially responsible.
- Service authorization procedures (Medicaid, managed care, and special education plans) are too complicated, too time-consuming, and too delayed. Services may be inappropriately denied as not “medically necessary.”
- Insurance personnel responsible for authorizations may not understand mental retardation or other conditions associated with mental retardation.

- Routine administrative practices may be inappropriate for an individual with mental retardation. For example, the individual may not understand a mail notice to choose a primary care physician, and may be automatically assigned to a physician who does not understand the individual's needs.

## **Growing Up and Living with Disabilities**

### **Age-Appropriate Health Services**

*“Just because people get older doesn't mean their disabilities disappear....” (Self-advocate)*

*“Many [persons] with cognitive limitations become parents and fall through the cracks [as they focus on getting health care for their own child].... There is a need for specific programs...with a commitment to help these families....” (Health care professional)*

- Pediatricians and pediatric dentists have historically continued to provide care for individuals after childhood; however, improved lifespans mean that these individuals need practitioners knowledgeable in primary adult care, in specialist care for conditions found in other adult populations, such as obesity and cardiovascular conditions, and in conditions occurring at elevated rates in certain individuals with mental retardation (e.g., dementia associated with premature aging).
- Age-related conditions, such as changes in medication needs, mobility, or arthritis, may be seen as part of an individual's disability and may be inadequately recognized or treated.
- Existing service models for end-of-life conditions, such as hospice or institutional care for Alzheimer's disease, may not be appropriate or acceptable for an individual and his or her family.

### **Continuity of Health Services Throughout Life**

*“...It is so hard to have your head in the trenches...day to day...and still be able to look ahead and find possibilities for the future....” (Family member)*

- The extent of Medicaid coverage may depend on age, not medical need, of an individual. For example, coverage for home care may end at age 21 for a ventilator-dependent individual.
- Coordination among medical specialists and with early intervention services for care of a medically complex person may work during the first years of life; however, when the medical condition is stabilized and the person's needs become more intensive and diverse as he or she grows, finding and coordinating multiple services may be left to the family.
- Transition from adolescent to adult care is especially complex.
- Care for an individual with multiple conditions may be fragmented. For example, different specialists may be managing an individual's seizures, gastrointestinal disorder, and abnormal destructive behaviors, resulting in adverse drug interactions or chronic drug toxicity. Age-related changes in health care needs may further complicate care if more or different providers are needed.
- There are severe shortages in care coordination services.

## **Healthy Lifestyles**

### **Promoting Health: Providers**

*“To prevent injuries, we need the same precautions as for the elderly who are less coordinated, less stable, less able to hear and see well, and less able to make quick decisions; health conditions [associated with employment] are not monitored, and it is hard for the individual to associate it to their job site or activity....” (Health care professional)*

*“Current [substance abuse] intervention and treatment programs are completely unsuitable for [individuals with mental retardation] since they often require communication and discussion. However, opportunities for abusing substances are abundant. They become a form of release and self-medication when there are no more suitable outlets....” (Health care professional)*

- Providers may not screen individuals with mental retardation for dietary and nutritional status, exercise habits, oral disease (e.g., periodontal disease), tobacco and alcohol use, depression and other mental illness, cancer (mammograms, Pap smears, prostate cancer), abuse or neglect, domestic violence, and occupational hazards.
- Providers may not have the specialized training and equipment needed to provide preventive interventions, such as oral prophylaxis and applications of protective materials to tooth surfaces. Providers may overlook the need for immunizations and opportunities to educate individuals and families in health-promoting behaviors such as exercise.
- High rates of turnover in personal care attendants may mean that an attendant does not know the medical history and concerns of an individual with mental retardation. Thus, the attendant may not be able to help either the individual or the provider in communications, maintaining needed courses of treatment, recognizing symptoms that need attention from a health care professional, and other matters.
- Gaps in, or unavailability of, medical records of an individual with mental retardation may compromise continuity of health care services.

### **Promoting Health: Individuals and Caregivers**

*“I would like to see programs for the whole body....”*  
(Self-advocate)

*“People with disabilities need help to know about diet....”* (Self-advocate)

- Training and education in self-care may not be offered to individuals with mental retardation. Opportunities to provide such training and education in community settings, such as special education programs, may be overlooked.
- Preventive interventions may not be designed to enable an individual to understand or participate in health-promoting behaviors, such as management of diabetes and routine oral hygiene.
- Personal care attendants may not be trained and may not help an individual maintain appropriate diet and nutrition, regular exercise, or good oral hygiene, and avoid tobacco use and other health risks. Attendants may allow or unintentionally encourage unhealthy lifestyles by their own example if they are not knowledgeable about health promotion.
- Job coaches and employment counselors may not be trained to identify and advocate against unsafe workplace conditions, such as exposure to toxic substances, repetitive motion injuries, and others. Occupational hazards may be viewed as a lower priority than securing employment for an individual with mental retardation.

November 2001



# **Appendix F: Surgeon General's Listening Session on Health Disparities and Mental Retardation**

October 10, 2001

## **Speakers**

### ***Welcome and Opening Comments***

Surgeon General David Satcher, M.D., Ph.D.,  
U.S. Department of Health and Human Services  
Duane Alexander, M.D., Director,  
National Institute of Child Health and Human  
Development, National Institutes of Health (NIH)  
Ms. Loretta Claiborne, Self-Advocate

### ***Panel Moderators, NIH Site***

Elin Cortijo-Doval, M.Ed.  
George Jesien, Ph.D.  
Deborah Spitalnik, Ph.D.  
Sheryl White-Scott, M.D.

### ***Participating Sites***

#### **Civitan International Research Center, University of Alabama at Birmingham**

Judy Barclay  
Matthew Foster  
Alvin Garvin  
Wendy Hardy  
Elouise Woods  
Patsy Wright

#### **Oregon Institute on Disability & Development, Oregon Health & Science University, Portland, Oregon**

Judy Cunio  
Michael Geheb  
Trent Minor  
Julie Quaid  
Sidney Stuller  
Sharon Turner  
Judy Wiley

#### **Eunice Kennedy Shriver Center, University of Massachusetts Medical School, Worcester, Massachusetts\***

Ana Arango  
Sandy Blanes  
Billie Chan  
David Coulter  
Kim Daniels  
Yvette Johnson  
Ann Ligums  
John Morgan  
Reginald Raphael  
Cindy Smith  
Charlotte Spinkston  
Bersford Wilson

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\* Due to technical difficulties, the speakers at the Massachusetts site were unable to participate at the time of the actual Listening Session. However, their recorded remarks have been added to the archived videocast of the session and are part of the official record. The entire Listening Session can be viewed at the following site: <http://videocast.nih.gov/PastEvents.asp?c=4>.

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Cindy Bentley  
Barbara Katz  
Lynne Schauls  
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Nancy Shook  
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Jose Cordero  
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Jackie Golden  
Julie Hacker-Yannes  
Katrina Johnson  
Wanda Jones  
Guy Leif  
Maureen Mitchell  
Liz Oppenheimer  
Victor Robinson  
Jamie Rutman  
Tim Shriver  
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Ginny Thornburgh











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