
THE INTERAGENCY COMMITTEE ON DISABILITY RESEARCH

2003 ANNUAL REPORT TO THE PRESIDENT AND CONGRESS



Office of Special Education and Rehabilitative Services

U.S. Department of Education



UNITED STATES DEPARTMENT OF EDUCATION

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES
NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

August 1, 2005

The Honorable George W. Bush
President of the United States
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20500

Dear Mr. President:

As chair of the Interagency Committee on Disability Research (ICDR), I am pleased to submit the enclosed "2003 Annual Report to the President and Congress." The report was prepared in close cooperation with the many federal agencies that participate in the ICDR.

The report details the many noteworthy activities in the 2003 reporting period, including ICDR scientific meetings and technical documents in Section 3 on pages 17–26. A major effort to systematically collect input from individuals with disabilities about assistive technology was initiated and is described in Section 4, pages 27–34. Other highlights include administrative improvements that will support future endeavors of the ICDR under the New Freedom Initiative.

The ICDR would like to draw your attention in particular to the recommendations contained in Section 7 of the report. They are overarching recommendations aimed at strengthening the federal research effort to the benefit of citizens with disabilities. These recommendations are endorsed by the full ICDR, representing 35 different federal departments, agencies, and institutes.

The ICDR is poised to be even more productive in the future, and we thank you for your continued support and interest in the work of this committee. We continue to work for the success of the New Freedom Initiative and thereby increase access to assistive technologies, expand educational opportunities, increase the ability of Americans with disabilities to integrate into the workforce, and promote their increased access into daily community life.

Respectfully yours,

A handwritten signature in cursive script that reads "Steven James Tingus".

Steven James Tingus, M.S., C.Phil.
Chair, Interagency Committee on Disability Research
Director, National Institute on Disability and Rehabilitation Research

THE INTERAGENCY COMMITTEE ON DISABILITY RESEARCH

2003 ANNUAL REPORT TO THE PRESIDENT AND CONGRESS



Prepared for: U.S. Department of Education
Office of Special Education and Rehabilitative Services
National Institute on Disability and Rehabilitation Research (NIDRR)

On behalf of: the Interagency Committee on Disability Research
Chaired by: Steven James Tingus, Director of NIDRR
Prepared by: Cherry Engineering Support Services, Inc., McLean, Va.

This report was produced under U.S. Department of Education Contract No. GS10F0006M, on behalf of the Interagency Committee on Disability Research (ICDR), with Cherry Engineering Support Services, Inc. (CESSI). Robert Jaeger served as the contracting officer's representative. The views expressed herein do not necessarily represent the positions or policies of the U.S. Department of Education or member agencies of the ICDR. No official endorsement by the U.S. Department of Education, or any ICDR member agency, of any product, commodity, service or enterprise mentioned in this publication is intended or should be inferred.

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August 2005

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This report is available on the ICDR Web site at: www.icdr.us.

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Executive Summary

The Interagency Committee on Disability Research (ICDR), authorized by the Rehabilitation Act of 1973 as amended, promotes coordination and cooperation among federal departments and agencies conducting disability and rehabilitation research programs. [1] Representatives of 35 entities regularly participate in the full ICDR. In addition to the full committee, five subcommittees address one of each of these issues:

- disability statistics;
- medical rehabilitation;
- technology;
- technology transfer; and
- the New Freedom Initiative (NFI).

The goals of the ICDR and its subcommittees are to:

- Increase public input and involvement in ICDR deliberations to ensure research efforts lead to solutions for identified needs;
- Improve the visibility of the ICDR and federal disability research in general;
- Identify and solve common problems through collaboration among agencies; and
- Initiate and monitor activities involving interagency coordination and cooperation in support of the New Freedom Initiative (NFI).

A particular focus, mandated by the NFI, is to ...

... prioritize the immediate assistive and universally designed technology needs in the disability community as well as foster collaborative projects between the federal laboratories and the private sector. [2]

In the reporting period encompassing Jan. 1 through Dec. 31, 2003, the ICDR realized significant accomplishments. This period was the first full year of the ICDR under the NFI. Part of this first year was spent laying the groundwork for future work by improving the administrative structure. A major accomplishment in this area was designing and implementing the ICDR public Web site that describes the activities of the ICDR, provides links to research findings, and provides a way for the public to send comments to the ICDR concerning the federal research agenda in disability and rehabilitation. The ICDR obtained grassroots-level consumer input on assistive technology needs by conducting 12 focus groups across the country. The ICDR also conducted various working groups, joint projects and multidisciplinary conferences demonstrating the close collaboration among member agencies. The topics addressed illustrate a wide range of concerns in the field.

Now that an improved administrative structure is in place, the ICDR can expand its efforts to gather information on research needs related to assistive technology and build on the information obtained in this first year.

Using findings from consumer input activities, conference proceedings and other relevant reports from government and scientific agencies, the ICDR developed recommendations for research and internal management to improve interagency coordination and guide the federal research agenda.

Research Recommendations

1. Recommend an Institute of Medicine (IOM) study focused on the federal research and development effort in rehabilitation science, to start in 2005.
2. Over a two – three year period, develop a plan to present to Congress for the design and implementation of an improved periodic national disability data collection effort.
3. Continue analysis and comparisons of disability and rehabilitation terminology in federal agencies in order to facilitate communication and coordination.
4. Encourage research addressing access to and the costs and benefits of various assistive technologies, including costs of equipment; potential financial savings, e.g., reducing need for home care, personal care assistance and al expenses related to secondary disabilities (e.g., falls and depression); health and quality-of-life outcomes; and impact on performance of daily activities.
5. Encourage public-private partnerships to support technology transfer of assistive technology devices.
6. Identify strategies to support longitudinal studies (10–15 years) on disability and rehabilitation issues.

ICDR Internal Management Recommendations

1. Catalog and describe all interagency committees, working groups, councils and task forces that are related to the ICDR. Devise a plan to monitor the activities of these related committees, working groups, councils and task forces, and report on them as needed to the ICDR and its subcommittees.
2. Complete in-depth examination—using the Web search portal—of currently funded research on assistive technology to identify research gaps, duplication of effort, etc., to facilitate coordination of this research.
3. Expand Web search portal to include program announcements and notices of federal funding opportunities. Also, devise procedures to share plans for priorities in advance of announcements to facilitate coordination efforts among the ICDR members.

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4. Increase dissemination of information about federal disability research activities.
 5. Improve documentation of research outcomes.
 6. Disseminate the *Report on Assistive Technology Mobility Devices* [3] prepared in response to President Bush's executive memorandum establishing the Interagency Working Group (IWG) on Assistive Technology Mobility Devices (ATMDs) issued on Feb. 12, 2003, [4] that challenged federal agencies to increase educational and employment opportunities for persons with disabilities by improving their access to ATMDs.

Section 1: Overview of the ICDR

Section 203 of the Rehabilitation Act of 1973 as amended, establishes the ICDR “to promote coordination and cooperation among federal departments and agencies conducting rehabilitation research programs, including programs relating to assistive technology research and research that incorporates the principles of universal design.” The act also specifies the work of the ICDR:

After receiving input from targeted individuals, the Committee shall identify, assess, and seek to coordinate all federal programs, activities, and projects, and plans for such programs, activities, and projects with respect to the conduct of research (including assistive technology research and research that incorporates the principles of universal design) related to rehabilitation of individuals with disabilities. [1]

The ICDR is required to submit an annual report to the president and to appropriate committees of Congress on recommendations for coordinating policy and developing objectives and priorities for all federal agencies related to disability and rehabilitation research.

ICDR Goals

The ICDR addresses the needs of persons with disabilities through a targeted, coordinated and effective federal disability and rehabilitation research program. The ICDR mandate requires consumer input and coordination across federal agencies to develop the most appropriate research agenda. The new paradigm of disability with an inclusive and integrated approach guide the ICDR in pursuing its goals. [5]

New Paradigm

In the scientific community, this new paradigm has gained a solid foothold as a framework for conducting research related to disability and rehabilitation. The new paradigm maintains that disability is an interaction between characteristics of an individual (e.g., conditions or impairments, functional status, or personal and social qualities) and characteristics of the natural, built, cultural and social environments. The 1997 IOM publication *Enabling America: Assessing the Role of Rehabilitation Science and Engineering* devoted an entire chapter to these concepts. [6] A disabled person is no longer viewed only as someone who cannot function because of impairment, but as someone who needs or uses accommodations in order to function. The new paradigm recognizes the continuing importance of medical rehabilitation and health within the context of disability. But, it also recognizes the civil rights protections given to people with disabilities under the Americans with Disabilities Act (ADA) of 1990, to include equal opportunity in public accommodations, employment, transportation, state and local government services and telecommunications. With the 1999 *Olmstead v. L.C.* decision, the Supreme Court construed Title II of the ADA to require all states to place qualified individuals with mental disabilities in community settings, rather than in institutions, whenever appropriate. [7] The *No*

Child Left Behind Act, signed on Jan. 8, 2002, requires progress reports on all student groups, as defined in the act. [8] These results must also be reported to the public disaggregated by race, gender, English language proficiency, disability and socioeconomic status. Thus, both the theoretical framework and policy environment are moving in similar directions in that the policy decisions may stimulate production of new data and research opportunities and the framework may encourage the development of new research methods leading to advances in knowledge and practice.

An Inclusive and Integrated Approach

The ICDR believes that to promote coordination and cooperation it must be inclusive in its approach, hearing all voices—including numerous federal agencies, researchers, individuals with disabilities and private organizations. At the same time, the federal agencies involved in disability and rehabilitation research each have their own specific missions and directives that must be honored. So, the ICDR believes that a coordinated and integrated approach is necessary to achieve broad and overarching goals that go beyond the focus of individual agencies.

Specific goals of the ICDR are to:

- Increase public input and involvement in the ICDR deliberations to ensure research efforts lead to solutions for identified needs;
- Improve the visibility of the ICDR and federal disability research in general;
- Identify and solve common problems through collaboration among agencies; and
- Initiate and monitor activities involving interagency coordination and cooperation in support of the NFI.

Structure

The director of the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, is designated to chair the ICDR. Statutory members include, in the order in which they appear in the Rehabilitation Act of 1973, as amended:

- Commissioner of the Rehabilitation Services Administration;
- Assistant Secretary of the Office of Special Education and Rehabilitative Services;
- Secretary of Education;
- Secretary of Veterans Affairs;
- Director of the National Institutes of Health;
- Director of the National Institute of Mental Health;
- Administrator of the National Aeronautics and Space Administration;
- Secretary of Transportation;
- Assistant Secretary of the Interior for Indian Affairs;
- Director of the Indian Health Service; and
- Director of the National Science Foundation.

Numerous other federal agencies play significant roles in disability and rehabilitation research, either by funding research or by being consumers of resulting research. By invitation of the chair, other agencies regularly participate on the ICDR, either in the full committee or on the various subcommittees. The agencies represented during 2003 are listed below.

Agencies Represented on the Full ICDR or Its Subcommittees

DEPARTMENT OF COMMERCE

BUREAU OF INDUSTRY AND SECURITY

BUREAU OF THE CENSUS

NATIONAL OCEANIC AND ATMOSPHERIC ADMINISTRATION

TECHNOLOGY ADMINISTRATION

DEPARTMENT OF DEFENSE

TRICARE MANAGEMENT ACTIVITY

Computer/Electronics Accommodation Program

DEPARTMENT OF EDUCATION

OFFICE OF THE CHIEF INFORMATION OFFICER

OFFICE FOR CIVIL RIGHTS

OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

National Institute on Disability and Rehabilitation Research

Office of Special Education Programs

Rehabilitation Services Administration

DEPARTMENT OF HEALTH AND HUMAN SERVICES

OFFICE OF THE SECRETARY

Immediate Office of the Secretary

Office on Disability

OFFICE OF THE ASSISTANT SECRETARY FOR HEALTH

Office of Public Health and Science

Office of Disease Prevention and Health Promotion

OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

Office of Disability, Aging, and Long-Term Care

ADMINISTRATION FOR CHILDREN AND FAMILIES

Administration on Developmental Disabilities

President's Committee for People with Intellectual Disabilities

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

Center for Financing, Access and Cost Trends

CENTERS FOR DISEASE CONTROL AND PREVENTION

Agency for Toxic Substances and Disease Registry

Division of Reproductive Health

Maternal and Child Health Epidemiology Program

National Center on Birth Defects and Developmental Disabilities

National Center for Chronic Disease Prevention and Health Promotion

Division of Adult and Community Health

Division of Diabetes Translation

National Center for Environmental Health

National Center for Health Statistics

National Center for Infectious Diseases

National Center for Injury Prevention and Control

National Immunization Program

Office of the Director

Office of Genomics and Disease Prevention

CENTERS FOR MEDICARE AND MEDICAID SERVICES

Office of Information Services

FOOD AND DRUG ADMINISTRATION

Center for Devices and Radiological Health

Office of Science and Technology

HEALTH RESOURCES AND SERVICES ADMINISTRATION

Maternal and Child Health Bureau

Traumatic Brain Injury Program

NATIONAL INSTITUTES OF HEALTH

Clinical Center

National Cancer Institute

National Institute on Aging

National Institute on Alcohol Abuse and Alcoholism

National Institute of Arthritis and Musculoskeletal and Skin Diseases

National Institute of Biomedical Imaging and Bioengineering

National Institute of Child Health and Human Development

National Center for Medical Rehabilitation Research

National Institute on Deafness and Other Communication Disorders

National Institute of Diabetes, Digestive, and Kidney Diseases

Division of Kidney, Urologic, and Hematologic Diseases

National Institute on Drug Abuse

Division of Neuroscience and Behavioral Research

National Institute of Mental Health

National Institute of Neurological Disorders and Stroke

National Institute of Nursing Research

National Library of Medicine

National Information Center on Health Services Research and Health Care Technology

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Center for Mental Health Services

DEPARTMENT OF THE INTERIOR

BUREAU OF INDIAN AFFAIRS

Office of Indian Education Programs

DEPARTMENT OF JUSTICE

CIVIL RIGHTS DIVISION

Disability Rights Section

OFFICE OF JUSTICE PROGRAMS
Bureau of Justice Statistics

DEPARTMENT OF LABOR

BUREAU OF LABOR STATISTICS
OFFICE OF DISABILITY EMPLOYMENT POLICY

DEPARTMENT OF TRANSPORTATION

BUREAU OF TRANSPORTATION STATISTICS
FEDERAL TRANSIT ADMINISTRATION
Office of Civil Rights
NATIONAL HIGHWAY TRAFFIC SAFETY ADMINISTRATION

DEPARTMENT OF VETERANS AFFAIRS

MENTAL HEALTH STRATEGIC HEALTH CARE GROUP
VETERANS HEALTH ADMINISTRATION
Office of Policy and Planning
Office of Research and Development
Rehabilitation Research and Development Service

UNITED STATES ACCESS BOARD

THE COMMITTEE FOR PURCHASE FROM PEOPLE WHO ARE BLIND OR SEVERELY DISABLED

EQUAL EMPLOYMENT OPPORTUNITY COMMISSION

FEDERAL COMMUNICATIONS COMMISSION

CONSUMER AND GOVERNMENTAL AFFAIRS BUREAU
Disability Rights Office

FEDERAL LABORATORY CONSORTIUM FOR TECHNOLOGY TRANSFER

GENERAL ACCOUNTING OFFICE

GENERAL SERVICES ADMINISTRATION

NATIONAL AERONAUTICS AND SPACE ADMINISTRATION

NATIONAL COUNCIL ON DISABILITY

NATIONAL INSTITUTE FOR LITERACY

NATIONAL SCIENCE FOUNDATION

SOCIAL SECURITY ADMINISTRATION

DISABILITY AND INCOME SECURITY PROGRAMS
Office of Disability Programs
Office of Program Development and Research Policy
Office of Research, Evaluation and Statistics

WALTER REED ARMY MEDICAL CENTER

DEFENSE AND VETERANS BRAIN INJURY CENTER

Meetings

The full ICDR meets at least quarterly, as required by statute. Subcommittees meet at least every two months. Subcommittees often invite individuals from outside the federal government to participate as external experts. These may include consumer advocates, university researchers

and representatives of private organizations. Some federal agencies may have an official designee to attend the full ICDR but have other staff members with specific research expertise to represent the agency on various subcommittees.

ICDR Subcommittees

To more effectively achieve its mission, the ICDR has established working subcommittees focused on specific topic areas.

Interagency Subcommittee on Disability Statistics

The Interagency Subcommittee on Disability Statistics (ISDS) has been in operation since 1982. It now has over 100 members from more than 20 federal agencies and, more recently, has welcomed researchers from outside the government and from international institutions. The ISDS has grown into an important forum for discussion of statistical issues and terminology related to disability. Summaries of the ISDS meetings are disseminated to approximately 600 researchers. The subcommittee conducts monthly meetings that utilize eight videoconferencing sites enabling communication among participants in: Washington, D.C.; Hyattsville, Md.; Baltimore, Md.; Atlanta, Ga.; Research Triangle, N.C.; San Francisco, Calif.; St. Louis, Mo.; and Geneva, Switzerland (World Health Organization). Others join by telephone only. It provides an opportunity for researchers from various agencies to share research activities, promote collaboration and use each other as intellectual resources.

