

## Free Executive Summary

### The Future of Disability in America



Committee on Disability in America, Marilyn J. Field and Alan Jette, editors

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*The future of disability in America will depend on how well this country prepares for and manages the demographic, fiscal, and technological developments that will unfold during the next two to three decades. Building upon two prior studies from the Institute of Medicine (the 1991 Institute of Medicine's report *Disability in America* and the 1997 report *Enabling America*), *The Future of Disability in America* examines both progress and concerns about continuing barriers that limit the independence, productivity, and participation in community life of people with disabilities. This book offers a comprehensive look at a wide range of issues, including the prevalence of disability across the lifespan; disability trends the role of assistive technology; barriers posed by health care and other facilities with inaccessible buildings, equipment, and information formats; the needs of young people moving from pediatric to adult health care and of adults experiencing premature aging and secondary health problems; selected issues in health care financing (e.g., risk adjusting payments to health plans, coverage of assistive technology); and the organizing and financing of disability-related research. *The Future of Disability in America* is an assessment of both principles and scientific evidence for disability policies and services. This book's recommendations propose steps to eliminate barriers and strengthen the evidence base for future public and private actions to reduce the impact of disability on individuals, families, and society.*

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## Summary

Today, between 40 million and 50 million people in the United States report some kind of disability. That number will likely grow significantly in the next 30 years as the baby boom generation enters late life, when the risk of disability is the highest. If one considers people who now have disabilities (at least one in seven Americans), people who are likely to develop disabilities in the future, and people who are or who will be affected by the disabilities of family members and others close to them, then disability affects today or will affect tomorrow the lives of most Americans. Clearly, disability is not a minority issue.

In considerable measure, the future of disability in America will depend on how this country prepares for and manages a complex array of demographic, fiscal, medical, technological, and other developments that will unfold in the next several decades. Much can be done now to make this future one that enables people with disabilities to lead full and productive lives. Inaction will lead to individual and societal costs—avoidable dependency, diminished quality of life, increased stress on individuals and families, and lost productivity.

### DEVELOPMENTS SINCE PUBLICATION OF THE 1991 AND 1997 IOM DISABILITY REPORTS

The 1991 Institute of Medicine (IOM) report *Disability in America* and the 1997 IOM report *Enabling America* highlighted disability as a topic of public health action and scientific inquiry. The reports also offered recommendations on the prevention of disability and the role of rehabilitation science and engineering.

For this report, which was supported by the Centers for Disease Control and Prevention (CDC), the National Institute on Disability and Rehabilitation Research (NIDRR), and the National Center for Medical Rehabilitation Research (NCMRR), a new IOM committee was charged with reviewing developments since the publication of the earlier IOM reports. As agreed upon with the study's sponsors, the review focused on several topics, including

- methodological and policy issues related to the definition, measurement, and monitoring of disability;
- trends in the amount, types, and causes of disability;
- secondary health conditions and aging with disability;

- transitions for young people with disabilities from pediatric to adult health care services;
  - assistive technologies and supportive physical environments;
  - coverage of assistive technologies and risk adjustment of payments to health plans;
- and
- directions for research.

The committee concluded that the United States has seen some progress since the publication of the earlier IOM reports. This progress includes a growing understanding that disability is not an inherent attribute of individuals. Rather, it results from interactions between individuals and their physical and social environments. Continuing advances in science and engineering have brought better assistive technologies that make these interactions with the environment easier. Likewise, advances in mainstream electronic and information technologies—combined with regulatory requirements for accessibility features—have been liberating for many people with disabilities.

In public health and clinical medicine, a range of new or improved preventive measures continue to reduce the incidence of certain kinds of injuries, developmental disorders, and other health conditions that can contribute to disability. Among older adults the chance of having an activity limitation has declined during the last two decades, although data suggest that younger adults and children have an increased chance of having an activity limitation. Most state Medicaid programs have increased the resources that they provide for community and home services that help people with serious disabilities to avoid institutional care. Programs for children with disabilities and other special health care needs have expanded.