Interagency Subcommittee on Technology

The Interagency Subcommittee on Technology (IST), created in December 1996, has as its mission to review current federal research in technology and to recommend changes in federal technology research to better accomplish its goals. The subcommittee is charged with determining the extent to which the federal research portfolios:

- Target the needs of people with disabilities appropriately;
- Are flexible enough to: (1) respond to changes in the technological needs of people with disabilities and (2) identify and respond to emerging technology while maintaining the stability of the research infrastructure;
- Have a balance of basic, applied and outcomes research; and
- Focus on projects that cover a spectrum of technological issues and disabilities so as to increase the likelihood of multiple benefits.

The subcommittee's purview includes assistive technology (AT), rehabilitation technology, educational technology, rehabilitation engineering and any other technology that benefits—or has the potential to benefit—people with disabilities of all ages.

Interagency Subcommittee on Medical Rehabilitation

Established in September 1997, the Interagency Subcommittee on Medical Rehabilitation (ISMR) is composed of representatives from federal agencies involved in medical rehabilitation research. Its objectives are to:

- Survey all medical rehabilitation projects in the federal government;

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- Identify needs for additional research;
 - Identify areas for potential joint funding; and
 - Recommend dissemination strategies for all medical rehabilitation research to wider audiences.

The subcommittee defines medical rehabilitation as:

...the field of study that encompasses basic and applied aspects of the health sciences, social sciences and engineering related to restoring and/or maintaining a person's health and functional capacity and improving their interactions with the surrounding environments. [9]

Interagency Subcommittee on Technology Transfer

Established in 2002, the Interagency Subcommittee on Technology Transfer (ISTT) focuses on problems of technology transfer from the laboratory to the marketplace once research is completed. While the focus of the ISTT is on planning, coordinating and monitoring the federal research agenda in technology, the problems surrounding technology transfer are so complex that members felt this additional subcommittee was required to ensure adequate attention to technology transfer. This subcommittee addresses postresearch issues such as application and adaptation of the technology developed in the research process, particularly the facilitation of public-private partnerships, a need identified in the NFI. The ISTT also considers the special aspects of intellectual property, patents and funding mechanisms, such as the Small Business Innovation Research (SBIR) program, as they relate to disability and rehabilitation research.

Interagency Subcommittee on the New Freedom Initiative

The Interagency Subcommittee on the New Freedom Initiative (ISNFI) was created in 2002 to fill a unique role within federal disability research activities. With the implementation of the NFI, each federal agency now has a designated individual responsible for carrying out the NFI within his or her respective agency. This subcommittee provides a forum for these agency representatives to share information and to facilitate communication and collaboration. It does not have a specific research agenda, but its mission has an overarching theme encompassing the work of the other subcommittees and research elements of the NFI. The ISNFI's broad scope includes technology, employment, education and community living for people with disabilities as it relates to NFI goals. Part of its role is to increase awareness of and access to research, and to develop policy input on crosscutting issues related to disability research.

Brief History

The ICDR came into existence in 1978 and has carried out congressionally mandated studies, offered recommendations on disability and rehabilitation policies and regulations, provided feedback to member agencies on long-range plans and priorities, coordinated research agendas and results, and utilized interagency agreements to promote cooperative research planning and agenda setting.

From 1995 to 1996 the ICDR was reorganized. In June 1995, the ICDR held a public forum to gather information from researchers and individuals with disabilities about the accomplishments and status of disability research, and recommendations for the future. In 1995–96, the ICDR compiled a catalog of selected funding sources for disability research. The catalog was disseminated through the National Rehabilitation Information Center (NARIC), a disability and rehabilitation documentation and Web-based information center (www.naric.com) funded by NIDRR. This resource was intended to assist researchers, government agencies and people with disabilities in gaining access to information about federally funded research.

In December 1996, the ICDR established the IST and in September 1997, it initiated the ISMR. These two coordinating groups, designed to expand collaboration and communication among researchers and agencies in two priority areas, joined the long-standing ISDS to promote a forward-looking research agenda.

The creation of these two subcommittees reflects two key points in a set of policy recommendations adopted by the ICDR in 1997: (1) to make disability and rehabilitation research more responsive to the needs and aspirations of people with disabilities, and (2) to more closely integrate other research with federal research and development policies and priorities. One of the first activities of the Subcommittee on Technology was to produce a compendium of assistive technology research projects funded by the federal government. This document was disseminated by NARIC.

In 2002, two more subcommittees were established: the ISTT and the ISNFI.

However, until fiscal year (FY) 2002 the effectiveness of the ICDR was hampered by a lack of resources for operations. On Feb. 1, 2001, President George W. Bush unveiled his New Freedom Initiative designed to break down remaining barriers to equality for Americans with disabilities. A key component called for an increased research budget, creation of a fund to help bring AT to the marketplace, improved coordination of the federal research and development effort, and funding for low-interest loan programs to help individuals purchase AT.

Under this component, the NFI directed the ICDR to improve coordination of federally funded assistive technology research and development activities. The NFI noted that there has been no effective coordinating body for assistive technology research and development within the federal government. The NFI further noted, “While the ICDR was designed to coordinate the federal effort, it has had no real authority and no budget.” In FY 2002, the administration provided funding to the ICDR to:

...prioritize the immediate assistive and universally designed technology needs in the disability community, as well as foster collaborative projects between the federal laboratories and the private sector. [2]

Section 2: ICDR Administrative Accomplishments

The reporting period encompassing Jan. 1, 2003, through Dec. 31, 2003, was the first year of the ICDR under the NFI. Part of this first year was spent laying the groundwork for future work by setting up an improved administrative structure.

Established the ICDR Public Web Site

The ICDR public Web site, www.icdr.us, was established to inform the public of the work of the ICDR and to provide a place where the public can comment on research needs related to disability and rehabilitation.

The U.S. Department of Education issued a press release in February 2003 announcing the public site and encouraging people to provide their comments related to disability research via the comments form posted on the site. A flyer was disseminated at disability conferences in 2003 to encourage people to visit the public site and complete the comment form. Articles about the public site also were also circulated in publications such as *Government Computer News*. [10] Two projects, the National Institute for Urban School Improvement (www.inclusiveschools.org) and the Urban Special Education Leadership Collaborative (www.urbancollaborative.org) featured the ICDR site as “Web site of the Month” on their respective sites during April 2003. The ICDR site was also featured in the electronic newsletters of said organizations.

Since the Web site began operation (February 2003) through Dec. 31, 2003, there were 308,300 hits and 32,012 visits. A hit is defined as “any request on a Web server for any file, such as a Web page, bitmap, common gateway interface, etc.” A visit is defined as “a series of requests from a uniquely identified client during a session.” [11]

Additional features of the site include a description of the ICDR statutory authority, mission and goals; a list of federal agencies represented on the ICDR and links to these agencies; a list of the ICDR subcommittees; links to publications related to disability research; and links to other disability related sites.

Established the Internal ICDR and Subcommittee Web Sites

In addition to the public Web site described above, an internal Web site was established for the full ICDR and each subcommittee. This capability houses information pertinent to the subcommittees; allows subcommittee members to communicate directly with each other to conduct the work of the subcommittee between meetings and plan subcommittee events, and serves as a repository for internal documents and reports prior to clearance for public release. Features of the internal site include an area for announcements, committee mission statements, a calendar of meeting dates and locations, past meeting summaries, an area for common files, a bulletin board and links to other disability-related sites.

Improved the Membership Database

The ICDR membership database was completely upgraded and improved in 2003. Its sophisticated functional capability can now: track membership, including updated contact information; produce membership rosters; track attendance at regular meetings, summits and conferences; generate correspondence, including electronic mail messages, paper mailings and faxes; generate participant lists; produce table tents and meeting sign-in sheets; and provide administrative reports. Reports were created to better capture federal representation on the ICDR and its subcommittees. The design of the database now allows enhanced analysis of membership and improved communication procedures. This will allow better tracking of agency participation and help the ICDR ensure that all agencies are regularly participating in the ICDR and subcommittee activities. It will also serve as a tool to improve communication among agency representatives as they participate in the various subcommittees of the ICDR.

Completed Annual Report

The 2002 Annual Report, sent to the president and Congress, is available for viewing at: www.icdr.us/annualReport_2001_02/index.htm (last accessed on Dec. 19, 2003).

Continued Work on the Web Portal

The portal project is designed to help the ICDR meet its statutory requirements on federal research coordination and cooperation, as well as presidential directives to promote assistive technology and universal design. Each federal agency provides public information about its disability research in different formats. This significantly complicates efforts to gather information for monitoring the federal research portfolio in disability and rehabilitation. The intent of enhancing the portal is to simplify and expedite this information gathering process and to improve the ability to analyze and summarize the information retrieved. When operational, the ICDR portal will provide an efficient Web-based means for the ICDR member agencies to find information on agency databases by entering keywords. These keywords will then be compared to the indexing terms used in the various federal databases to maximize success in retrieving the desired information. This will allow data on federally funded research projects to be reformatted for use in technical reports, responses to requests from Congress and communications with other federal agencies.

Among other benefits, portal users will be able to:

- “Crosswalk” and refine keyword searches in multiple databases;
 - Identify duplication in research funding;
 - Delineate gaps in critical research areas to support strategic planning efforts;
 - Identify universities and investigators consistently receiving funding;
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- Analyze funding patterns within agencies and across the federal government as a whole, by topic area, geographic distribution or research approach; and
 - Assess funding trends over time.

This year the ICDR investigated various alternatives for obtaining data from individual agencies. Two different methods—periodically uploading information from agency public Web sites into the ICDR database or developing a search engine to simultaneously search the publicly available Web sites containing data on currently funded projects—were investigated. The last approach seemed most feasible and is currently being pursued.

ICDR Workshop at the Perspectives Conference

The ICDR held a workshop on Dec. 10 and 12, 2003, as part of the annual symposium, “Perspectives on Employment of Persons with Disabilities” in Bethesda, Md., sponsored by the Department of Labor (DOL). The symposium provided information for federal agencies to facilitate employment opportunities for people with disabilities throughout the federal government. The ICDR workshop described the ICDR mission, subcommittees, recent accomplishments and membership. The goals were to inform participants about federally funded research in disability and rehabilitation and the ICDR itself, and to encourage involvement from agencies not currently represented on the ICDR.

Section 3: ICDR Research Activities

In order to meet its statutory obligation to identify, assess and coordinate federal disability research, the ICDR must ensure that federal representatives share relevant information in disability and rehabilitation research. The ICDR offers three ways to achieve this information sharing:

1. Summit meetings on topics developed by consensus of the ICDR;
2. Meetings sponsored by the subcommittees on topics of their choosing to support their goals, with reports back to the full ICDR; and
3. Cosponsorship of other interagency meetings not initiated by the ICDR.

ICDR Summit

Wheeled Mobility and Accessible Transportation Summit

The purpose of an ICDR summit is to identify gaps in current research and to recommend future disability research agendas to federal agencies conducting disability and rehabilitation research. The first summit took place on July 22, 2003, in Washington, D.C. as part of a week-long accessible transportation forum in commemoration of the 13th anniversary of the ADA.

The ICDR's "Wheeled Mobility and Accessible Transportation Summit" brought together researchers from universities throughout the country, individuals with disabilities, service providers and federal representatives. Researchers and providers gave presentations on their work in the fields of wheeled mobility designed specifically for transit; safe accessible paratransit; intelligent transportation systems (ITS); and universal design. Extensive debate and discussion among participants resulted in the development of priority issues and research needs in three main areas of wheeled mobility and transportation. The key issues and priorities are listed (in random order) for each area, using the wording agreed upon by the participants.

Wheeled Mobility Usage and Interface With the Environment

1. Power-assisted wheels for manual-style usage and other secondary conditions of power usage for people in transition as an intermediate style of power.
2. Evidence-based practice guidelines to inform reimbursement policy so that people can obtain wheelchairs and seating systems through third-party carriers that can best assist their activities of daily living without negatively impacting their medical condition, while still addressing the standards of clinical practice.
3. Use of the ICF framework and structure within research and clinical applications in all phases of wheelchair usage.

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4. Increased knowledge and understanding of smart wheelchairs with respect to how they identify environmental situations and interact with the setting.
 5. The impact of smart chairs on the mobility of people with a combination of physical, perceptual and cognitive disabilities.
 6. Development of advanced mathematical and computer modeling in rehabilitation to be used for design of controls, upper extremity use for manual propulsion, smart chair operation in different environments, virtual reality and environmental detectors.
 7. Lack of research funding for physical fitness for wheelchair users, including projects address this issue, such as:
 - a. The Robert Wood Johnson Foundation in Princeton, N.J. in collaboration with the Centers for Disease Control and Prevention (CDC) –Active Living by Design www.activelivingbydesign.org/ and
 - b. Increased coordination between the NIDRR and physical fitness programs, such as the President’s Council on Physical Fitness and Sports. (A resource guide is available at www.usc.edu/dept/gero/RRTConAging/paper1.html#anchor1, last accessed Dec. 19, 2003).
 8. Intervention studies that pertain to wheeled mobility and interface in the community with larger sampling and randomized clinical trials.
 9. Anthropometry of wheeled mobility devices through the Rehabilitation Engineering Research Center (RERC) on Universal Design at Buffalo, N.Y. and the U.S. Access Board, the government entity supporting this research, including coordination of resources across the government.
 10. Increased information and long-term studies to investigate the cause and prevention of secondary injuries as a result of assistive technology use, such as arm pain in individuals who propel manual wheelchairs.

Safe and Accessible Transportation in Private and Public Vehicles

1. A registry of wheelchair users willing to answer research questions in order to develop a population that facilitates research that complies with the Health Insurance Portability and Accountability Act’s (<http://aspe.hhs.gov/admsimp/pl104191.htm>, last accessed Dec. 19, 2004) privacy regulations; training of users, to become active participants in framing research questions and design (e.g., in the Fortune Project at (http://www.dinf.ne.jp/doc/english/Us_Eu/conf/tide98/94/buhler_christian.html, last accessed on Dec. 19, 2004),
2. Identification of crashes or incidents in a timely manner for in-depth investigations of people seated in wheelchairs; use of the FDA’s medical device

reporting system (MDRS) for notification of when adverse events occur; the creation of an MDRS-capture transport accident subset, specifically for a listing of accidents that involve the transport of people in wheelchairs.

3. Research on risk analysis for a better balance of risk and operational issues based on vehicle type and transportation mode.
4. Taking advantage of software and multifunction interfaces to support easy aftermarket modification; standards development for vehicle modification and software interfacing. (For example, hand controls for rental cars should be universal and able to be installed quickly and easily.)

Standards for Public Transportation

1. The establishment of reimbursement mechanisms to pay for wheelchairs that meet standards to serve as seats in a motor vehicle.
 2. Topical studies to identify means of reducing the incidence of injury, such as:
 - a. The Agency for Healthcare Research and Quality (AHRQ)'s study of quality of health care and cost,
 - b. Case studies of real-world incidents for manufacturers and providers,
 - c. Education of people in absence of federal requirements, and
 - d. Education of manufacturers' information derived from studies.
 3. Research of accident investigation data to identify successful safety features.
 4. Information on best practices in universal design (i.e., the process of creating products that are usable by people with the widest possible range of abilities, operating within the widest possible range of situations) in transportation.
 5. Research to determine whether standards should accommodate trends in larger-wheeled mobility devices, or if the devices should be designed to meet basic requirements for use on public transportation vehicles.
 6. Designing mobility devices for different uses and encouraging people to have more than one wheeled-mobility device.
 7. Labeling wheelchairs to indicate what standards they meet, so consumers would be informed of the implications.
 8. The design of equipment to fit the environment and accommodate tie-downs.
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Meetings Sponsored by ICDR Subcommittees

Interference to Hearing Technologies by Digital Wireless Telephones

■ *Sponsor: Interagency Subcommittee on Technology*

On Sept. 4, 2003, the IST sponsored a meeting on “Interference to Hearing Technologies by Digital Wireless Telephones” at Gallaudet University in Washington, D.C. The topic of concern was the lack of usability of digital cellular phones by both hearing aid users and cochlear implant wearers due to significant overriding screeching and pounding noises that are picked up by those hearing instruments, making speech totally unintelligible. These sounds were demonstrated effectively via computer simulations for the audience. Presentations by researchers, engineers and consumers included: (1) explanations of new technological developments and laboratory testing; (2) review of public policies that pertain to hearing aid compatibility; and (3) results of consumer experiences using recently designed phones for improved accessibility. An additional concern centered on technology transfer and outreach to users, academic instructors and health providers.

The speakers and participants were selected from the hearing aid and telecommunications industry (both handset manufacturers and wireless service providers); consumer advocacy groups; academic research centers; and federal agencies such as the Federal Communications Commission (FCC) and the FDA. This topic received considerable attention in the industry, and attracted internationally as well as U.S.-based technologists. The workshop was particularly pertinent to the industry as it occurred only one month after the FCC released its final “Report and Order,” requiring U.S. telecommunications handset manufacturers to design hearing aid-compatible telephones. [12]

Basis of the Interference Issue

Interference to hearing technology occurs in a number of ways. Understanding the dynamics of the problem requires the expertise of electronic engineers and hearing manufacturers, and the knowledge of how radio frequency waves affect hearing aids and magnetic loops used in assistive listening devices. When wireless telephones were first introduced in Europe, it was generally known that there was interference between wireless telephones and hearing aids. Generally, hearing aid users were not encouraged to utilize wireless telephones. To effectively address the interference problems with hearing technologies, design changes had to be made to hearing aids and assistive listening devices as well as on the cellular telephones, so that the interference issues could be resolved.