At the same time, little progress has been made in adopting a number of the public policy and practice recommendations made in 1991 and 1997. For example, the 1997 IOM report bluntly stated that the federal research effort in the area of disability was inadequate. Despite modest increases in funding during the late 1990s, research spending on disability is miniscule in relation to current and future needs. Medicare, Medicaid, and private health plans continue to apply outdated policies that restrict access to assistive technologies and services. Other significant environmental barriers remain, for example, in hospitals and clinics that lack buildings, equipment, and services suitable for people with mobility, sensory, and other impairments. In 1991, the newly enacted Americans with Disabilities Act (ADA) was a source of great hope for those concerned about such barriers. Although the legislation has helped to increase awareness of the barriers in health care facilities, transportation, workplaces, and elsewhere, its implementation and enforcement have often been disappointing. These and other areas of inaction raise serious questions about how individuals, families, and society will cope with the challenges of disability in America during the coming decades.

This report argues that concerted action—taken sooner rather than later—is essential for this nation to avoid a future of harm and inequity and, instead, to improve the lives of people with disabilities. Its main themes and recommendations can be summarized and grouped around four general topics—disability monitoring, disability research, access to health care and other support services, and public and professional education—and 10 key points. Table S-1 presents an overview of the recommendations by showing the topic areas, the key points within these areas, the relevant actors, and the related recommendations. The complete list of 18 recommendations appears at the end of this summary.

SUMMARY

**TABLE S-1** Report Recommendations in Overview

Actions Needed: Key Points	Primary Actors	Recommendation Number
<i>Disability Monitoring</i>		
Adopt and refine the <i>International Classification of Functioning, Disability and Health</i> .	CDC, U.S. Census Bureau, BLS, ICDR	2.1
Create a comprehensive disability monitoring system.	CDC, U.S. Census Bureau, BLS	2.2
<i>Disability Research</i>		
Fund a program of disability research that is commensurate with the need.	U.S. Congress, NIDRR, NIH, VHA, CDC	6.1
		7.1
		10.1
		10.2
Increase the visibility and coordination of disability research.	U.S. Congress, CDC, U.S. Department of Education, ICDR	10.2
		10.3
<i>Access to Health Care and Support Services</i>		
Improve accessibility in health care facilities and strengthen implementation of the Americans with Disabilities Act.	U.S. Congress, U.S. Department of Justice, accrediting agencies, Access Board	6.2
		6.3
Reduce barriers to health insurance for people with disabilities.	U.S. Congress	8.1
		8.2
Make needed assistive services technologies more available.	Research agencies	7.2
		U.S. Congress, DHHS
Promote models of coordinated chronic care and other strategies to support the transition of young people to adult health care.	Policy makers, professional societies, public and private payers	
		Congress, SSA, CDC, Department of Education; MCHB

*Public and Professional Education*

Develop evidence-based reviews and other tools to support health professionals in caring for people with disabilities.	AHRQ, professional societies, educators, others	5.1 5.2
Launch a campaign to increase public and professional awareness of assistive and accessible technologies.	CDC, NIDRR	7.3

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NOTE: CDC = Centers for Disease Control and Prevention; BLS = Bureau of Labor Statistics, NIH = National Institutes of Health; NIDRR = National Institute on Disability and Rehabilitation Research; AHRQ = Agency for Healthcare Research and Quality; VHA = Veterans Health Administration; DHHS = U.S. Department of Health and Human Services; ICDR = Interagency Committee on Disability Research; MCHB = Maternal and Child Health Bureau; Access Board = Architectural and Transportation Barriers Compliance Board; SSA = Social Security Administration.