The trend toward less expensive telephones and the change from analog to digital phones, along with the growing use of cellular phones, intensified the interference problem. In many cases, newer phones did not perform as well as the telephones manufactured in the 1950s due to a weaker inductive field in the telephone receiver. There is now an effort underway across the telecommunications industry to transfer all analog phones to digital telephone technology. While there are a number of advantages to switching to digital technology, as it allows greater use of computer technology, the interference problems regarding the new digital telephone technology and hearing aid use need to be thoroughly addressed before complete transfer occurs.

Solving the Interference Problem

Two approaches exist to addressing interference issues. One is technology-based and the other is legal rights-based. To address these interference issues, the hearing aid and cellular telephone industries collaborated on a standard called the American National Standards Institute (ANSI) C63.19, which measures the electromagnetic emissions from wireless telephones and the immunity to interference in hearing aids. [13] From the legal perspective, legislation called the *Hearing Aid Compatibility Act of 1988* (HAC) required all wired telephones manufactured after 1989 to be compatible with hearing aids. [14] Initially, wireless telephones were exempted from the HAC Act. In 1995, a coalition called HEAR-IT NOW requested that this loophole be closed and that wireless telephones be compatible with hearing aid use. On July 10, 2003, the FCC voted to partially remove the exemption of wireless telephones from the HAC Act for the next several years.

Included in the government agencies that participated in this meeting was the U.S. Access Board, which has a special interest in this issue because of a provision in Section 508 of the Rehabilitation Act (for which the U.S. Access Board issued standards) that requires federal agencies to consider minimized interference to hearing instruments when procuring telecommunications products. The topic also was largely driven by Section 255 of the *Telecommunications Act* (for which the U.S. Access Board issued guidelines) that requires telecommunications manufacturers to make their products accessible when readily achievable. [15]

Conclusion

The state-of-the-art materials presented and the opportunity for exchange of information among key players were the elements that made this event a success. It was the goal of the IST to raise awareness about key findings and increase outreach efforts to stakeholders so that all interest groups would be informed and work together to find viable solutions to the interference problem. In keeping with the mission of the ICDR to receive input from individuals with disabilities or their representatives for future federal rehabilitation and disability research, this meeting provided much discussion and input into the future design of both digital wireless phones and hearing technologies.

ICF: Development of Clinical Measurement Tools

■ *Sponsor: Interagency Subcommittee on Medical Rehabilitation*

On Oct. 9, 2003, the ISMR sponsored a workshop on the “International Classification of Functioning, Disability and Health: Development of Clinical Measurement Tools.”

This workshop brought together federal partners, researchers and directors of scientific programs, clinicians, academicians, nongovernmental organizations and people with disabilities to discuss the role of the ICF in future research endeavors. The ICF, a new multipurpose classification system introduced by the World Health Organization in 2001, establishes a common language among countries, disciplines, populations and cultures to better understand health-related states and outcomes. The goal of the meeting was to determine how the ICF can be used more effectively as a classification system and in disability research through the

development of applicable clinical measurement tools. The participants developed the following recommendations:

1. Develop an inventory of the research being supported by federal agencies in the various domains of the ICF.
2. Conceptual models of disability are useful in guiding measurement research and federal agencies should encourage investigators who are developing measurement tools to be explicit about and reference the conceptual models they are using as well as define their variables.
3. There is relatively little current research in measuring participation and environment, and researchers should be encouraged to submit applications in those areas. Participation and environment are standard terms in the ICF. Participation means a person's involvement in a life situation. It represents the societal perspective of functioning. Environment means the physical world, buildings, sidewalks, and so forth.
4. There is a need for continuing dialogue about the progress being made in measurement, what tools might be shared, as well as the controversies that still exist. Federal agencies should hold a meeting on measurement and disability at least once a year.
5. To make sure the measurements are meaningful for people with disabilities, include the people who are the subject of the research in the process of developing the instrument and in establishing the validity of the instruments being used.

Best Practices for Surveying People With Disabilities

■ *Sponsor: Interagency Subcommittee on Disability Statistics*

During the reporting period of calendar year 2003, planning began for the conference on best practices for surveying people with disabilities, scheduled for April 19 and 20, 2004, in Washington, D.C.

Personal Assistance Services

■ *Sponsor: Interagency Subcommittee on the New Freedom Initiative*

During the reporting period of calendar year 2003, planning began for a groundbreaking summit entitled "Personal Assistance Services and Caregiving Across the Life Span: Forging a Disability and Aging Partnership to Build Capacity Through Research and Development." The meeting is scheduled for Feb. 2–3, 2004 and its objective will be to formulate an action plan that will guide development of a research agenda.

Cosponsored Interagency Meetings

The ICDR is able to provide modest support for travel of nonfederal participants to interagency meetings not initiated by the ICDR when the meeting topic is relevant to the disability and rehabilitation research coordination mission of the ICDR. This support generally promotes consumer involvement in federal research of concern to persons with disabilities. The ICDR provided support for three interagency meetings in 2003 as described below.

Drug-free Workforce Conference

The goal of the “Drug-Free Workforce Conference” was to support participants in providing comprehensive coordinated services concerning employee substance abuse. The conference organizers sought to identify strategies that can be adopted and also shared more widely to support broader systems change. Ultimately, better coordination will lead to better outcomes for employers and workers. The ICDR provided support for four advocates to attend this conference on July 10–11, 2003. The DOL led this effort with the support of the following federal partners:

- Office of National Drug Control Policy;
- Department of Education;
 - Rehabilitative Services Administration
 - National Institute on Disability and Rehabilitation Research
- Department of Health and Human Services;
 - Substance Abuse and Mental Health Services Administration
 - National Institute on Alcohol Abuse and Alcoholism
 - National Institute on Drug Abuse
 - Administration for Children and Families
- Department of Justice; and
 - National Institute of Justice
 - National Institute of Corrections
 - Bureau of Justice Assistance
- Small Business Administration (SBA).

Evidence-based Practice in Spina Bifida: Developing a Research Agenda

The Office of Rare Diseases at the National Institutes of Health (NIH) collaborates with institutes, centers and other offices at the NIH to stimulate rare disease research by cosponsoring scientific conferences where research is lagging or to take advantage of scientific opportunities. The outcomes of these 2003 conferences have included the establishment of research priorities, development of collaborative research protocols, criteria for diagnosing and monitoring rare diseases, specific discoveries, publications and new research endeavors. These conferences also have contributed to the exchange of ideas and information among basic and clinical investigators, voluntary patient support groups, the NIH staff and pharmaceutical industry representatives.

The output from this spina bifida conference, convened in response to a congressional recommendation, will lead to the establishment of a research agenda for the future. Fifty leading experts in spina bifida care and research presented papers at this specific meeting. The papers

summarized the evidence base for health and related care for people with spina bifida and drew conclusions about the evidence base for current practice and needs for additional research. Presenters at the meeting were experts in treating the many conditions that complicate this serious birth defect. The ICDR provided travel support for seven advocates to attend this meeting held May 8–10, 2003, sponsored by the:

- Centers for Disease Control and Prevention;
- Agency for Healthcare Research and Quality;
- Office of Rare Diseases, National Institutes of Health;
- National Institute of Child Health and Human Development, National Institutes of Health;
- Spina Bifida Association of America; and
- Spina Bifida Foundation.

Physical Disabilities Through the Lifespan

This conference focused attention on a set of frequently overlooked problems that have human and economic significance. The conference brought together scientists, policy makers and individuals with disabilities to discuss issues of mutual concern. The plenary sessions were designed to provide a common frame of reference for all participants on broad issues such as demographics of disabilities; the biological processes of aging that affect all individuals; and consumer participation in research and policy formation. Breakout sessions were constructed to address crosscutting issues that affect many disability groups, as well as issues specific to individual disability areas. The charge to each breakout session was to determine the questions that need to be answered to advance science and to inform public policy. The ICDR provided travel support for 16 nonfederal researchers to attend the meeting held July 21–22, 2003 in Bethesda, Md. Hosting organizations included the:

- Agency for Healthcare Research and Quality;
- American Academy of Physical Medicine and Rehabilitation;
- American Physical Therapy Association;
- Commission on Accreditation of Rehabilitation Facilities-Continuing Care Accreditation Commission;
- Centers for Disease Control and Prevention;
- National Center for Medical Rehabilitation Research, National Institute of Child Health and Human Development;
- National Eye Institute;
- National Institute on Aging;
- National Institute on Deafness and Other Communication Disorders;
- National Institute of Neurological Disorders and Stroke;
- National Institute of Nursing Research (NINR);
- Office of Disability, Aging and Long-Term Care Policy, Department of Health and Human Services;
- Office of Rare Diseases, National Institutes of Health;
- Rehabilitation Research and Development Service (RRDS), Department of Veterans Affairs; and
- Substance Abuse and Mental Health Services Administration.

Research Support Documents and Reports

The primary work of the ICDR involves planning and coordinating research efforts. In order to plan effective conferences and develop research recommendations, the ICDR requires current information on the status of disability and rehabilitation research and related events. The research support documents and reports developed by the ICDR provide the necessary background information for the ICDR decision-making, research coordination activities and dissemination. These research support documents and reports are prepared for the internal use of the ICDR; in some cases, selected documents and reports are cleared for public release.

Federal Statutory Definitions of Disability

This internal document to be cleared for public release is a collection of federal statutory definitions of disability as contained in the United States Code. [9] It is an update of the February 1995 report prepared by Conwal, Inc. for NIDRR, Department of Education. This useful reference document is posted on the ICDR's Web site (www.icdr.us/documents/definitions.htm, last accessed on Dec. 19, 2003).

Compendium of Federally Funded Research on Assistive Technology

This document was prepared to assist the ICDR in its mandate under the NFI. It identifies current research programs related to AT. The compendium organizes research programs by agency, includes currently funded research projects, and cross-references research projects by subject area.

Resource Documents

The following internal documents have been produced in response to the ICDR and subcommittee requests for additional information to assist their deliberations.

- Agency peer review procedures and implications for collaboration compiled in support of the ISMR;
- A chart cross-referencing the International Organization for Standardizations' 9999 and the National Library of Medicine's Medical Subject Headings compiled for the ISMR;
- A compilation of current government and privately sponsored research in smart house technology compiled in support of the IST;
- Federal technology transfer resources compiled in support of the ISTT;
- Listing of databases that contain federal government research projects compiled in support of the ICDR;
- Current research on school-based rehabilitation compiled in support of the ISMR;
- Resources for spinal cord injury (SCI) research compiled in support of the ISMR;

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- Listing of current interagency working groups compiled for the ICDR from an Internet review of federal interagency working groups and committees;
 - Current research on personal assistance services compiled in support of the ISNFI;
 - Current research on employment of persons with disabilities compiled in support of the ISNFI;
 - Review of indirect costs incurred in providing reasonable accommodations in connection with federal research grants for the ICDR; and
 - Listing of congressional committees with oversight for the ICDR agency activities.

Section 4: ICDR Consumer Input Activities

In his New Freedom Initiative, President Bush stated that the administration would provide new funding to the ICDR so that it could prioritize the immediate assistive and universally designed technology needs in the disability community, as well as foster collaborative projects between the federal laboratories and the private sector. To begin its NFI activities, the ICDR decided to identify gaps in research and obtain input on technology research. Specifically, the ICDR sought grass-roots level input on a future research agenda on technology that would improve the employment, independence and community integration of individuals with disabilities. This is fully consistent with the ICDR's statutory mission. The ICDR is obtaining input from people with disabilities in three categories using distinct but coordinated methods, as summarized in the table below.

ICDR Consumer Input Activities	
Constituent Group	Method for Obtaining Information
Individuals who represent advocacy organizations or who have a track record of advocacy on technology issues for individuals with disabilities.	Stakeholder meeting on AT.
Individuals who would be likely to complete a survey over the Internet, such as members of disability advocacy groups.	<ul style="list-style-type: none">▪ Invitation to submit comments on the ICDR Web site; and▪ Web survey through the ICDR Web site.
People with disabilities who: do not generally provide input to government officials or policy makers, may not receive traditional disability services, may be considered an underserved disability group, or may not view themselves as part of a disability constituency.	Regional focus group meetings arranged through community organizations.

Stakeholder Meeting on Assistive Technology

This meeting was held June 26, 2003, in Washington, D.C. Representatives from 23 professional and service organizations offered their advice on AT research needs. A panel presented considerations in prioritizing research needs. As the keynote speaker, Kathie Olsen from the Office of Science and Technology Policy (OSTP) spoke on "The Federal Research System: Setting Priorities."

After the formal presentations, the attendees formed small breakout groups to develop consensus recommendations for the ICDR. The ICDR members participated in the small groups to facilitate the process.

Several recurring themes were apparent from the consumers making the recommendations. These themes and their explanations are as follows:

Technology Interfaces

At one end of this research spectrum are multiple recommendations for making AT more user-friendly; at the other end of this spectrum are recommendations for research on the specific design of computer interfaces for specialized disability conditions. Also included in this theme is the recommendation that research is needed to adapt all technology to become more universal in design, that is, useable by many persons, whether disabled or nondisabled, literate or nonliterate, and old or young. Several groups articulated the need to address language and cultural differences among disabled people that may impede awareness and access to AT solutions.

AT Environments

Recommendations in this research area focus on the effect of AT not only on its consumer, but the consumer's environment. Conversely, the participants recommended research on the effect of a consumer's environment on AT. This type of research is particularly important in education technology, but has applications for all areas of AT design. Medical settings are important labs for this type of research because of the controllability of variables.

Cost Benefits and Cross-Benefits of AT

More data on the cost-benefits of AT is needed to ensure continuation of AT research and to provide evidence of better insurance coverage of AT. Careful and systematic cost-benefit analysis would not only prove (or disprove) the value of research in AT, but would also assist in making AT in certain situations more efficient and effective. Likewise, cross-benefit studies of AT could suggest to consumers and developers fruitful directions for pursuing technology ideas based on previous technology development. It could also show where technology developed for one population or disability type could be utilized efficiently for consumers with other disabilities. An underlying concern of the consumers who are proponents of these studies is that data from such studies are basic to policy arguments in funding technology research.

Long-term Population Studies

There is a great need to see the effects of long-term AT use (and discontinuance) on consumers. Such studies would also give data about evidence-based practices, the effect of various professions and personnel on AT use, and how consumers find information about and obtain AT devices. Such studies also would have the advantage of focusing on geographically and ethnically diverse populations to ascertain differences in access, needs and use of AT.

Research Infrastructure Improvement

Besides recommendations for research topics, there were many recommendations for improving the structure of research in government.

1. The **dissemination** of research findings is currently a critical problem. Only a few consumers know of the availability of AT, and finding their way through the maze of information to find correct AT, being able to afford it, knowing how to use it, and maintaining it is daunting. Therefore, even fewer consumers know about current research in AT that may offer promise for the future or provides opportunity for participation in development. Recommendations ranged from making dissemination of information on activities and results mandatory to establishing more clearinghouses to make useful data more available.
2. The process of priority setting, peer review, award monitoring and dissemination needs **coordination and collaboration**. The ICDR is charged with this and needs more capacity to not only assist its own members with research coordination, but to liaison with the OSTP and other research oversight committees to develop a recognized role for AT research in the U.S. research program.
3. There is great need for **education and training** to accompany any plans for AT research. Not only should there be capacity building of AT researchers, service delivery personnel as well as consumers should be trained in the practical aspects of AT use.

Consumer Focus Groups

Regional focus groups were held between April 30 and Aug. 2, 2003, in different parts of the country to solicit input from constituencies normally not consulted (i.e., those not involved in public policy and formal advocacy). Focus groups are part of a larger effort to solicit consumer input that includes the ICDR Web site and an AT Web survey for individuals who have computer access. The information from these sources will be used to develop recommendations for future research needs.

The focus groups include seven to ten individuals who informally discuss a topic with a trained moderator. The plan is to conduct 12 focus groups each year for three years. This project sought to obtain grass-roots level input from consumers with a variety of disabilities and demographic characteristics on their use of AT and adaptive equipment, as well as their use of equipment and technology designed for the general public. We asked participants to describe problems with the technology they use and to suggest areas for improvement. The purpose of the focus groups is not to have consumers develop research recommendations but rather from the descriptions of problems consumers are experiencing with AT, it is possible to translate those comments into issues that research can address.

In 2003, 12 focus groups were completed with 110 participants who had a wide range of disabilities and included some who had multiple disabilities. The focus groups involved veterans; Hispanics; people with asthma and other breathing disorders; students with sensory disabilities; people with psychiatric disabilities; and caregivers. The focus groups were held in these cities: Arlington and Denton, Texas; Boise, Idaho; Boston; New York; Decatur, Ga.; Miami; and Arlington, Va. One focus group was held via teleconference with people from around the country.

Findings

The major themes across all groups are summarized below.

Lack of Information

A striking finding of the focus groups is the lack of information among participants about AT, including both high- and low-tech equipment. In every group, a participant would mention the need for a particular item, only to be told by another group member where the item could be obtained. Based on these comments, the ICDR should explore methods to increase public awareness of existing resources for identifying and locating AT. Federal and state governments currently fund organizations that provide technology information and referral and equipment information and referral, including some of the state partnership projects funded under the Assistive Technology Act and the ABLEDATA database, which provides assistance with identifying and locating technology via the World Wide Web and telephone inquiries. However, these resources are not reaching certain segments of the community as evidenced by the fact that the focus group participants were largely unaware of these resources. It was agreed that marketing activities should include outreach to consumers, disability organizations, state and local governmental agencies, caregivers and their organizations, senior citizens and their organizations, and medical and human services professionals.

Importance of Low-tech Equipment

Somewhat surprising was the importance of simple, low-tech equipment in the lives of focus group members. Although computers and computer technologies are playing an increasingly important role in participants' lives, the significance of simple items such as reachers should not be overlooked. Participants claimed that the ICDR should insure that funding for the development of low-tech items continues to be a priority and that the research it funds results in equipment or technology which is readily affordable for consumers.

Affordability

The high cost of adaptive equipment and technology and the lack of insurance coverage for needed equipment came up frequently in our focus groups. Participants expressed frustration that although the equipment they needed to live more independently was available, it was unattainable due to the high cost. Part of this problem relates to the relatively small market for many of the products participants need. Another significant problem is the lack of insurance coverage, both public and private, for costly items. Still, a third problem is that public and private insurance will cover only the least costly alternative (e.g., heavier wheelchairs rather than the more modern light-weight chairs, or mechanical rather than electronic lifts). The ICDR

should investigate cost-effective policy alternatives that would enable individuals with disabilities to obtain the technology they need through public and private insurance.

Research Priorities

Participants had a number of suggestions for research for product enhancement and development. Some of their suggestions are listed below:

- Smart homes that would enable the dweller to regulate household appliances such as lights, heating, stoves and alarms automatically or by computer or remote control;
- A transfer device that would enable the assistant to transfer the consumer more easily than with a Hoyer lift, but would not require the installation of a ceiling track;
- A more efficient mechanism to get oxygen into the lungs of an individual with breathing problems;
- Nebulizers and oxygen machines that are less complex to hook up and use;
- A device that would assist a blind person to walk in a straight line;
- A more portable and less expensive global positioning system accessible to blind people;
- Hearing aid research and development to address multiple factors, such as hearing aids for nerve damage, hearing aids that are completely inside the ear, and hearing aids that are easier for people with arthritis or dexterity problems to use;
- Cellular telephones with audio output and larger screens;
- A portable computer device that would enable communication between a deaf and a hearing person;
- Augmentative communication devices that can be readily connected to a computer and that are appropriate for individuals at a wide variety of intellectual and developmental levels;
- A portable device that would convert text into speech or Braille;
- A scientific calculator that can be used by blind and low-vision students and by students with dexterity problems; and
- Screen reader and voice recognition software that is more reliable, more efficient and easier to use.

Web Site Comment Form

One of the purposes of the ICDR Web site is to provide a place where the public can comment on research needs related to disability and rehabilitation. Since the Web site was established (Feb. 24, 2003) through Dec. 31, 2003, the site has received 2,868 comments from 942 respondents and continues to receive comments on a daily basis. The ICDR has analyzed the comments received through the end of June 2003.

As with the focus groups, the purpose of the comment form was not to have consumers develop research recommendations. Rather, from their comments, the ICDR constructed a coding scheme

to sort the data into smaller aggregates to summarize. The coding scheme includes future directions for research in the areas of the various disability groups, cross-cutting research issues, policy issues, service delivery issues, transportation issues and other nonresearch issues. Below is a summary of data in each of the five major Web site categories that pertain to research issues: technology, education, employment, health care and community living. As expected when soliciting public comments on the topic of disabilities, only about 26 percent of comments were about research issues. The remainder of the comments concerned service delivery, benefits and medical care issues.

Technology

There were 39 comments during this time period pertaining to research and technology. The majority of comments related to hearing impairment and technology issues. The majority of these comments called for research to improve existing technologies, including assistive listening devices, cochlear implants, transducer hearing aids, telephone and cellular phone technologies, speech-to-text software, microphones and public address systems. Among the issues that cut across disabilities, the majority of comments related to computer technology research.

Another cross-cutting area of concern was the low utilization of existing and available technologies for people with disabilities. One respondent remarked, "In addition to technology, in particular AT, we as researchers need to pay attention to issues associated with choice and use of AT by consumers. Many persons with SCI choose not to use the AT recommended based on their own personal concerns. As professionals, we need to pay closer attention to consumer needs in this respect and make sure they are part of our recommendations for use. More research needs to be done."

Another reoccurring theme was the importance of disseminating pertinent information to the public. One respondent remarked, "Research on the effectiveness of implementing Section 508 requirements for accessibility of electronic information technology needs to be made available to the public." Another stated, "There is a national telephone service for people with speech disability mandated by the FCC. Unfortunately, no effort has been made to educate the speech disabled population as to the availability of the service. A research effort is needed to determine the most effective way to inform and train consumers to use the service."

There were also a number of calls for efficacy and outcome studies. Areas of interest included research on the efficacy of using amplified classrooms to reduce both vocal strain on teachers but also assist those students with attention and hearing loss, research that would establish a relationship between the use of AT and educational benefits, and research on the efficacy of hearing assistance technology.

In addition, there were calls for research on AT for disability groups that are often overlooked in terms of their needs in this area (e.g., those with learning disabilities, psychiatric disabilities and autism). One respondent stated, "We need more research that focuses on access to technology among people with psychiatric disabilities. Most access studies concentrate only on access issues for people with communication and sensory disabilities, and yet, people with mental illnesses

have very limited access to information technology that is not acknowledged and is poorly understood.”

Education

There were 64 comments pertaining to research and education. The majority of comments called for more research in educational strategies for various disability groups. The second largest area of interest within education was a call for research on students transitioning from high school or college into employment. One respondent suggested that a Rehabilitation Research and Training Center (RRTC) be dedicated to this topic. Several individuals raised concern that the recent federal interpretation of research-based evidence as consisting of only randomized, experimental design studies is limiting.

A number of respondents called for the collection of data. This included information regarding the matriculation of students with disabilities in two- and four-year colleges; the numbers of students with disabilities transitioning into employment; numbers regarding types of employment; numbers regarding supports in school; and numbers of adults in the transition process. One respondent inquired as to the feasibility of collecting data on the number of educators and student teachers with disabilities in schools today, by state as well as by number of support networks and mentoring programs.

Another respondent suggested the development of “documentation processes that would create data sets for the study of children, with regard to early intervention and school-based services” to allow for later determination of outcomes and integration into the community.

Employment

There were 28 comments during this 2003 time period pertaining to research and employment. The majority of comments called for research in employment for various disability groups including individuals with depressive disorder, psychiatric disability, autism, hearing loss, mental retardation and developmental disability, narcolepsy as well as Native Americans and Alaskan Natives with disabilities and the caregivers for all the groups listed.

The second largest area of interest was research into best practices. One respondent suggested exploring the effectiveness of customized employment and one-stop centers. Another suggested exploring why most federal and state programs do not fund best practice programs. There were a number of calls for research into employment barriers, in particular with regard to: transportation issues, professionals with disabilities, and policy and program barriers for people with psychiatric disabilities. Respondents also suggested that studies were needed on the transition to employment from secondary and post-secondary education in order to improve employment outcomes.

Community Life

There were 15 comments during this 2003 time period pertaining to research and community life. The majority called for research in the area of community integration. One respondent suggested exploring how family, class and cultural variables affect the values people hold concerning inclusion. Another stated, “Strategies to make ‘community living’ mean inclusion rather than mere residence need to be developed and disseminated. Application of community organization and education techniques can reduce the fear of individuals with cognitive disabilities. Emphasis should be given to culturally appropriate strategies.”

Health Care

There were 77 comments during this 2003 time period pertaining to research and health care. The majority of comments called for the funding of further medical research or for finding cures for specific types of disability. There were calls for further medical research in the following areas: hearing loss, cystic fibrosis, multiple sclerosis, SCI, blindness, brain injury, stroke recovery, autism, cerebral palsy, psychiatric disability, developmental disability, fibromyalgia, thoracic outlet syndrome, obstetrical brachial plexus injury, osteogenesis imperfecta, developmental disabilities, the effects of aging, the long-term use of psychotropic drugs and stem cell research.

The next most salient theme was that of the need for research into policy and program barriers to quality health care. Respondents suggested research into such areas as systemic problems with health care coverage including Medicaid, Medicare and private insurance; the lack of coordination of care among providers; the lack of doctors willing to take Medicaid; systemic problems with managed care; access to treatment for chemical dependency; access to treatment for specialized care and multiple disabilities; how to best promote prevention and improve personal health; the denial of coverage for durable medical equipment; and the lack of early diagnosis of children with autism, Asperger’s syndrome and Tourette’s syndrome.

The final major area of interest was research into psychiatric disability and access to health care and mental health care. Research questions included how to develop liaisons between service providers, how to improve access to mental health care for ethnic minorities with psychiatric disabilities, and how to improve access and treatment for individuals with psychiatric disabilities who are chemically dependent. Other respondents suggested the need for research into recovery from psychiatric disability.

Section 5: ICDR Member Interagency Activities

Many ICDR member agencies sponsor interagency disability research activities. While these events are not the ICDR activities per se, they do support the mission of the ICDR and are briefly summarized below.

Working Groups

Employment Rate Measurement Methodology Work Group

Chaired by a DOL, Bureau of Labor Statistics representative, this group is developing a set of questions that will accurately and reliably determine the employment rate of people with disabilities in future releases of the monthly Current Population Survey (CPS). The CPS is the basis of the U.S. unemployment rate and other official statistics. This information will not only provide the DOL Office of Disability Employment Policy (ODEP) and other state and federal agencies with more accurate data on the number of people with disabilities and their employment rate, but it will also be used to analyze other types of data on the disability population in the United States. Thus far, the National Institute of Mental Health (NIMH) has provided technical support for cognitive tests, field tests and the design and implementation of the Delphi procedures in support of the development of disability survey questions. In addition, the survey questions to be tested were incorporated into the National Comorbidity Survey (NCS). More information about the NCS is at www.hcp.med.harvard.edu/ncs/index.php (last accessed on Dec. 19, 2003). The baseline NCS, fielded from the fall of 1990 to the spring of 1992, was the first nationally representative mental health survey in the United States to use a fully structured research diagnostic interview to assess the prevalence and correlates of Diagnostic and Statistical Manual of Mental Health Disorders, Third Edition, Revised (DSM-III-R) disorders. Interagency participants include the: U.S. Access Board, Department of Commerce, Department of Defense (DOD), Department of Education, Department of Justice (DOJ), DOL, Department of Transportation (DOT), Equal Employment Opportunity Commission (EEOC), NIH, Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services (HHS), Social Security Administration (SSA), and Substance Abuse and Mental Health Services Administration (SAMHSA).

Interagency Working Group on Long-Term Care Data Development and Research Planning

This work group, established in 2001, meets periodically to share progress in long-term care research and data development activities, and to facilitate collaborations between agencies. Long-term care services are defined by the group to include home care, personal assistance services and assistive technologies, services to promote education for children with special needs, services to foster employment for the disabled and rehabilitation services, among others. Led by the AHRQ under the auspices of the HHS Data Council, member agencies include the National Center for Health Statistics (NCHS), the Centers for Medicare & Medicaid Services (CMS), the HHS ASPE, the National Institute on Aging, the Administration on Aging (AOA) and the NINR.

Muscular Dystrophy Coordinating Committee

The Muscular Dystrophy Community Assistance, Research and Education (MD-CARE) Amendments of 2001 [16] mandated the establishment of the Muscular Dystrophy Coordinating Committee (MDCC) to coordinate activities across the NIH and with other federal health programs and activities relevant to the various forms of muscular dystrophy. The MD-CARE Act directs the committee to develop a plan for conducting and supporting research and education on muscular dystrophy through the national research institutes, and to submit this plan to Congress within the first year of the establishment of the MDCC. This plan will encompass a wide range of issues including rehabilitation issues. At the first meeting of the MDCC on July 1, 2003, committee members each presented an overview of their organization's programs and/or personal interests in muscular dystrophy, and discussed a strategy for developing the muscular dystrophy research plan. Development of a plan by a working group of the MDCC began in the calendar year 2003 reporting period and will have to be approved by the full MDCC before it is submitted to Congress in the summer of 2004. Interagency participants include the: Administration for Children and Families (ACF), CDC, CMS, congressionally directed medical research programs, U.S. Army Research and Materiel Command, DOD, FDA, Health Resources and Services Administration (HRSA), NIH, and Office of Special Education and Rehabilitative Services of the Department of Education (OSERS).

Transportation Work Group

The HHS Office on Disability (OD) is cofacilitating the Transportation Work Group, with the Federal Transit Administration (FTA) and the HHS Office on Intergovernmental Affairs, to address barriers for persons with disabilities. Work group participants represent the HHS service-based agencies. The work group is addressing coordination of current funding and developing plans to evaluate the impact of this cross-agency planning approach.

Interagency Working Group on Assistive Technology Mobility Devices

An executive memorandum establishing the IWG on ATMDs was issued from the White House to the secretary of education on Feb. 12, 2003. [3] It required an IWG to look at programs and services related toward access to and provision of mobility devices (wheelchairs and scooters). OSERS at the Department of Education was designated to take the lead on this effort. Other member agencies include the: HHS, DOL, SSA, Department of Veterans Affairs (VA), Department of Commerce, DOD, DOT, Department of Housing and Urban Development (HUD), and National Council on Disability (NCD).

Joint Projects

2002 Implementing the Vision Forum and the 2000 Vision for the Decade Symposium

In the fall of 2003, the CDC and its collaborators published the reports and proceedings of the "2002 Implementing the Vision Forum" and the "2000 Vision for the Decade Symposium"

(www.cdc.gov/ncbddd/dh/hp2010.htm, last accessed on Dec. 19, 2003). The publication synthesizes interagency research and activities relating to disabilities, and it supports the *Healthy People 2010* agenda for improving the health of all Americans during this decade. Partner agencies for this effort include the Department of Education's OSERS NIDRR and the OD within the Office of the Secretary, HHS.

Aging With a Disability

The CDC has collaborated with the HHS on the NFI, which emphasizes caregiving across the lifespan of the disabled individual. In 2003, the CDC supported two conferences that addressed aging with a disability as well as addressing broad clinical and policy issues on the topic. Additional collaborators on aging issues have included the Rancho Los Amigos National Rehabilitation Center, Western Michigan University, Mississippi State University and the University of Heidelberg.

Arm Pain in Paraplegia

The VA Rehabilitation Research & Development (RR&D) centers and NIDRR are jointly supporting a series of longitudinal collaborative investigations of arm pain in paraplegia. Due to lower limb paralysis, veterans with SCI rely extensively on their upper limbs for mobility and activities of daily living. Thus, any loss of upper limb function significantly affects mobility and independence. This work is taking place at the RR&D Center of Excellence on Wheelchair and Related Technologies, located in Pittsburgh. Furthering previous work, they have discovered a causal relationship between propulsion biomechanics and the occurrence of injury. With an eye towards intervention, they have discovered propulsion techniques that may reduce the prevalence of arm injury.

CAHPS[®] for People With Mobility Impairments

CAHPS[®] (formerly the Consumer Assessment of Health Plans Study) has become an industry standard for obtaining and reporting consumers assessments of their care to help consumers identify the best health care plans and services for their needs. CAHPS[®] surveys are used by the Medicare program, more than 20 state-run Medicaid and State Children's Health Insurance Program agencies, employer groups and business coalitions, the Federal Employees Health Benefits Program, the DOD and a wide range of health plans. It is an ongoing collaborative effort whose goals are to: (1) develop and test questionnaires that assess health plans and services; (2) produce easily understandable reports for communicating survey information to consumers; and (3) evaluate the usefulness of these reports for consumers in selecting health care plans and services. A multiyear partnership among the AHRQ, NIDRR and the CDC to develop a CAHPS[®] to assess care experiences of people with mobility impairments, was initiated in 2002. The team first decided that, for the present, they would focus on Medicaid and Medicare as the primary users of this CAHPS[®] People with Mobility Impairments (PWMI) instrument. Their next decision was to define "people with mobility impairments" for the purposes of this study. During 2003, this CAHPS[®] project developed and cognitively tested a set of screener items to help define and identify the PWMI. In the current reporting period of calendar year 2003, the project planning began for these items to be added to the MassHealth Medicaid survey, which

will be fielded in 2004. These PWMI screener items will be matched to responses to other chronic disease questions from CAHPS[®] chronic disease instrument and International Classification of Diseases-9 codes for respondents. This match will further the knowledge about characteristics of people in terms of chronic conditions and diagnosis categories who respond positively to each screener item. After these analyses are completed, if funding is available, development and field-testing of items for the actual PWMI questionnaire will begin. For information see www.cahps-sun.org (last accessed on Dec. 19, 2003).

Development of a Retinal Prosthetic Device

This ongoing project, supported by the VA RR&D program and the National Science Foundation (NSF), looks at supporting the development and testing of a prototype prosthetic device for restoring useful vision to blind individuals who have retinal disease. Currently—age-related macular degeneration—a retinal disease affecting a significant number of veterans, is the target population for the device. The research is taking place at the RR&D Center of Excellence on Innovative Visual Rehabilitation located in Boston. The ultimate goal of this research group is to develop a retinal prosthetic device.