## DISABILITY MONITORING

### **Adopt and refine the *International Classification of Functioning, Disability and Health* as the conceptual framework for disability monitoring and research.**

Since publication of the 1991 IOM report, many organizations have taken significant steps to improve disability monitoring, but further improvements are needed. These further improvements include adoption of the *International Classification of Functioning, Disability and Health* (ICF) of the World Health Organization (WHO) as the conceptual framework for disability monitoring and research, promoting improvements in the framework, and working to align measures of disability with the ICF. Achieving agreement on concepts for describing and measuring different aspects of disability should increase the comparability of research findings and make research more useful for decision makers. Directions for improving the ICF framework include further development of the classification of environmental and personal factors that contribute to disability.

Although national and international efforts to develop these refinements are important and although it would be desirable to achieve resolution of these and other issues through WHO, U.S. agencies and researchers can act—as many are already doing—to apply the ICF concepts and terminology. This report follows the ICF by using “disability” as an umbrella term for physical or mental impairments (e.g., limitations in joint mobility), activity limitations (e.g., limitations in dressing), and participation restrictions (e.g., restrictions in working).

### **Create a comprehensive disability monitoring system.**

The lack of a comprehensive disability monitoring program, highlighted in the 1991 IOM report, remains a serious shortcoming in the nation’s health statistics system. Today, disability statistics must be patched together from multiple, often inconsistent surveys. The committee’s

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review suggests that, overall, monitoring efforts continue to fall short of providing the nation with the basic data that it needs to monitor disability and manage for the future.

### DISABILITY RESEARCH

**Fund a program of clinical, health services, social, behavioral, and other disability research that is commensurate with the need.**

Since 1997, rehabilitation and disability research has made some gains at the federal level. Funding has increased modestly for NIDRR, NCMRR, and the Rehabilitation Research and Development Service of the Veterans Health Administration. Overall, however, disability research continues to be funded at levels inconsistent with the current and projected impact of disability on individuals, families, and communities. Spending remains highly skewed toward basic and clinical research, with inadequate support for research on the physical, social, and other environmental contributors to disability and insufficient attention to the evaluation of interventions to minimize activity limitations and participation restrictions. In addition to further research in these areas, another priority is the identification of better strategies to develop and bring to market improved assistive technologies and accessible mainstream technologies.

**Increase the visibility and coordination of federally supported disability research.**

Disability research continues to lack adequate visibility and recognition within federal research agencies. This report reiterates the call for actions to address this problem made in the 1997 report. Among other steps, it proposes that the U.S. Congress consider making NCMRR a full institute or freestanding center within the National Institutes of Health. A similar step would be the creation of an Office of Disability and Health in the director's office at CDC to work with and support the Disability and Health Team in the Center for Birth Defects and Developmental Disabilities and to more fully integrate disability issues into CDC programs.

Inadequate coordination of disability research, highlighted in the 1997 IOM report, also remains a problem. With tighter federal budgets, the advantages of coordination—to avoid an insufficient emphasis on important issues as well as wasteful duplication—are even more important today than they were in 1997. The report recommends a more active role for the existing Interagency Committee on Disability Research in coordinating the identification and administration of high-priority, multiagency research.

### ACCESS TO HEALTH CARE AND SUPPORT SERVICES

**Improve the accessibility of health care facilities and strengthen implementation of the provisions of the ADA related to health care facilities.**

Accessible environments are a matter of equity for adults and children with disabilities. People with mobility, sensory, or other impairments should expect that health care facilities will

be accessible, but instead these facilities often present significant barriers to the receipt of timely, high-quality health care.

Both public and private groups can act to improve access to health care facilities and equipment and strengthen the levels of awareness of and compliance with the relevant provisions of the ADA. The U.S. Department of Justice should continue to vigorously pursue and publicize effective settlements and, if necessary, the litigation of complaints of accessibility violations by major health care institutions. It should also issue and widely disseminate guidelines for health care professionals and executives that describe the government's expectations for compliance with the ADA. Likewise, the Joint Commission and other organizations that accredit health care organizations or that set federal program participation conditions should consider a facility's level of compliance with federal accessibility standards and guidelines in their accreditation and participation decisions. In addition, the Architectural and Transportation Barriers Compliance Board should develop standards for accessible medical equipment to be supported with technical assistance, dissemination, and enforcement by appropriate federal agencies.