Early Hearing Detection and Intervention Program

The CDC has an Early Hearing Detection and Intervention Program that collaborates with the HRSA, the National Institute on Deafness and Other Communication Disorders (NIDCD) and the Department of Education to screen newborns for hearing loss and to provide appropriate interventions. The primary goal of the program is to ensure that children with hearing loss develop and reach their full learning potential. The program also conducts research on the cause of hearing loss and the best interventions that allow children to develop their learning potential. For more information on this program, go to: www.cdc.gov/ncbddd/ehdi/research.htm (last accessed on Dec. 19, 2003).

“Feet Can Last a Lifetime” Campaign

Led by the National Institute of Diabetes and Digestive and Kidney Diseases, the “Feet Can Last a Lifetime” foot care awareness campaign was produced by the National Diabetes Education Program, a partnership of the NIH, the CDC and over 200 other organizations. Current scientific findings estimate that comprehensive foot care programs can reduce amputation rates in diabetic patients by 45–85 percent. Thus, the campaign is aimed at increasing awareness among health care providers about the importance of affected persons maintaining a preventative foot care program. This includes assessing patients’ risk for developing foot problems; examining patients for onset of foot problems either yearly or at every visit, depending on the risk; and educating patients on ways that they can incorporate a foot care program into their daily lives. Because of the tremendous burden of amputation, vigilance by both health care providers and patients is critical for preventing diabetic foot problems. Interagency participants include the: NIH, CDC, CMS, HRSA, the Indian Health Service (IHS) and the Veterans Health Administration (VHA).

The First National Healthcare Quality Report

The HHS AHRQ was mandated by Congress to produce a national annual report on health care quality beginning in 2003. The First National Healthcare Quality Report (NHQR) will include a broad set of performance measures that will be used to monitor the nation's progress toward improved health care quality. [17] The AHRQ is coordinating this effort with other HHS agencies including the: NCHS, HHS ASPE, CDC, CMS and NIH. The National Academies' IOM provided a conceptual framework for the report that includes the category of "living with illness or disability" as a key area for the report. The NHQR measure set currently contains items relevant to quality of care for patients with disabilities. The first report was released in December 2003. Areas relevant to persons with disabilities include measures on home health, nursing home and mental health. For more information, visit www.qualitytools.ahrq.gov (last accessed on Dec. 19, 2003).

The First National Healthcare Disparities Report

The *Healthcare Research and Quality Act* charged the HHS AHRQ with submitting an annual report to Congress on "prevailing disparities in health care delivery as it relates to racial and socioeconomic factors in priority populations" (defined by the act to include individuals with disabilities). [18] A National Healthcare Disparities Report (NHDR) IWG was established that includes members from the: AOA, ACF, CDC, CMS, FDA, HRSA, IHS, NCHS, NIH, SAMHSA, Office of Civil Rights, Assistant Secretary for Health, Assistant Secretary for Legislation, ASPE and Assistant Secretary for Public Affairs.

The NHDR and the NHQR have been designed and planned as companion reports. To ensure uniformity, these two reports will use identical measures of quality of health care to the extent possible with available data. In addition to quality of health care, the NHDR also includes access to care, utilization and cost of services measures. The first report, released in December 2003, included measures of health care disparities for persons with special health needs including children with special health care needs, persons with disabilities, nursing home patients and persons who utilize home health care. The Web site is: www.qualitytools.ahrq.gov (last accessed on Dec. 19, 2003).

Hearing Aid Trial Follow-up Study

The NIDCD contributed support to the VA hearing aid trial. The study is a multicenter, clinical trial designed to compare the safety and efficacy of commonly used hearing aid circuits, including long-term follow-up. A main paper from this study will be documentation of long-term benefits of hearing aid use. A series of secondary papers is planned. Secondary papers may include speech perception research findings, defining "successful" hearing aid use, user satisfaction findings and documentation of long-term hearing aid performance. Presentations at professional meetings are also planned. A future hearing aid clinical trial, to address various aspects of technology and hearing aid circuitry features, is being considered.

Interagency Disability and Rehabilitation Research Initiative

In 2003, NIDRR established a memorandum of understanding with the Physical Disabilities Branch (PDB) of the Warren Grant Magnuson Clinical Center of the NIH. The purpose of this memorandum of understanding was to establish a framework for cooperation across the spectrum of disabilities research between NIDRR and the PDB. This entails the definition of an administrative process for the development, documentation, approval, support, execution and review of collaborative activities, including research projects and educational and consensus building initiatives involving NIDRR and the PDB. This may include: (1) assistance to NIDRR grantees funded through the peer review process. The PDB may collaborate with NIDRR grantees (similar to the regional network or center of excellence format) to: enhance research, technology transfer, educational activities and training initiatives of mutual interest, enhance capacity building activities in clinical rehabilitation research, and provide technical support in the development and use of methodologies and instrumentation for disability and rehabilitation research; (2) the conduits for and support of research projects that are necessary to provide a sound scientific foundation for NIDRR policy development, or other mission-relevant and time-critical issues that lead to the development of rapid, independent, goal-oriented information for the development of NIDRR policy and funding initiatives; and (3) support of NIDRR and the PDB jointly sponsored educational and consensus building initiatives such as conferences and seminars.

Interagency Spinal Cord Injury Coordination Effort

The agencies involved in the SCI coordination effort include the: VA, National Center for Medical Rehabilitation Research (NCMRR), National Institute of Neurological Disorders and Stroke (NINDS) and NIDRR. The primary objective is to organize a SCI multisite network, or system to look at SCI intervention, or therapies from acute to postacute to all chronic stages. The agency participants are considering bringing together researchers from their respective funded institutions to identify the most salient protocols before determining procedures for a multisite project that would combine financial, clinician, patient population and medical center resources. The next steps include: (1) issuing solicitations collectively or through individual agencies; (2) determining how to handle the review and peer review processes; and (3) specifying how to share financing, either with matching dollars or with each agency paying costs under their jurisdiction. Consideration also must be given to the proximity of medical centers to allow patients and clinicians to be located close to one another and to the VA medical centers, where a model system of care will be a guide.

Joint Meeting of the Diabetes Mellitus Interagency Coordinating Committee and the Skin Diseases Interagency Coordinating Committee

The Diabetes Mellitus Interagency Coordinating Committee and Skin Diseases Interagency Coordinating Committee convened a joint meeting to bring together leading researchers in the area of diabetic foot ulcers. Experts included epidemiologists examining incidence and prevalence, researchers designing clinical trials, and physicians treating diabetic foot ulcers on a daily basis. The researchers identified many areas that need to be addressed to improve prevention and treatment strategies for patients with this often chronic and debilitating condition that can result in amputation. Furthermore, members of both committees identified steps that the

agencies can take to propel progress in basic and clinical research in this field, as well as to educate patients and physicians about ways to prevent and treat diabetic foot ulcers. Interagency participants include the: NIH, CDC, FDA, IHS and VHA.

Mobility and Transportation Meetings

The DOT FTA held meetings to identify strategies of enhancing ridership on public transportation. Over 175 representatives of both the public and private sector attended. They are working with the NCD on ADA issues. In addition, regional dialogs were held to facilitate communication between the transportation and disability communities on enhancing accessible transportation. Meetings were held in Anchorage, Alaska; Los Angeles; Des Moines, Iowa; and Louisville, Ky.

National Health and Nutrition Examination Survey 1999–2004 and the National Health Interview Survey

The NIDCD contributed support to the NCHS to develop the hearing and balance component of the National Health and Nutrition Examinations Survey. In addition, the NIDCD helped support the development of, and data collection for, survey questions related to hearing for the National Health Interview Survey.

Nursing Home CAHPS[®]

The Nursing Home Consumer Assessment of Health Plans Study (NH-CAHPS[®]) project is jointly supported by the CMS and the AHRQ, and its purpose is to test and design a satisfaction questionnaire instrument for care provided to residents of nursing homes. During 2003, NH-CAHPS[®] researchers completed cognitive testing of a draft questionnaire with nursing home residents with varying levels of cognitive capacity to assess the relevance of different domains and items, and to see how well they could respond to alternate sets of response options. They have also prepared a preliminary assessment of sampling strategies for use in nursing homes to take into account facility size, residents' cognitive ability and length of stay, and recommendations for conducting a field test. The goal for work under CAHPS[®] II (the second phase of CAHPS[®]) will be to prepare a fully field-tested instrument, sampling strategy and data collection protocol for the resident survey, and to develop and field test a survey for family members of nursing home residents.

Rehabilitation Research and Training Centers in Mental Health

In 2003, NIDRR continued to fund four RRTCs in the area of psychiatric disability, long-term mental illness and serious emotional disturbance. These centers are cofunded with SAMHSA at the HHS. The four centers are:

- National Research and Training Center on Psychiatric Disability (University of Illinois at Chicago);
- RRTC for Children's Mental Health (University of South Florida);

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-
- RRTC to Improve Services for Children With Serious Emotional and Behavioral Disabilities and Their Families (Portland State University); and
 - RRTC in Rehabilitation of Persons With Long-Term Mental Illness (Boston University).

Research Partnership on Disability Employment Research

The Department of Education OSERS and DOL ODEP, signed a memorandum of understanding in 2003 to collaborate in developing a research partnership across the spectrum of disability employment research. ODEP and OSERS will work collaboratively to advance research in disability and rehabilitation including an ongoing exchange and dissemination of new knowledge gained from employment-related research, enhance research and training and to provide for capacity building activities in employment research, and to develop jointly sponsored educational and consensus-building initiatives.

Roundtable on Transition and Employment

The President's Committee for People with Intellectual Disabilities held a roundtable forum on transition and employment on Sept. 8–9, 2003 in Washington, D.C. The roundtable included experts in collaboration with other federal agencies focusing on transition to employment.

Survey of Assistive Technology Industry

Technology Assessment of the U.S. Assistive Technology Industry, cofunded by the Commerce Department, the Federal Laboratory Consortium and NIDRR, was published in February 2003 and is available at: www.icdr.us/atreportweb/index.htm (last accessed Dec. 19, 2003).

Telework Options for People With Significant Disabilities

ODEP has taken the lead on this congressionally mandated project to explore how federal agencies can use telework and telecommuting in innovative ways to support high quality employment for people with significant disabilities. This research will provide the federal government with the means to assess the extent to which training, technology and supportive mechanisms can facilitate various telework arrangements for people with significant disabilities. The project already has generated data on both the benefits and the challenges encountered in creating home-based telework or telecommuting options for people with significant disabilities. In 2003, three Washington, D.C. pilot locations were established: (1) the call center operations at the DOL; (2) the HHS CMS; and (3) the VA medical transcription services. The agencies will test telecommuting by allowing some workers to do this and also collect data.

Young Adult Initiative

Led by the HHS OD, initial planning was completed in the 2003 calendar year reporting period for a cross-agency and intergovernmental Young Adult Initiative, scheduled to begin implementation in 2004. The initiative will help states and local communities develop and implement infrastructure-based action plans to comprehensively address the health, human

services, employment, education, housing, public entitlements and transportation needs of young adults (ages 16 to 30 years) with disabilities. It will include two policy academies focused on planning and provision of ongoing technical assistance to help participating states implement action plans developed there. The HHS agency partners include the: ACF, Administration on Developmental Disabilities, AHRQ, CDC, CMS, HRSA, IHS, NIH, Office for Civil Rights and SAMHSA. Interagency partners include the: Department of Education, FTA, HUD, DOL and SSA.

Conferences

Adult Learning Disabilities

The National Institute for Literacy (NIFL) worked with OSERS, the Office of Vocational and Adult Education, the Policy and Programs Study Service (PPSS) and the National Institute for Child Health and Human Development (NICHD) to cosponsor a meeting in September 2003 to discuss the issue of learning disabilities in the adult population and to plan a research study to be conducted in the future.

Several researchers in the field of learning disabilities were participants, as were representatives from the HHS agencies, the DOL agencies, the SSA and legal staff from the Office for Civil Rights at the HHS. From state agencies, participants who are conducting research projects that involve adults with diagnosed learning disabilities attended. This was the first in a series of meetings that will be held to develop an appropriate methodology for a proposed study to determine the number in adult education classes who have learning disabilities.

Autism Summit Conference

The “Autism Summit Conference: Developing a National Agenda” was held on Nov.19–20, 2003, in Washington, D.C. The purpose of the meeting was to discuss the federal government’s role in biomedical research, early screening and diagnosis, and improving access to autism services. The goal of the meeting was to provide information to the public on federal activities relevant to autism, to provide an opportunity for the public to share information with federal agencies, and to initiate a series of activities to develop a national agenda for federal autism research activities. The biomedical research component of the conference provided an opportunity to engage in a public presentation of the autism research matrix. The autism screening and diagnosis component focused on review of existing screening instruments and discussion of current clinical practices. The conference session on autism services throughout the lifespan included discussions of integrating services provided by several different systems of providers.

The HHS and the Department of Education officially cosponsored the meeting. The conference planning committee included several federal and public members of the Interagency Autism Coordinating Committee. The committee’s chair is the director of the NIMH; therefore, the NIMH was largely responsible for organizing the meeting. Within the NIH, institutes that are members of the NIH-Autism Coordinating Committee also supported the meeting. This includes the NICHD, the NINDS, the NIDCD and the National Institute of Environmental Health

Sciences. Interagency participants include the: NIH, CDC, CMS, HRSA, Department of Education, and SAMHSA.

Department of Veterans Affairs and Department of Defense Conference on Prosthetics Research

With an increasing number of soldiers suffering limb loss due to combat in Iraq and Afghanistan, prosthetics researchers and clinicians from the VA and Walter Reed Army Medical Center (WRAMC) met on November 17 and 18, 2003, in Arlington, Va. to outline joint initiatives to further prosthetics research and improve care for military and veteran amputees. The conference, sponsored by the VA RRDS, also attended by industry and university experts, fostered discussion on several proposed projects now under consideration by the VA and the WRAMC, such as the development of a shared database on military and veteran amputees and rigorous clinical trials comparing high-tech artificial limbs to less costly conventional devices. This was the first such joint research conference on prosthetics between the two agencies.

One topic of discussion at the meeting was the much-publicized “C-Leg,” an artificial leg with a sophisticated microprocessor-controlled knee that costs around \$50,000 and is widely regarded as state-of-the-art.

The meeting also featured exchanges on the merits and drawbacks of computer-aided design and manufacture, widely accepted as the quickest, most cost-effective means of producing the sockets into which prosthetic legs are fitted.

Attendees also proposed an agenda to standardize the way clinicians and researchers measure functioning and outcomes for amputees, so data can be more easily shared among the VA and the DOD practitioners. The conference participants agreed on the need for more objective and consistent measures of gait—how a person walks—to determine how well lower limb components are performing. An additional area of consensus among the researchers, clinicians and engineers at the meeting was the need for lighter-weight and more versatile upper-extremity prostheses. Another central theme at the meeting was the importance of a team approach to prosthetics care with engineers working closely with clinicians to ensure that devices are designed to fit the needs of patients. Slide presentations and other materials from the meeting can be viewed on the VA RR&D Web site at: www.vard.org.

Emergency Preparedness for People With Disabilities: An Interagency Seminar of Exchange for Federal Managers

This conference (hosted by the DOL on Dec. 2–3, 2003, in Washington, D.C.) highlighted the importance of developing emergency preparedness plans in the federal workplace inclusive of the unique needs of its employees with disabilities. More than 200 federal managers and other personnel involved in emergency preparedness attended and shared information about specific issues in the development, implementation and maintenance of emergency preparedness plans for people with disabilities. Nationally and locally renowned experts provided information and facilitated an exchange of experiences between federal managers geared toward promoting

consistent and effective emergency preparedness practices that afford equal protection for people with disabilities.

Pathways to Work in the 21st Century: A UK-U.S. Seminar of Exchange

This international summit was cosponsored by ODEP and the United Kingdom's (UK) Department for Work and Pensions (in Washington, D.C. on May 1–2, 2003) and brought together representatives from the two countries in an exchange of ideas and information. The sessions were designed to allow members to compare and exchange information about effective strategies and practices for increasing employment opportunities for people with disabilities through an examination of the existing employment and disabilities systems in both countries. Approximately 75 experts, including disability advocates, government officials and employers representing a variety of critical perspectives from the United States and the UK attended the event.

Perspectives on Employment of People With Disabilities in the Federal Sector

This annual conference held Dec.10–12, 2003 was chaired by ODEP and cosponsored by six federal agencies (the Department of Agriculture, the DOD, the HHS, the Environmental Protection Agency, the EEOC and the NIH). The conference brought together 350 people including federal Equal Employment Opportunity officials and personnel representatives directly involved with issues that affect the employment of people with disabilities within the federal government. The 22 workshops included introductory sessions for those members who are new to working with federal employees with disabilities. Conference topics included: reasonable accommodations, mediation, technology and telework options. A panel created and staffed by the ICDR answered attendees' questions.

The NSF's disability-related research portfolio was described in a three-hour workshop at the conference. Four NSF program officers presented highlights of research supported in the areas of human-computer interaction, universal access, smart homes, robotics, AT devices (Braille readers), and research in disabilities education and undergraduate design projects. A special presentation about a high risk and high payoff research program to develop retina prostheses, neuromuscular prostheses and cortical prostheses was made by researcher James Weiland of the NSF-supported Engineering Research Center on Biomimetic Microelectronic Systems, Doheny Eye Institute, University of Southern California.