### **Reduce barriers to health insurance for people with disabilities.**

Although people with disabilities are slightly more likely than others to have health insurance, especially through public programs, access to insurance is not universal, especially among working-age individuals. To reduce the hardships facing many working-age people who have newly qualified for Social Security Disability Insurance (SSDI), the U.S. Congress should reduce or eliminate the waiting period between the time of qualification and eligibility for Medicare. The U.S. Congress and federal administrative agencies should also continue to test modifications in SSDI and Supplemental Security Income rules that would encourage people who are able to return to work to do so without losing Medicare or Medicaid coverage.

One persistent problem with government efforts to promote competition among managed care and other health plans and to enroll people with disabilities in such plans is that the methods that Medicare and Medicaid use to pay health plans have overpaid for individuals with few health conditions and underpaid for people with serious health conditions or disabilities. Despite recent improvements in Medicare's method for the risk adjustment of health plan payments, it remains financially more attractive for health plans to seek low-risk beneficiaries than to provide efficient, high-quality care to people with chronic health conditions and disabilities. The U.S. Congress should continue to support the research needed to improve risk adjustment methods.

### **Make needed assistive services and technologies more available to people with disabilities.**

Research suggests that assistive technologies are playing important and increasingly prevalent roles in the lives of people with disabilities. One persistent problem that research agencies should further investigate is strategies that can be used to counter the current weak incentives for developing better assistive technologies and bringing them to market.

The committee recommends that policy makers eliminate or modify the "in-home-use" requirement for Medicare coverage of durable medical equipment and revise coverage criteria to consider the contribution of a technology to an individual's independence and participation in community life, including work. Policy makers should also investigate new approaches for

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supplying covered technologies and providing timely and appropriate repairs to equipment that is damaged or not working.

### **Promote models of coordinated chronic care and other strategies for improving the transition of young people from pediatric to adult health care.**

For many young people with disabilities, the transition from pediatric to adult health care brings complex challenges. These challenges include the fragmented organization and financing of health care, dysfunctional provider reimbursement methods, and the limited adoption of sophisticated information technology to support information exchange among the generalists and the specialists who care for young people with complex health conditions.

The convergence of the medical home model of care for children with special health care needs and the chronic care model designed primarily with adults in mind offers much promise. If the principles and practices underlying these models were widely adopted, young people would be much more likely to receive the comprehensive assessments, guidance, and services that correspond to the recommendations of professional societies for managing the transition from pediatric to adult health care. Among other steps needed to support the successful movement of young people from pediatric to adult care, the U.S. Congress should extend Medicaid and State Children's Health Insurance Program coverage through age 21 for all beneficiaries with chronic conditions or disabilities and specify that program benefits cover appropriate transition assessment, coordination, and management services for these young people.

## **PUBLIC AND PROFESSIONAL EDUCATION**

### **Develop educational programs, evidence-based reviews, practice guidelines, and other materials to support health professionals in caring for people with disabilities.**

Health care professionals are not necessarily well informed about the primary health care needs of people with disabilities, the prevention and management of secondary health conditions, the challenges that adults face in aging with disabilities, and the transition of young people with disabilities from pediatric to adult services. Among other actions, this report recommends strengthening education in chronic illness and disability management in curricula for health care professionals, including education on the specific topics of secondary conditions and aging with disability.

To increase awareness of the secondary conditions and premature aging associated with many chronic health conditions and disabilities, the report also encourages the development of systematic reviews of existing evidence, the identification of knowledge gaps, and the formulation of evidence-based guidelines. These reviews can be used as the basis for collaborative efforts by professional societies, people with disabilities, and others to develop clinical practice guidelines, guides for consumers, and other educational materials.

## **Launch a national public health campaign to increase public and health care professional awareness of assistive and accessible technologies.**

Health care professionals also face difficulties in keeping abreast of developments in assistive technologies and their use. People with disabilities may themselves be unaware of technologies that could help them lead easier and more independent lives. The report recommends that the CDC collaborate with other public and private groups to launch a national campaign to increase public and health care professional awareness and acceptance of the assistive and accessible technologies that can benefit people with disabilities.

## **CHOOSING THE FUTURE FOR DISABILITY IN AMERICA**

Given the demographic, societal, and disability trends outlined above and discussed in detail within this report, a critical question is: how will Americans individually and collectively make the choices that will help define the future of disability? That is, will the country commit to actions to limit the development and progression of physical and mental impairments in late life, promote good health for children and young adults with early-onset disability, and reduce environmental barriers for people with existing impairments? The record of the past 17 years offers reasons for serious concern, especially given the cost projections for public programs that are critical to people with disabilities.

The trade-offs or choices that Americans make about future spending will reflect their fundamental values about the balance between community and individual responsibility. Still, it should be recognized that health, social, and other policies that assist people with disabilities do not only represent current transfers of resources from those without disabilities to those with disabilities—or from mostly younger people to mostly older people. Over their life spans, the majority of Americans will experience disabilities or will have family members who do. People may not realize it, but the support that they give today for policies that affect future funding for disability-related programs is a statement about the level of support that they can expect at later stages in their own lives.

This report underscores the growing evidence that disability is not an unavoidable consequence of injury and chronic disease but is substantially affected by the actions that society takes—in the public arena and in commerce and other private domains. Ultimately, the future of disability in America rests with Americans.

## **COMPLETE LIST OF RECOMMENDATIONS**

### *Disability Monitoring*

**RECOMMENDATION 2.1:** The National Center for Health Statistics, the U.S. Census Bureau, the Bureau of Labor Statistics, and other relevant government units involved in disability monitoring should adopt the *International Classification of Functioning, Health and Disability* (ICF) as their conceptual framework and should actively promote continued refinements to improve the framework's scope and utility for disability monitoring and research. The Interagency Subcommittee on Disability Statistics of the Interagency Committee on Disability Research should coordinate the work of these agencies to

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develop, test, validate, and implement new measures of disability that correspond to the components of the ICF, consistent with public policy priorities.

**RECOMMENDATION 2.2:** The National Center for Health Statistics, in collaboration with other relevant federal agencies, should continue to improve the scope and quality of data—including longitudinal or panel data—on disability, its causes, and its consequences. These improved data sources should serve as the cornerstone of a new national disability monitoring system.

### *Health Care Transitions, Secondary Conditions, and Aging with Disability*

**RECOMMENDATION 4.1:** To improve the transition of young people with disabilities from pediatric to adult health care, policy makers, professional societies, public and private payers, and educators should work to

- align and strengthen incentives in public and private health care programs to support coordinated care and transition planning;
- expand the use of integrated electronic medical records for chronic disease management and during the transition of young people with disabilities from pediatric to adult health care; and
- expand chronic care education in pediatric and internal medicine residency programs and add skills in the management of individuals with chronic health care needs to specialty board requirements.

**RECOMMENDATION 4.2:** To support the successful transition of young people with disabilities from pediatric to adult health care and independent living, the U.S. Congress should

- extend Medicaid and State Children's Health Insurance Program (SCHIP) coverage through age 21 for children with disabilities and specify that Medicaid and SCHIP benefits cover transition assessment, coordination, and management services for these young people;
- fund the U.S. Maternal and Child Health Bureau to expand its work to develop and implement medical home and other services for young people with special health care needs who are over age 21 and who need continued transition support;
- revise the Ticket to Work program by lowering the eligibility age to 16 years and directing the U.S. Department of Education and the Social Security Administration to develop guidance for the coordination of Ticket to Work services with the transition services and supports provided under the Individuals with Disabilities Education Act; and
- direct the Centers for Disease Control and Prevention to work with other relevant agencies to examine opportunities for the monitoring of transitions through additions to state and national youth surveys or other cross-sectional and longitudinal data collection efforts.