Physical Disabilities Through the Lifespan

With improvements in health care, developed nations face an unprecedented increase in the number of individuals living longer lives. At the same time, there is an increasing number of aging people with disabilities. To address the special problems that people with disabilities face as they age, the NICHD, in collaboration with other NIH institutes and centers, federal agencies, and nongovernmental organizations held a conference in July 2003 to discuss these issues. The conference goals were to: (1) understand the relationship between the aging process and its effect on disabilities; (2) identify effective strategies for coping with disabilities and maintaining productive lives; (3) set an agenda for integrating research and policy issues; and (4) provide policymakers with key information on aging with disabilities. The summary slides of the meeting

presentations are currently available on the NCMRR Web site at: www.nichd.nih.gov/about/ncmrr/disabilities/index.htm (last accessed Dec. 19, 2003). Interagency participants included the: NIH; AHRQ; CDC; ICDR; Department of Education; Office of Disability, Aging and Long-Term Care Policy at the HHS; RRDS at the VA; and SAMHSA.

Symposium on Homeownership for Persons With Disabilities

The HHS OD held the “Symposium on Homeownership for Persons With Disabilities” on Nov. 5, 2003, co-sponsored with HUD, Fannie Mae, the HHS CMS and the NIH, targeting national disability constituent organizations. The overall objective was to provide a roadmap to help all consumers understand how states, communities and local constituent organizations can advocate for homeownership. Best practices models were discussed. The symposium supported participation through both in-person and live Web cast capacity.

EU-U.S. International Conference on Aging, Disability and Independence

The NSF, the Engineering and Physical Sciences Research Council (in the UK) and the Information Society Directorate-General at the European Commission, supported the “Preparatory Workshop to the EU” (European Union) and the “U.S. International Conference on Aging, Disability, and Independence.” The preparatory workshop held June 26–27, 2003, at the Royal Academy of Engineering in London, had two specific objectives:

- Develop the smart home portion of the technical program for the high technology track of the international conference; and
- Identify strategies for future research and development.

Information from the preparatory workshop report was incorporated in the high technology track of the “International Conference on Aging, Disability and Independence” held December 4–6, 2003, in Washington, D.C. to address the needs of older persons with disabilities, and people aging with disabilities. The international conference focused on research, practice and policy in the areas outlined in the NFI. Recognizing the challenge faced by the aging of our population, the preparatory workshop and the EU-U.S. international conference brought together experts in technology, research, development and applications to document the state-of- the-science and to identify research needs in AT, e-health, e-homecare and smart home technologies. The Web site for the complete proceedings of the preparatory workshop is: <http://icadi.icta.ufl.edu/pre-icadi/> (last accessed on Dec. 19, 2003).

Section 6: ICDR Member Research Activities

This section summarizes key research activities undertaken by the individual ICDR member agencies. These activities are listed to make the other ICDR members aware of important activities and potentially foster increased interagency collaboration. This listing will also be of interest to the general public and the private sector.

Agency for Healthcare Research and Quality, Department of Health and Human Services

The National Guideline Clearinghouse™

The National Guideline Clearinghouse™ (NGC) is a public online resource for evidence-based clinical practice guidelines. The NGC was developed by the AHRQ in partnership with the American Medical Association and the American Association of Health Plans. The database is continually updated and includes over 100 guidelines either included or updated during 2003. Examples of 2003 guidelines relevant to persons with disabilities include: eye examination in infants, children and young adults by pediatricians; health supervision for children with Turner's syndrome; hearing assessment in infants and children: recommendations beyond neonatal screening; physician's roles in coordinating care of hospitalized children; prevention of medication errors in the pediatric inpatient setting; screening for dementia: recommendations and rationale (revised in 2003); and wheelchair biking for the treatment of depression. The Web site is located at: www.guideline.gov/resources/guideline_index.aspx (last accessed on Dec. 19, 2003).

New AHRQ Policy of Including Priority Populations in Research

The AHRQ's reauthorizing legislation, signed into law on Dec. 6, 1999, authorized the agency in carrying out its mission to conduct and support research and evaluations for priority populations, which include low income groups, minority groups, women, children, the elderly and individuals with special health care needs—including individuals with disabilities and individuals who need chronic care or end-of-life health care. On Feb. 28, 2003, the AHRQ announced its new policy on the inclusion of priority populations in research conducted and supported by the agency as of Oct. 1, 2003. The policy was published in the "NIH Guide for Grants and Contracts" (www.grants.nih.gov/grants/guide/notice-files/NOT-HS-03-010.html, last accessed on Dec. 19, 2003) and will be available on the AHRQ Web site along with a list of frequently asked questions.

Medical Expenditure Panel Survey Updates

The AHRQ addresses critical research and policy issues pertaining to the access, use and cost of health care. Of special concern are the agency's priority populations including persons with disabilities. The agency sponsors the Medical Expenditure Panel Survey (MEPS) among other activities, to monitor changes in access, use and expenditures for persons of all ages. The MEPS is designed to provide policy-makers, health care administrators, businesses and others with

timely, comprehensive information about health care use and costs in the United States, and to improve the accuracy of their economic projections. Moreover, the MEPS is the only national survey that provides a foundation for estimating the impact of changes in sources of payment and insurance coverage across all persons in the civilian noninstitutionalized population (regardless of age, disability status or program participation status). The MEPS design permits analysis at the family and person-level, comparing persons with disabilities and chronic conditions to those without disabilities and chronic conditions. In 1997, the MEPS oversampled persons with functional impairments and activity limitations. Oversampling is a statistical technique used to make sure there is a large enough sample from which to draw conclusions; it is used for low incidence populations. In 1997 and 1998, the household component of MEPS included the Long-Term Care (LTC) Supplement and a Caregiver Supplement. Responses to the LTC and Caregiver supplements were edited and released in 2003 as a MEPS public use file (1997 Supplemental Public Use File HC-042 and 1998 Long-Term Care Public Use File HC-049), which are available on the MEPS Web site (www.meps.ahrq.gov/, last accessed on Dec. 19, 2003). Analysts can link these data to other 1997 and 1998 public use files. Beginning in late 2002 and continuing through 2003, the AHRQ has been working on the development of new questions regarding coresiding caregivers for potential inclusion in the MEPS. The intent is to measure household members' time associated with providing personal care assistance and other help, to disabled members of the household. As an initial step, a literature search regarding survey questions related to informal care giving was completed in 2003. Also, beginning in late 2002 and continuing through 2003, the AHRQ has been analyzing different ways of oversampling disabled persons in the MEPS.

Evidence-based Practice Centers

The AHRQ awarded new contracts to 13 evidence-based practice centers in June 2002. The contract mission is to promote evidence-based practice in everyday health care by facilitating the translation of evidence-based research findings into practice. Recent evidence reports awarded or published include: *Multiple Sclerosis: Criteria to Determine Disability*; *Sexuality and Reproductive Health Following Spinal Cord Injury*; and *Occupational Asthma, Burden of Illness/Economic Consequences*. Copies of the reports and additional details are available at: www.ahrq.gov/clinic/epc (last accessed on Dec. 19, 2003).

AHRQ's Technology Assessment Program

The AHRQ's Technology Assessment Program provides technology assessments (TAs) for the CMS; these are used as the basis of the CMS coverage decisions for the Medicare program. TAs may be done in-house by the AHRQ staff, or they may be done in collaboration with one of the AHRQ's evidence-based practice centers. Examples of 2003 TAs include "Acupuncture for Fibromyalgia," [19] "Screening Immunoassay Fecal Occult Blood Testing" [20] and "Electrical Bioimpedance for Cardiac Output Monitoring." [21] During 2003, the AHRQ's TA program began working with the CMS staff on plans to conduct background analysis and hold a working conference that would address key issues related to the coverage of telemedicine services within the Medicare program. The TA Web site is: www.ahrq.gov/clinic/techix.htm (last accessed on Dec. 19, 2003).

National Quality Measures Clearinghouse™

The National Quality Measures Clearinghouse™ (NQMC), sponsored by the AHRQ, is a database and Web site for information on specific evidence-based health care quality measures and measure data sets. The NQMC is sponsored by the AHRQ to promote widespread access to quality measures by the health care community and other interested individuals. Users can search the NQMC for measures that target a particular disease or condition, treatment or intervention, age range, gender, vulnerable population, setting of care, or contributing organization. Factors specific to persons with disabilities and rehabilitation include measures on physical function, mental illness, rehabilitation outcomes and home health care. For additional information, see the Web site at: www.qualitymeasures.ahrq.gov/ (last accessed Dec. 19, 2003).

Child Health Care Toolbox

The AHRQ-developed Web-based Child Health Care Toolbox provides concepts, tips and tools for evaluating the quality of health care in Medicaid, the State Children's Health Insurance Program, Title V and other health-care service programs for children. The toolbox is designed to be especially useful to busy state policymakers and others concerned about the quality of care. The toolbox contains links to tools for identifying children with special health care needs and for measuring the quality of their health care. For more information see: www.ahrq.gov/chttoolbx/ (last accessed on Dec. 19, 2003).

AHRQ-funded Extramural Research

In addition to the projects already mentioned, the AHRQ regularly funds extramural research projects. These projects focus on the themes of improving: health care outcomes, health care quality, patient safety, access, use, and expenditures and information available to consumers and decision makers. Examples of major funding initiatives and other grant examples are given below.

Translating Research Into Practice Initiative

As part of the AHRQ's strategic goal to improve health care quality, the Translating Research Into Practice initiative is generating new knowledge about approaches that promote the utilization of rigorously derived evidence to improve patient care. The agency's goal is to enhance the use of research findings, tools and scientific information that would work in diverse practice settings, among diverse populations and under diverse payment systems. Examples of grants that are ongoing or funded in 2003 with particular importance to persons with disabilities are: "Developing an Asthma Management Model for Head Start," "A Model for Use of the Urinary Incontinence Guideline in U.S. Nursing Homes," "Improving Pain Management in Nursing Homes" and "Optimizing Antibiotic Use in Nursing Homes."

Partnerships for Quality

This AHRQ initiative is a coordinated set of projects, that develop partnerships among researchers, health plans, medical and nursing facilities and services, employers, consumer groups, and professional societies to test prototype activities aimed at accelerating the health system's adoption of research findings that have been shown to improve quality of care for patients. Projects of particular relevance to persons with disabilities include: implementing

quality improvement strategies in long-term care facilities; testing learning collaborative for quality improvement in home health care settings; and improving care for children with attention-defecit/hyperactivity disorder (ADHD).

Patient Safety

The AHRQ's reauthorizing legislation, signed into law on Dec. 6, 1999, gave the agency the mission of establishing a comprehensive Patient Safety Initiative. The AHRQ conducts and supports research and builds private-public partnerships to: identify the causes of preventable health care errors and patient injury in health care delivery; develop, demonstrate and evaluate strategies for reducing errors and improving patient safety; and disseminate such effective strategies throughout the health care industry. The AHRQ's safety research portfolio addresses questions such as when, how and under what circumstances errors occur; how to develop the tools, data and training to answer future questions; how to work with public and private partners to apply evidence-based approaches to the improvement of patient safety; and how to monitor and evaluate threats to patient safety. Areas of disability-related patient-safety activities include:

- Working conditions: Several projects examine the effect of working conditions on health care workers' ability to provide safe, high-quality care in ambulatory, inpatient (both hospital and LTC institutions) and in-home care settings;
- Reducing errors in LTC: Several projects evaluate the effects of clinical information systems on reducing errors and predicting risks of adverse outcomes for patients in nursing home and home health care;
- Potentially inappropriate medications: A number of studies assess the prevalence of, and risk factors for, potentially inappropriate drugs for the elderly living in the community and in LTC settings;
- The Falls Management Program: This is a quality improvement program designed to help staff in nursing facilities reduce falls and related injuries, and is based on interventions previously tested in LTC facilities;
- Hospital-acquired incontinence: This study estimates the incidence of, and identifies risk factors for, hospital-acquired incontinence in female elderly hip fracture patients; and
- Use of handheld technology to reduce errors in ADHD care.

Other Relevant Grants Funded by the AHRQ

Additional subjects of grants related to disability include: persons with disabilities: quality of care or service use; comprehensive outcomes of frail elders in the community; program of collaborative care for Alzheimer's disease; study of functional outcome after trauma in adolescence; persistent poor quality in nursing homes; and violence and SCI: understanding the rehabilitation context. For additional information on the grants listed above and other AHRQ grants, see the online grants database at: www.gold.ahrq.gov/ (last accessed on Dec. 19, 2003).

AHRQ Workshops for State and Local Policymakers

The AHRQ's User Liaison Program disseminates health services research findings for state and local health policymakers in easily understandable and usable formats through interactive workshops, teleconferences, distance learning programs and research syntheses (www.ahrq.gov/news/ulpix.htm, last accessed on Dec. 19, 2003). Recent national workshops and audio conferences related to disability have included:

- "Improving Care in Nursing Homes and Chronic Illness," cosponsored with the American Health Quality Association "Annual Technical Conference," Feb. 5–7, 2003;
- "Health Workforce Shortages: Quality Concerns and Policy Options" (Web-assisted audio conference), included session on "Caregivers and Quality in Long-Term Care," April 30, 2003;
- "Improving Long-Term Care for American Indians in Region VIII," Bismarck, N.D., July 21–23, 2003;
- "Making a Difference in America: Creating Caring Communities," cosponsored by the AHRQ and the AOA, Sept. 21–23, 2003; and
- "Monitoring the Health Care Safety Net Audio Conference," cosponsored and funded by the HRSA, Sept. 23–25, 2003.

Centers for Disease Control and Prevention, Department of Health and Human Services

Health Policy

In *Healthy People 2010*, chapter six (i.e., "Disability and Secondary Conditions in the Nation's Health Agenda") specifically targets people with disabilities in 13 objectives, three of which are developmental. This chapter shifts the public health focus from preventing disability to promoting health across the life span of children and adults living with a disability. In 2003, the CDC continued to provide leadership for chapter six of *Healthy People 2010* by publishing proceedings from the "2002 Implementing the Vision Forum" and the "2000 Vision for the Decade Symposium" (www.cdc.gov/ncbddd/dh/hp2010.htm, last accessed Dec. 19, 2003). The CDC also continues to examine data on people with disabilities for the other nine leading health indicators, particularly in terms of physical activity.

In 2003, the CDC funded 16 states through contracts and cooperative agreements to implement effective state-level health promotion and wellness programs for people with disabilities (www.cdc.gov/ncbddd/dh/DHstateprograms.htm, last accessed Dec. 19, 2003).

Health Promotion

The CDC supports health promotion programs for people with specific disabilities, particularly mental retardation, developmental problems, limits to physical activity, limb loss and paralysis. The Mental Retardation Initiative supports efforts to improve the health of people with mental

retardation and developmental disabilities (www.cdc.gov/ncbddd/dd/ddmr.htm, last accessed Dec. 19, 2003). Research shows that children born with fetal alcohol syndrome are at high risk for secondary conditions like developmental, substance abuse and mental health problems. The CDC funds three projects that examine interventions with children or adolescents with fetal alcohol syndrome to evaluate the interventions that are most effective in reducing these secondary conditions (www.cdc.gov/ncbddd/fas/intervening.htm, last accessed Dec. 19, 2003). The Physical Activity for People with Disabilities Program is a collaborative effort with the National Center on Physical Activity and Disability to promote physical activity and exercise among people with a disabling condition (www.ncpad.org/). The Limb Loss Program area supports information dissemination, research, support group development and health promotion for people with a limb loss or limb deficiency (www.amputee-coalition.org/nllic_about.html, last accessed Dec. 19, 2003). The program which supports the Christopher and Dana Reeve Paralysis Resource Center focuses on people with a paralysis and addresses the impact of paralysis including quality of life issues, peer support, educational information for people experiencing paralysis and the prevention of secondary conditions (www.paralysis.org/). The Guidelines for Improving Access series provides recommendations for improving accessibility for people with a disability to health care facilities and providers, recreation and fitness facilities, health communication venues, and health conferences and informational meetings (www.cdc.gov/ncbddd/dh/accessibilityguides.htm, last accessed Dec. 19, 2003). Not all disabilities are congenital and may be inflicted through accidents or injury. The Linking Survivors to Services Program addresses the health needs of people who have suffered a traumatic brain injury (www.cdc.gov/ncipc/factsheets/tbiactivities.htm, last accessed Dec. 19, 2003). Finally, the Improving Nutrition and Increasing Physical Activity Program targets people with and without disabilities to improve health status through nutrition and exercise (www.cdc.gov/nccdphp/bb_nutrition/index.htm, last accessed Dec. 19, 2003).

Research and Training

In 2003, the CDC continued the funding for 22 disability and health research projects at the state and university level, to assess the health status and quality of life for people with disabilities, describe risk factors and costs associated with secondary conditions and poor health, and develop, test and evaluate health promotion interventions to reduce secondary conditions to promote the health of people with disabilities (www.cdc.gov/ncbddd/dh/DHstateprograms.htm, last accessed Dec. 19, 2003). The Aging with a Disability Project builds upon the NFI, which emphasizes caregiving across the lifespan by supporting conferences that disseminate information on aging with a disability. The Center for Research on Women with Disabilities is a collaborative effort between the National Center on Birth Defects and Developmental Disabilities, the NCHS, the AHRQ, Baylor College of Medicine and the University of Illinois at Chicago (www.4woman.gov/wwd/index.htm, last accessed Dec. 19, 2003). The researchers completed a report entitled, "Health and Well-being for Women With Disabilities," [22] which has been submitted for publication as a Series 10 report (i.e., having to do with data from the National Health Interview Survey).