**RECOMMENDATION 5.1:** The U.S. Congress should direct and fund the Agency for Healthcare Research and Quality so that it may take the lead in

- evaluating the evidence base to support the development of clinical practice guidelines, quality goals, and monitoring standards for the prevention and management of secondary health conditions among people with disabilities and for the monitoring and management of people aging with disability;
- evaluating the evidence base about environmental contributors to secondary health conditions; and
- identifying research gaps and directions for further research on secondary health conditions and aging with disability.

**RECOMMENDATION 5.2:** As part of broader efforts to improve the quality of care provided to people with disabilities, health care professionals, educators, people with disabilities, and their family members should work together to

- develop, disseminate, and apply guidelines for the prevention and management of secondary conditions and for the monitoring and care of people aging with disability;
- design educational modules and other curriculum tools for all relevant types of health care professionals and all levels of education; and
- develop competency standards for these educational programs.

### *Environmental Barriers*

**RECOMMENDATION 6.1:** Given the limited research on the effects of environmental factors on disability, the National Institute on Disability and Rehabilitation Research, the National Institutes of Health, the Veterans Health Administration, the Centers for Disease Control and Prevention, and other relevant agencies should collaborate to develop a program of research in this area. As part of developing such a program, these agencies should

- organize a symposium to engage people with disabilities, relevant governmental agencies, researchers, methodologists, and other interested parties in a collaborative process to recommend priorities for research on environmental factors, as defined in the *International Classification of Functioning, Disability and Health*;
- apply these priorities in a plan for outcomes research to investigate the relative effects of different aspects of the environment on disability; and
- intensify current efforts to improve epidemiological, observational, and experimental measures and methods to assess the effects of specific environmental features on independence, participation, and quality of life over the short term and long term for people with disabilities.

**RECOMMENDATION 6.2:** To improve the accessibility of health care facilities and equipment and to strengthen the awareness of and compliance with the provisions of the Americans with Disabilities Act related to accessible health care facilities,

- the U.S. Department of Justice should continue to vigorously pursue and publicize effective settlements and litigation (if necessary) of complaints of accessibility violations in major health care institutions;
- the U.S. Department of Justice should issue and widely disseminate guidelines for health care providers that describe expectations for compliance with the accessibility provisions of the act; and
- the Joint Commission and other organizations that accredit or set federal program participation conditions for health care organizations should explicitly consider compliance with federal accessibility standards and guidelines in making their accreditation and participation decisions.

**RECOMMENDATION 6.3:** The U.S. Congress should direct the Architectural and Transportation Barriers Compliance Board (the Access Board)

- to develop standards for accessible medical equipment to be supported with technical assistance and with dissemination and enforcement efforts by the appropriate federal agencies and
- to collaborate with the U.S. Department of Veterans Affairs, groups representing people with disabilities, and other relevant experts to assess whether the accessibility standards developed by the Access Board are appropriate for health care facilities serving people with disabilities and an aging population.

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### *Assistive and Accessible Technologies*

**RECOMMENDATION 7.1:** Federal agencies that support research on assistive technologies should collaborate on a program of research to improve strategies to identify, develop, and bring to market new or better assistive technologies for people with disabilities. Such research should involve consumers, manufacturers, medical and technical experts, and other relevant agencies and stakeholders.

**RECOMMENDATION 7.2:** To extend the benefits of accessibility provided by existing federal statutes and regulations, the U.S. Congress should direct the Architectural and Transportation Barriers Compliance Board (the Access Board) to collaborate with relevant public and private groups to develop a plan for establishing accessibility standards for important mainstream and general use products and technologies. The plan should

- propose criteria and processes for designating high-priority product areas for standard setting;
- identify existing public or private standards or guidelines that might be useful in setting standards; and
- include medical equipment as an initial priority area.

**RECOMMENDATION 7.3:** The Centers for Disease Control and Prevention, working with the National Institute on Disability and Rehabilitation Research, should launch a major public health campaign to increase public and health professional awareness and acceptance of assistive technologies and accessible mainstream technologies that can benefit people with different kinds of disabilities.

**RECOMMENDATION 8.1:** The U.S. Congress should support continued research and data collection efforts to

- evaluate and improve the accuracy and fairness of methods of risk adjusting payments to health plans serving Medicare and Medicaid beneficiaries with disabilities;
- assess how these methods affect the quality of care for people with disabilities, including those enrolled in special needs plans; and
- evaluate differences in the risk adjustment methods that state Medicaid programs use to pay health plans that enroll people with disabilities.

**RECOMMENDATION 8.2:** To improve access to health insurance for people with disabilities, the U.S. Congress should

- adopt a plan to reduce or eliminate the 24-month waiting period for Medicare eligibility for people who have newly qualified for Social Security Disability Insurance;
- encourage continued testing of methods to reduce disincentives in public insurance programs for people with disabilities to return to work; and
- direct states to limit recertification and reenrollment for the State Children's Health Insurance Program to no more than once a year for children with disabilities.

**RECOMMENDATION 9.1:** The U.S. Congress and the U.S. Department of Health and Human Services should begin a process of revising Medicare and Medicaid laws and regulations and other relevant policies to make needed assistive services and technologies more available to people with disabilities and to put more emphasis on beneficiaries' functional capacities, quality of life, and ability to participate in work, school, and other areas of community life. Priorities include

- eliminating or modifying Medicare's "in-home-use" requirement for durable medical equipment and revising coverage criteria to consider the contribution of these devices and equipment to an individual's independence and participation in community life;

- evaluating new approaches for supplying assistive technologies (such as time-limited rentals and recycling of used equipment) and providing timely and appropriate equipment repairs; and
- continuing research to assess and improve the appropriateness, quality, and cost-effectiveness of the assistive services and technologies provided to people with disabilities.

### *Organizing and Financing Disability Research*

**RECOMMENDATION 10.1:** Federal agencies should invest in a coordinated program to develop, test, and disseminate promising interventions, practices, and programs to minimize activity limitations and participation restrictions and improve the quality of life of people with disabilities.

**RECOMMENDATION 10.2:** To support a program of disability research that is commensurate with the need for better knowledge about all aspects of disability at the individual and the societal levels, the U.S. Congress should increase the total amount of public funding provided for disability research. To strengthen the management and raise the profile of this research, the U.S. Congress should also consider

- elevating the National Center for Medical Rehabilitation Research to the status of a full institute or freestanding center within the National Institutes of Health with its own budget;
- creating an Office of Disability and Health in the Director's Office at the Centers for Disease Control and Prevention (CDC) to promote the integration of disability issues into all CDC programs; and
- directing the U.S. Department of Education to support the National Institute on Disability and Rehabilitation Research in continuing to upgrade its research review process and grants program administration.

**RECOMMENDATION 10.3:** To facilitate cross-agency strategic planning and priority setting around disability research and to expand efforts to reduce duplication across agencies engaged in disability research, the U.S. Congress should authorize and fund the Interagency Committee on Disability Research to

- undertake a government-wide inventory of disability research activities using the *International Classification of Functioning, Disability and Health*;
  - identify underemphasized or duplicative areas of research;
  - develop priorities for research that would benefit from multiagency collaboration;
  - collaborate with individual agencies to review, fund, and administer this research portfolio;
- and
- appoint a public-private advisory committee that actively involves people with disabilities and other relevant stakeholders to provide advice on the activities described above.