Surveillance

An important component of disability research is surveillance, which assists in understanding the impact of disabling conditions upon the population and offers an opportunity to target health-promoting interventions to people with a disability. Various centers at the CDC utilize existing federally sponsored health surveys to monitor the health status of people with disabilities. These surveys include the Behavioral Risk Factor Surveillance System (administered by the National Center for Chronic Disease Prevention and Health Promotion), the National Health Interview Survey and others administered by the NCHS. The outcome of surveillance work assesses the prevalence of disability, describes health status, identifies health risks, and evaluates the quality of life for people with disabilities. A specific program run by the National Center for Chronic Disease Prevention and Health Promotion is the Measuring Behaviors That Endanger Health Project, which draws data from the Behavioral Risk Factor Surveillance System and the CDC's Youth Risk Behavior Surveillance System (www.cdc.gov/nccdphp/bb_brfss_yrbss/, last accessed Dec. 19, 2003). In some cases, special systems are developed and supported for surveillance work. The Colorado Traumatic Brain Injury Registry and Follow-up System is one example of an internally developed surveillance system (www.cdc.gov/ncipc/factsheets/tbiactivities.htm, last accessed Dec. 19, 2003). The Early Hearing Detection and Intervention Surveillance System exists in 32 states and territories to identify infants with a hearing loss (www.cdc.gov/ncbddd/ehdi/goal4.htm, last accessed Dec. 19, 2003). The CDC collaborates with four states to develop surveillance systems for Duchenne and Becker muscular dystrophies, and to collect information on treatment choices and outcomes. Additionally, the CDC funds one of the largest, community-based research projects on ADHD among school-aged children (www.cdc.gov/ncbddd/adhd/institutes.htm, last accessed Dec. 19, 2003).

Information Dissemination

The CDC funds and supports information dissemination at national centers for a target group of people with disabilities (www.cdc.gov/ncbddd/dh/infocenters.htm, last accessed Dec. 19, 2003). The Amputee Coalition of America and the National Limb Loss Information Center, the Christopher and Dana Reeve Foundation, the National Center on Physical Activity and Disability, and the Children and Adults with ADHD are four organizations that receive CDC support for maintaining Web sites and other programs that provide information for their members and for the public.

National Council on Disability

During 2003, the NCD produced a range of research and policy briefs that were disseminated to decision-makers in the White House and all members of Congress, key leaders in the executive branch of the federal government, and various stakeholders in the nation. The research and policy briefs addressed a range of issues including: family supports; school vouchers; the ADA and the Internet; postsecondary education; and the range of legal and civil rights issues which devolved from a series of recent U.S. Supreme Court decisions affecting the civil rights of Americans with disabilities. The research and policy briefs may be found at: www.ncd.gov/newsroom/publications/ (last accessed Dec. 19, 2003).

The NCD has also initiated a series of new evaluation studies including:

- An evaluation of consumer-directed health care reform within the context of the Medicare and Medicaid programs;
- An investigation of the status of infrastructure planning and program implementation for people with disabilities within the context of the federal government's homeland security operations;
- A study of livable communities and factors that create or sustain such communities on behalf of people who are elderly and people who have disabilities;
- An analysis of outcome-producing evidence-based practices and programs within the context of the *No Child Left Behind Act* and the *Individuals with Disabilities Education Act*;
- An assessment of the role, status and direction of this nation's long-term services and supports financing and systems reform efforts on behalf of people with disabilities and people who are elderly; and
- An evaluation of this nation's return-to-work programs, policies and practices particularly as they are directed by key federal agencies.

National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services

NIDRR-funded Extramural Research

NIDRR supports comprehensive and coordinated programs of research and related activities to maximize the full inclusion, social integration, employment and independent living of individuals of all ages with disabilities. NIDRR's focus includes research in areas such as employment; health and function; technology for access and function; independent living and community integration; and other associated disability research areas. NIDRR's research is conducted via a network of individual research projects and centers of excellence throughout the country. Most NIDRR grantees are universities or providers of rehabilitation or related services. NIDRR's funding categories include:

- RRTCs;
- RERCs;
- Model systems of care (SCI, traumatic brain injury, and burn);
- Disability and rehabilitation research projects;
- Field-Initiated Projects;
- Advanced Rehabilitation Research Training Projects;
- Mary E. Switzer Fellowships; and
- SBIR projects.

For information on specific grants, see NIDRR program directory at: www.naric.com.

Long-range Plan

NIDRR began developing its plan for disability and rehabilitation research for the next five years. They formed a steering committee composed of 17 experts from the community of researchers, service providers, individuals with disabilities and private industry. NIDRR sponsored three national videoconferences (June 18, June 25 and July 16, 2003) and solicited written comments on research needs. NIDRR collected valuable input from thousands of stakeholders to consider in the development of its long-range plan.

State-of-the-Science Conferences

NIDRR requires each RERC and RRTC to conduct a state-of-the-science conference during its five-year funding cycle. These are major events that focus on different areas of disability and rehabilitation research. In 2003, the following conferences were conducted:

Grantee: RERC on Technologies for Children with Orthopedic Disabilities
Topic: “State-of-the-Science Conference on Children’s Prosthetics and Orthotics”
Date: May 14, 2003, preceding the “Annual Conference of the Association for Children’s Prosthetic-Orthotic Clinics”

Grantee: RRTC for Measuring Rehabilitation Outcomes
Topic: Outcome Measures in Post-acute Care: The Intersection of Science, Practice and Policy
Date: April 24–25, 2003

Grantee: RRTC on Blindness and Low Vision
Topic: “State-of-the-Science Conference on Blindness and Low Vision”
Date: April 14–16, 2003

Grantee: RRTC on Health and Wellness
Topic: Health and Wellness of People With Disabilities
Date: March 17–18, 2003

Grantee: RRTC on Positive Behavior Support
Topic: “The First International Conference on Positive Behavior Support”
Date: March 27–29, 2003

Grantee: RRTC on Rehabilitation Interventions Following Traumatic Brain Injury
Topic: Rehabilitation Interventions Following Traumatic Brain Injury
Date: Sept. 4–5, 2003

Grantee: RRTC for Children’s Mental Health
Topic: “The 16th Annual Research Conference—A System of Care for Children’s Mental Health: Expanding the Research Base”
Date: March 2–5, 2003

Grantee: RRTC on Community Living
Topic: Keeping the Promises: National Goals, the State-of-Knowledge and a National Research Agenda on Intellectual and Developmental Disabilities
Date: Jan. 6–8, 2003

Grantee: National RRTC on Psychiatric Disability
Topic: “Invitational Strategies Conference on Self-Determination for People With Psychiatric Disabilities: Using the Past to Guide Our Future”
Date: Oct. 2–3, 2003

Program Review

NIDRR conducted 14 program review sessions during 2003. Formative reviews are conducted early in a center’s five-year cycle, typically between the 12th and 18th month, and Summative reviews are conducted towards the end of the cycle, around the 48th to 50th month. NIDRR conducts both types of program reviews utilizing an expert panel model of six to twelve constituent reviewers, composed of external researchers, practitioners, service providers, consumers and consumer advocates, and where appropriate, federal partners and industry representatives. Since its inception, NIDRR’s program review system has undergone continuous quality improvement to make it more useful to grantees and to align it with internal developments at NIDRR, such as the Web-based annual performance reporting system, and with the Education Department’s new strategic goals—emphasizing accountability for results and evidence-based decision-making.

Formative reviews were for:

- University of Florida – RERC on Technology for Successful Aging;
- Georgia Institute of Technology – RERC on Mobile Wireless Technology for Persons With Disabilities;
- University of Pittsburgh – RERC on Wheelchair Transportation Safety;
- University of Arkansas – RRTC for Persons Who Are Deaf or Hard of Hearing; and
- Mississippi State University – RRTC for Individuals Who Are Blind or Have Low Vision.

Summative reviews were for:

- North Carolina State University – RERC on Universal Design and the Built Environment;
- State University of New York at Buffalo – RERC on Universal Design at Buffalo;
- University of Wisconsin at Madison – RERC on Telecommunications Access;
- Boston University - RRTC for Measuring Rehabilitation Outcomes;
- Institute for Rehabilitation and Research (Houston) – RRTC on Rehabilitation Interventions Following Traumatic Brain Injury;
- Oregon Health and Science University – Health and Wellness Consortium for Persons With Long-term Disabilities;
- University of South Florida – RRTC for Children’s Mental Health;

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- Boston University – RRTC in Rehabilitation of Persons With Long-term Mental Illness; and
 - Portland State University – RRTC on Family Support and Children’s Mental Health.

Information Dissemination

NIDRR continues to support projects designed to promote dissemination of information and research results. NARIC offers a library of rehabilitation publications, referral resources and NIDRR’s program directory. ABLEDATA is a database that contains information on more than 26,000 commercially produced and custom-made assistive devices, provides information and referral services on special technology product needs, and provides the data to major dissemination points to ensure wide distribution and availability of the information. The National Center for the Dissemination of Disability Research (Austin, Texas) promotes the utilization of research results developed through NIDRR grants and contracts by identifying effective dissemination practices, demonstrating effective utilization outcomes, and providing technical assistance to NIDRR grantees.

In 2003, NIDRR funded a new disability and rehabilitation research project, the Research Utilization Support and Help (RUSH) Project at the Southwest Educational Development Laboratory in Austin, Texas. RUSH Project develops and tests models for increasing the effective use of NIDRR research results. RUSH Project intends to assess utilization successes in terms of benefits produced for intended user audiences including: people with disabilities and their families, disability researchers and disability service providers, among others. The goal is to expand awareness, strategies and evaluation of knowledge utilization outcomes among NIDRR-supported researchers in order to increase the access and use of research results by those who can benefit the most from them.

National Institute for Literacy

The NIFL supports research and training in the area of learning disabilities, and through a joint project with the American Foundation for the Blind (AFB) for adults with low vision or blindness and literacy difficulties.

The NIFL has completed a three-year joint project with the AFB that was funded through private foundation grants to provide training to adult education teachers and tutors about adults with low literacy skills and vision impairment or blindness. The AFB received the funding for this project and the NIFL contributed staff time for the development of a training manual on reading and learning disabilities that accompanied the AFB material on vision. Four national training sessions were conducted. Participants were given minigrants to encourage activities and small research projects that utilized the information from the training. A final symposium was held in Atlanta in 2003, and participants were encouraged to continue their work through a connection with the NIFL training programs.

In conjunction with 12 states and their Temporary Assistance to Needy Families (TANF) agencies, the NIFL gathered information in calendar year 2003 reporting period on the incidence of learning disabilities in TANF population and plan to produce a report in 2004. Paid for by a grant to the Seattle-King County Workforce Development Council, this project involved the training of caseworkers in the screening, referral for diagnosis and appropriate placement in jobs of adults who have learning disabilities or were identified as potentially having learning disabilities. Common information was gathered from the 12 states, and the information has been shared with the HHS in a joint effort to increase the employment opportunities for single mothers on TANF who may have disabilities that prevent them from working without accommodations. This is an attempt to save federal funds by preventing the movement from TANF to Social Security Disability Insurance programs unless the person is absolutely unable to work.

National Science Foundation

Information Dissemination

In 1988, the NSF began to fund the Research to Aid Persons with Disabilities Program. These awards provide support for undergraduate student engineers to construct custom-designed assistive devices and software for specific individuals with disabilities. Seventeen design projects' awards were active in 2003.

Annual reviews of successful projects have been published since 1989, with the 2001 edition published both electronically and in paper in 2003. Some 134 custom-designed assistive devices are described in the 2001 review. All 13 volumes of the *Annual Review* are available at: <http://nsf-pad.bme.uconn.edu/> (last accessed on Dec. 19, 2003).

The primary goal of this NSF activity is to provide a meaningful design experience for the engineering student that will directly aid specific disabled individuals. Both the students and the project directors (i.e., faculty members) work with institutions providing care or education for the disabled. Faculty project directors annually submit reports to the NSF that include a description of the design projects successfully completed during the previous academic year. Such completed design projects are eligible for publication in the Annual Review.

Research in Disabilities Education

During 2003, the NSF restructured the Persons with Disabilities Program and replaced it with the Research in Disabilities Education (RDE) Program, which is described in Program Solicitation NSF 03-587 (www.nsf.gov/pubs/2003/nsf03587/nsf03587.htm, last accessed on Dec. 19, 2003). The anticipated funding for FY 2004 is \$4.9 million.

The RDE program provides funding opportunities to increase the participation and achievement of persons with disabilities in science, technology, engineering and mathematics (STEM) education and careers. Meritorious projects from diverse institutions are to be supported via a RDE demonstration, enrichment and information dissemination standard grants. Promising research efforts may then be developed further, via continuing grants under the focused-research

initiatives program track. Broadly applicable methods and products are to be disseminated for widespread use, commercialization or inclusion in the activities of program-sponsored regional alliances for persons with disabilities in STEM education. The RDE alliances serve to inform the public, government and industry about proven good practices in the classroom, promote broader awareness of disabilities issues, and define specific areas of accessibility and human learning in need of further attention by educators and the research community.

Office of Disability Employment Policy, Department of Labor

Evaluation of the Workforce Development System for Clients With Disabilities

During the calendar year 2003 reporting period, ODEP studied the practices and needs of how the workforce development system serves individuals with disabilities. It is anticipated that this work will continue into 2004. This research will provide the DOL and the workforce development system with comprehensive reports on the best practices, concerns, and lessons learned serving both adult and youth clients with disabilities. These research streams will disseminate the best practices and inform the DOL, other agencies and the workforce development system of potential issues and concerns raised by the One-Stop Career Center directors, staff and clients. ODEP has undertaken two streams of research to explore these questions:

1. An ODEP-funded contractor is conducting detailed interviews and drafting case studies of 12 One-Stop Career Centers across the nation that have not received ODEP funding to provide services to clients with disabilities. In addition to individual analyses of each location, this research also summarizes and aggregates trends and issues noted across the locations. This research will provide a rich composite picture—in context—of the knowledge, skills and abilities of those serving individuals with disabilities in Workforce Investment Act programs.
2. ODEP has contracted with an independent research firm to conduct an outside evaluation of all ODEP grant recipients from FYs 2001, 2002 and 2003 grant cycles. The evaluators created extensive protocols in conjunction with ODEP staff and subject matter experts, and tailored each protocol to the types of grants awarded by ODEP. The evaluators will spend approximately one full year traveling to each ODEP grantee for multiple days of interviewing grant directors, staff members, clients and families of clients. Findings from the evaluators will be summarized and tied to the DOL's Government Performance and Results Act goals. The summaries of the research findings will also focus on the impact the grantees have had on systems change through the workforce investment system. ODEP will use this research to distill and disseminate best practices and lessons learned at each grant site. In addition to the final reports that the evaluator will issue in summer 2004, interim reports and briefing meetings with ODEP staff allow ODEP to disseminate this

information to the DOL, the workforce investment system and the community at large.

Survey of Clients of the Job Accommodations Network

Working with another outside evaluator, ODEP is conducting phone interviews with clients of the DOL Job Accommodations Network. Each year, the network receives 32,000 requests, and ODEP is conducting a random sample of telephone interviews of these requests for job-related accommodations, small business and self-employment services, educational and training accommodation, information and referral requests, and requests for marketing materials. The surveys used during the interviews will include collected data on caller demographics, satisfaction with services provided, benefits and impacts, and the implementation decisions and costs associated with making the accommodation to employees with disabilities.

Federal Transit Administration, Department of Transportation

Linking Technology With Accessibility and Mobility for Seniors and People With Disabilities

In December 2003, the DOT FTA Office of Research Demonstration and Innovation and the Office of Civil Rights began work on a joint research program on using the ITS to improve accessibility and mobility for seniors and people with disabilities.

In recent years, new capabilities and opportunities to improve accessibility are being created in the transportation and rehabilitation communities. Pioneering public transportation agencies are using the ITS to provide centralized coordination of community transportation providers, one-stop shopping, service brokering through integrated automatic vehicle location systems, advanced communications, and universal benefit cards. Others are providing on-vehicle audio announcement, accessible traveler information and flexible routing to assist passengers with disabilities in using conventional transit services. In the rehabilitation community, innovative AT such as personal global positioning systems using mobile communications to provide assistance to those with cognitive disabilities, pedestrian signals, and “talking” bus stops and signs are also being developed.

The goal of the joint research program is to identify and promote promising and emerging technologies that assist the mobility of seniors and people with disabilities, and to coordinate the work of the transportation and rehabilitative systems communities in this area. The program will result in demonstration projects featuring the ITS. During the calendar year 2003 reporting period, the FTA Office of Civil Rights also plans to feature the ITS and its potential to improve mobility and accessibility at a conference in July 2004, with exact dates and venue to be established.

Office on Disability, Department of Health and Human Services

The HHS Secretary Thompson created the OD in October 2002 to advise him on disability-based issues and initiatives, and to serve as the focal point within the HHS for the implementation and

coordination of policies, programs and special initiatives related to disabilities. The secretary's four expectations for the OD are to:

- Lead the HHS NFI initiative;
- Oversee, coordinate, develop and implement disability programs and initiatives within the HHS that impact people with disabilities;
- Ensure that persons with disabilities, across their lifespan, have a voice within the HHS; and
- Heighten the interaction of programs within the HHS and with federal, state, community and private sector partners.