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Committee on Disability in America  
Board on Health Sciences Policy

Marilyn J. Field and Alan Jette, *Editors*

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*“Knowing is not enough; we must apply.  
Willing is not enough; we must do.”*

—Goethe



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## Reviewers

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published reports as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations, nor did they see the final draft of the report before its release. The review of this report was overseen by **George W. Rutherford**, University of California at San Francisco School of Medicine, and **Elena O. Nightingale**, Institute of Medicine. Appointed by the National Research Council and the Institute of Medicine, these individuals were responsible for making certain that an independent examination of this report was carried out in accordance with the institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

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## Preface

The 1991 Institute of Medicine (IOM) report *Disability in America: Toward a National Agenda for Prevention* identified disability as a significant social, public health, and moral issue that affects every individual, family, and community across America. This seminal volume articulated a series of comprehensive changes necessary to prevent disability in American society. Its recommendations included, for example, the development of new public and private leadership in disability prevention, the adoption of a unified conceptual framework to guide collaborative research, a national disability surveillance system, a comprehensive research program, coordinated approaches to delivering health and social services, and professional and public education to promote enlightened attitudes about disability. In 1997, the IOM followed with a second report, entitled *Enabling America: Assessing the Role of Rehabilitation Science and Engineering*, which critically evaluated the current federal programmatic efforts in science and engineering related to rehabilitation and disability. The 1997 IOM report called attention to the major shortcomings in the organization and administration of federal research programs pertinent to disability and rehabilitation. In doing so, it set forth a series of specific recommendations for more research, improved coordination, and a need for enhanced visibility of rehabilitation-related research within federal research programs.

Beginning in the fall of 2005, a dedicated group of clinicians, researchers, and consumers have collaborated in reviewing the nation's progress on disability since 1991 and 1997. As chair, I have had the privilege of working with an outstanding group of individuals who, despite their diverse backgrounds and disparate perspectives, listened, probed, and discussed to reach a consensus around our major findings and recommendations presented in this report. Let me thank each of them, along with our outstanding IOM staff, particularly Marilyn Field, the project director, who did an outstanding job of guiding us in our work. I also wish to extend my gratitude to numerous other individuals and organizations (listed in Appendix A) who provided us with information, background papers, and other assistance in our work.

Our conclusions, as detailed in this report, entitled *The Future of Disability in America*, document the sobering reality that far too little progress has been made in the last two decades to prepare for the aging of the baby boom generation and to remove the

obstacles that limit what too many people with physical and cognitive impairments can achieve. Disturbingly, many of the major recommendations contained in the two earlier reports have received little or no serious consideration, and they remain as germane today as they were in 1991 and 1997. This report therefore reiterates several still pertinent goals from the earlier reports and offers new recommendations that, if enacted promptly, could create a future in which Americans of all abilities and ages can participate fully in society.

After reviewing the state of disability in America, the committee concluded that although important progress has been made over the past 17 years in our understanding of disability, its causes, and strategies that can prevent its onset and progression, society must do more now before a crisis is upon us. The chapters in this report cover a broad range of critical topics, including the prevention of secondary conditions, the role of technology and universal design, selected issues in health care organization and financing, as well as the environmental context of disability.

Our society faces several fundamental challenges, which are highlighted within this report. Will this country commit to actions that will limit the progression of physical and mental impairments into disabilities and prevent the development of secondary conditions? Will society provide affordable and accessible health care and technological aids that promote good health and maximize societal participation for people with disability? Will society reduce environmental barriers for people with existing impairments? And will society demand that all levels of government invest in more research, the improved coordination of research, and the need for the enhanced visibility of disability-related research within our public research programs? The answers to these questions will undoubtedly define the future of disability in America and leave lasting legacies for future generations.

The poet Archibald MacLeish once wrote, “America was always promises.” There is still much work to do, but never have America’s promises been within closer reach for people with disabilities, if only we harness the innovative spirit of American science and industry, promote and assist compliance with existing civil rights legislation, and remove outdated restrictions in public and private health plans. Working together, I know that we can transform the future of disability in America.

Alan M. Jette, *Chair*  
April 2007

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