The OD held the Constituent Expert Input Meeting, first in a series, on June 26, 2003. Fifty-two constituent and agency representatives attended in person or joined in by conference call. It was designed to enhance constituent input regarding the OD's development of its Three-Year Action Agenda. The comments focused primarily on services across all the NFI domains (health, transportation, housing, employment, education, AT and integrated community services). Specifically, health services for persons with disabilities were frequently mentioned, as was the need for improved access to health care. The need for research to improve health, employment, housing and community living was also identified.

The HHS OD developed the *Annual Disability-Based Management Data Report* to:

- Review how the HHS funds (including research funds) for all disabilities have been expended and budgeted;
- Compare the fiscal analysis with constituent input needs analysis; and
- Support program and budget policy planning on behalf of persons with disabilities in conjunction with the NFI domains.

The OD, in conjunction with members of its NFI Workgroup, is addressing the nation's workforce and caregiver crisis that affects all persons with disabilities. In August 2003, it conducted a technical assistance-based meeting on "Informal and Formal Caregiver/Workforce Challenges and Best Practices in Enhancing the Workforce" for constituents and members of the NFI Workgroup. A content analysis was initiated to identify strengths, gaps and areas for enhancement on how the HHS agencies are providing formal and informal caregiving. The content analysis will inform the development of budget and program policy recommendations.

The OD facilitated a symposium on "Understanding Disability Functioning Assessment Tools—Understanding the International Classification of Functioning, Disability and Health" for the NFI Workgroup in September 2003. This symposium was a first step for assessing the use of the ICF in supporting research to screen and assess the rehabilitation needs of persons with disabilities by the HHS agencies.

The OD facilitated a "Round Table on Autism" that appeared on the Public Broadcasting Service on Nov. 12, 2003. This public documentary provided an opportunity to understand the knowledge and gaps in addressing autism as a developmental disability from service delivery and research perspectives, including attention to necessary next steps for each.

The OD provided support for the annual Secretary's Celebration of Persons With Disabilities, held during Disability Awareness Month on Oct. 30, 2003. Nationally recognized persons, including those representing business, entertainment, media, providers, elected officials and consumers were honored for their work on behalf of persons with disabilities. During the calendar year 2003 reporting period, planning for the 2004 celebration established new awardee categories that included research that has improved the lives of people with disabilities.

The OD planned for a national physical fitness initiative for youth with disabilities in conjunction with the President's Council on Physical Fitness and Sports. It will identify adults with disabilities to serve as mentors for youth with disabilities. It will encourage these youth to participate in their own physical fitness goals. An evaluation component of the initiative will provide key information on the benefits of exercise and physical fitness on participating youth with disability self-opinion, impact on reduction of discrimination of persons with disabilities, and others to be identified as performance measures.

The OD became the HHS entity responsible for Section 508 adherence. As the Section 508 coordinator, functions include reviewing and analyzing all the HHS Section 508 exception requests and providing survey data as requested by the DOJ and other government oversight organizations.

The OD has completed memoranda of understanding with:

- The DOT, supporting interdepartmental coordination efforts on behalf of persons who are transportation disadvantaged including persons who are disabled, across the lifespan;
- The SBA, supporting the development of an initiative addressing persons with disabilities operating small businesses targeting veteran-owned and service-disabled veteran-owned companies; and
- The NIH NICHD and the Department of Education's NIDRR, supporting an interagency partnership on addressing the research gaps in helping to address the domains of the president's NFI (i.e., AT, community living, education, employment and health).

Section 7: Recommendations

Federal Interagency Recommendations for Research and Research Coordination

In accordance with statutory requirements, the ICDR received input from individuals with disabilities and their representatives in 2003 for research-related recommendations. In addition, the ICDR considered relevant reports from government and scientific agencies, government-wide research goals, policy directions and the ICDR agency member perspectives. Taking into account the above data, the ICDR developed the following recommendations to improve interagency coordination and guide the federal research agenda.

Research Recommendations

1. *Recommend an IOM study focused on the federal research and development (R&D) effort in rehabilitation science to start in 2005.*

The IOM conducted a review of the federal effort in rehabilitation science and engineering that was published in 1997. Since that time, a number of significant developments have occurred within the federal government that merit new examination—the NFI, the *Olmstead v. L.C.* decision, the creation of ODEP in the DOL and the HHS OD, the doubling of the NIH budget, and the creation of the National Institute for Biomedical Imaging and Bioengineering at the NIH. In addition, a new model of disability—the ICF—represents an expansion and interpretation of the enabling-disabling process described in the 1997 IOM study, with additional focus on concepts of activities and participation. We recommend that Congress request a new IOM study to incorporate these new developments, and that the ICDR and its member agencies contribute funding to support the study.

2. *Over a two—three year period, develop a plan to present to Congress for the design and implementation of an improved periodic national disability data collection effort.*

The ICDR envisions the development of a periodic national disability data collection effort. Member agencies agree such an effort is needed, but have different views on how best to accomplish this goal. One approach is the development of a separate national disability survey and another is the systematic collection of disability data, including improved disability questions within existing national surveys. The use of a combined approach might also be possible. This is further complicated by the broad spectrum of areas in which various agencies need to collect information on topics such as employment, health care, education, housing, transportation and others. We recommend the formation of a task force of key agencies (including statistical experts and decision-makers) to describe the characteristics of an ideal national disability data collection effort across all agencies, and how such an effort might be implemented.

In addition, we recommend encouraging improvements in data collection efforts of government programs (e.g., health care programs, workforce and employment programs, and

education programs) to ensure that people with disabilities involved in these programs are properly identified and counted. These data are not routinely collected in programs that are not specifically focused on disability. It is critical to improve these efforts to fully understand the patterns of use of general government services by people with disabilities. These data will provide useful information for policy development and implementation.

3. *Continue analysis and comparisons of disability and rehabilitation terminology in federal agencies in order to facilitate communication and coordination.*

In 2002, the ICDR completed an analysis of federal statutory definitions of disability. The variety of definitions identified raised concerns about the differences in terms and classification systems used by agencies to categorize funded research in archival databases. We recommend an analysis of agency terminologies, classification systems, indexing terms, etc., to document the range of terms and harmonize terminologies across federal agencies when possible to facilitate clear communication and coordination among different agencies and research programs.

4. *Encourage research addressing access to and costs and benefits of various assistive technologies. Research should examine: costs of equipment; potential financial savings, for example—from reducing the need for home care, personal care assistance, and reducing medical expenses relating to secondary disabilities (e.g., falls and depression); health and quality of life outcomes; and performance of daily activities.*

Coverage policies of Medicare, Medicaid and private insurers greatly influence the ability of persons with disabilities to obtain AT. Analyses of the National Health Interview Survey Disability Supplement demonstrate that persons without health insurance who have major mobility limitations are 40 percent less likely to have wheelchairs or walkers than insured persons with similar mobility difficulties. [23] Surveys of Medicaid programs demonstrate that if reductions occur in covered benefits, assistive technologies and other disability-related services are among the first benefits to be reduced. [24] Questions arise about whether reducing access to assistive technologies may actually result in higher overall system-wide costs. Methodologically rigorous research needs to be done to evaluate whether providing AT saves systemwide costs (e.g., by reducing the need for other services, or reducing secondary conditions such as depression and injuries). Some of this research could emerge from the support of longitudinal studies (see Recommendation 6).

5. *Encourage public-private partnerships to support technology transfer of AT devices.*

AT devices have the potential to facilitate the lives of people with disabilities, but limited markets and uncertain research and development funding often inhibits transfer of new devices to the market. Public-private partnerships are critical to fostering such transfer. Existing federal programs designed to support this effort (e.g., the SBIR and Cooperative R&D Agreements) are underutilized by private entities with respect to AT. We recommend the implementation of an outreach effort to encourage greater interest in and use of existing federal programs to support technology transfer of AT devices.

6. *Identify strategies to support longitudinal studies (10–15 years) on disability and rehabilitation issues.*

Longitudinal studies on disability have been few. Considering the increased life expectancy of individuals with disabilities, there is a great need for longitudinal research. For example, longitudinal research is appropriate for studying: the course and prevention of secondary conditions, the effects of long-term technology use, what it is like to live with a disability, and the employment and community involvement experience over time. There is value in allowing different time frames for longitudinal studies for particular research questions. For some studies a five-year time frame might be adequate whereas for others, a much longer timeframe would be needed. Most research agencies are limited to awarding five-year grants. Having alternative funding mechanisms in place might make it easier to do long-term longitudinal studies. Current funding mechanisms need to be examined. Management issues such as determination of appropriate topics, types of competition (priority-driven versus field-initiated), development of new and more stringent review and evaluation criteria for proposals, and methods for monitoring progress of funded studies must be determined.

ICDR Internal Management Recommendations

The following internal management recommendations are designed to establish mechanisms and strategies to support interagency coordination efforts and are provided for information purposes only.

1. Catalog and describe all interagency committees, working groups, councils, task forces that are related to the ICDR. Devise a plan to monitor the activity of these related committees, working groups, councils and task forces, and make reports as needed to the ICDR and its subcommittees.
2. Complete an in-depth examination, using the Web search portal, of currently funded research on AT to identify research gaps, duplication of effort, etc., to facilitate coordination of this research.
3. Expand the Web search portal to include program announcements and notices of federal funding opportunities. Also, devise procedures to share plans for priorities in advance of announcements to facilitate coordination efforts among the ICDR members.
4. Increase dissemination of information about federal disability research activities.
5. Improve documentation of research outcomes.
6. Disseminate the *Report on Assistive Technology Mobility Devices* [3] prepared in response to President Bush's executive memorandum establishing the IWG on ATMDs issued on Feb. 12, 2003, [4] that challenged federal agencies to increase education and employment opportunities for persons with disabilities by improving their access to ATMDs.

Appendix A: Statutory Authority for the ICDR

Section 203 of the Rehabilitation Act of 1973, as amended

Interagency Committee

Sec. 203.

(a)(1) In order to promote coordination and cooperation among federal departments and agencies conducting rehabilitation research programs, there is established within the federal government an Interagency Committee on Disability Research (hereinafter in this section referred to as the “Committee”), chaired by the director and comprised of such members as the president may designate, including the following (or their designees): the director, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services, the secretary of Education, the secretary of Veterans Affairs, the director of the National Institutes of Health, the director of the National Institute of Mental Health, the administrator of the National Aeronautics and Space Administration, the secretary of Transportation, the assistant secretary of the Interior for Indian Affairs, the director of the Indian Health Service and the director of the National Science Foundation.

(2) The Committee shall meet not less than four times each year.

(b) After receiving input from individuals with disabilities and the individuals’ representatives, the Committee shall identify, assess and seek to coordinate all federal programs, activities and projects, and plans for such programs, activities and projects with respect to the conduct of research related to rehabilitation of individuals with disabilities.

(c) The Committee shall annually submit to the president and to the appropriate committees of the Congress a report making such recommendations as the Committee deems appropriate with respect to coordination of policy and development of objectives and priorities for all federal programs relating to the conduct of research related to rehabilitation of individuals with disabilities.

Appendix B: ICDR Membership

The director of NIDRR is designated as chair of the ICDR.
www.ed.gov/about/offices/list/osers/nidrr

Statutory members include:

Commissioner of the Rehabilitation Services Administration
www.ed.gov/about/offices/list/osers/rsa

Assistant Secretary for the Office of Special Education and Rehabilitative Services
www.ed.gov/about/offices/list/osers

Secretary of Education
www.ed.gov

Secretary of Veterans Affairs
www.va.gov

Director of the National Institutes of Health
www.nih.gov

Director of the National Institute of Mental Health
www.nimh.nih.gov

Administrator of the National Aeronautics and Space Administration
www.nasa.gov

Secretary of Transportation
www.dot.gov/ost

Assistant Secretary of the Interior for Indian Affairs
www.doi.gov/bureau-indian-affairs.html

Director of the Indian Health Service
www.ihs.gov

Director of the National Science Foundation
www.nsf.gov

Numerous other federal agencies play significant roles in disability and rehabilitation research, either as producers of research or consumers of research results. By invitation of the chair, the following additional agencies are now regularly represented on the ICDR:

U.S. Access Board
www.access-board.gov

Administration on Aging
www.aoa.gov

Administration on Developmental Disabilities
www.acf.hhs.gov/programs/add

Agency for Healthcare Research and Quality
www.ahrq.gov

Centers for Disease Control and Prevention
www.cdc.gov

Department of Commerce
www.doc.gov

Department of Defense
www.defenselink.mil

Department of Education, Office of Special Education Programs
www.ed.gov/about/offices/list/osers/osep/index.html

Department of Justice
www.usdoj.gov

Department of Labor
www.dol.gov

Department of Veterans Affairs Rehabilitation Research and Development Service
www.var.d.org

Federal Communications Commission
www.fcc.gov

National Center for Health Statistics
www.cdc.gov/nchs

National Center on Medical Rehabilitation Research
www.nichd.nih.gov/about/ncmrr/ncmrr.htm

National Council on Disability
www.ncd.gov

Office of the Assistant Secretary for Planning and Evaluation, Department of Health and
Human Services
www.aspe.hhs.gov

President's Committee for People with Intellectual Disabilities
www.acf.hhs.gov/programs/pcpid

Social Security Administration
www.ssa.gov

Appendix C: Acronym List

ACF	Administration for Children and Families
ADA	Americans with Disabilities Act of 1990
ADHD	Attention-Deficit/Hyperactivity Disorder
AFB	American Foundation for the Blind
AHRQ	Agency for Healthcare Research and Quality
ANSI	American National Standards Institute
AOA	Administration on Aging
ASPE	Office of the Assistant Secretary for Planning and Evaluation
AT	Assistive Technology
ATMD	Assistive Technology Mobility Devices
CAHPS [®]	formerly the Consumer Assessment of Health Plans Study
CDC	Centers for Disease Control and Prevention
CESSI	Cherry Engineering Support Services, Inc.
CMS	Centers for Medicare and Medicaid Services
CPS	Current Population Survey
DC	District of Columbia
DOD	Department of Defense
DOJ	Department of Justice
DOL	Department of Labor
DOT	Department of Transportation
DSM-III-R	<i>Diagnostic and Statistical Manual of Mental Disorders</i> , Third Edition, Revised
EU	European Union
FCC	Federal Communications Commission
FDA	Food and Drug Administration
FTA	Federal Transit Administration
FY	Fiscal Year
HAC	Hearing Aid Compatibility
HHS	Department of Health and Human Services
HRSA	Health Resources and Services Administration
HUD	Department of Housing and Urban Development
ICDR	Interagency Committee on Disability Research
ICF	International Classification of Functioning, Disability and Health
IHS	Indian Health Service
IOM	Institute of Medicine (National Academies)
ISDS	Interagency Subcommittee on Disability Statistics
ISMR	Interagency Subcommittee on Medical Rehabilitation
ISNFI	Interagency Subcommittee on the New Freedom Initiative
IST	Interagency Subcommittee on Technology
ISTT	Interagency Subcommittee on Technology Transfer

ITS	Intelligent Transportation Systems
IWG	Interagency Working Group
LTC	Long-Term Care
MD-CARE	Muscular Dystrophy Community Assistance, Research and Education
MDCC	Muscular Dystrophy Coordinating Committee
MEPS	Medical Expenditure Panel Survey
NARIC	National Rehabilitation Information Center
NCD	National Council on Disability
NCHS	National Center for Health Statistics
NCMRR	National Center for Medical Rehabilitation Research
NCS	National Comorbidity Survey
NFI	New Freedom Initiative
NGC	National Guidelines Clearinghouse™
NH-CAHPS	Nursing Home Consumer Assessment of Health Plans Study
NHDR	National Healthcare Disparities Report
NHQR	National Healthcare Quality Report
NICHD	National Institute for Child Health and Human Development
NIDCD	National Institute on Deafness and Other Communication Disorders
NIDRR	National Institute on Disability and Rehabilitation Research
NIFL	National Institute for Literacy
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NINDS	National Institute of Neurological Disorders and Stroke
NINR	National Institute of Nursing Research
NQMC	National Quality Measures Clearinghouse™
NSF	National Science Foundation
OD	Office on Disability (HHS)
ODEP	Office of Disability Employment Policy (DOL)
OSERS	Office of Special Education and Rehabilitative Services (Department of Education)
OSTP	Office of Science and Technology Policy
PDB	Physical Disabilities Branch
PPSS	Policy and Programs Study Service
PWMI	People with Mobility Impairments
R&D	Research & Development
RDE	Research in Disabilities Education
RERC	Rehabilitation Engineering Research Centers
RR&D	Rehabilitation Research & Development
RRDS	Rehabilitation Research and Development Service
RRTC	Rehabilitation Research and Training Centers
RUSH	Research Utilization Support and Help

SAMHSA	Substance Abuse and Mental Health Services Administration
SBA	Small Business Administration
SBIR	Small Business Innovation Research
SCI	Spinal Cord Injury
SSA	Social Security Administration
STEM	Science, Technology, Engineering and Mathematics
TA	Technology Assessment
TANF	Temporary Assistance for Needy Families
UK	United Kingdom
US	United States
VA	Department of Veterans Affairs
VHA	Veterans Health Administration
WRAMC	Walter Reed Army Medical Center

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