

REPORT BRIEF • APRIL 2007

## THE FUTURE OF DISABILITY IN AMERICA

Today more than 40 million Americans live with a disability. If we consider people who now have disabilities, people who are likely to develop disabilities, and people who are or will be affected by the disabilities of family members and others close to them, then disability will affect the lives of most Americans. Members of the baby boom generation—people born between 1946 and 1964—face an especially uncertain future as they grow older, as their risk of disability increases, and as programs such as Social Security and Medicare face serious funding challenges.

Disability in the form of limited activities and restricted participation in social life is not an unavoidable result of injury and chronic disease. It results, in part, from choices society makes about working conditions, health care, transportation, housing, and other aspects of our environment. The United States faces important decisions that could reduce—or increase—the extent to which people can live independently and be involved in their communities. Inaction may lead to diminished quality of life, increased stress on individuals and families, and lost productivity.

To better understand disability in the United States, the Centers for Disease Control, the Department of Education, and the National Institutes of Health (NIH) asked the Institute of Medicine (IOM) to assess the current situation and provide recommendations for improvement, which culminated in the report *The Future of Disability in America*. The committee reviewed the developments since two previous IOM reports on disability, analyzed a number of shortcomings in the nation's disability policies and programs, and raised serious questions about how individuals and society will cope with the challenges of disability. This report concludes that immediate action is essential for the nation to avoid harm and to help people with disabilities lead independent and productive lives.

### DEVELOPMENTS IN DISABILITY SINCE THE 1990s

In 1991, the IOM report *Disability in America* focused on the prevention of injuries, chronic illnesses, and other conditions that contribute to disability. The 1997 report *Enabling America* examined rehabilitation science and engineering. Both reports highlighted disability as a significant topic of public health action and scientific inquiry. They emphasized that disability is not an inherent attribute of the individual but that it results from interactions with the physical and social environment.

Some progress has been made since the release of these widely cited reports. The growth of assistive and “mainstream” electronic technologies allows many people to interact more easily with their environments. Advances in public health and medicine have contributed to reduced incidences of certain injuries, developmental disorders, and other potentially disabling health conditions.



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However, too little progress has been made in adopting the major public policy and practice recommendations made in the 1991 and 1997 IOM reports. Due in part to inadequate implementation and enforcement, the 1991 Americans with Disability Act (ADA) has not lived up to its promise. Physical and other barriers still exist in many places—even hospitals and medical offices. Research spending on disability is inadequate. Medicare, Medicaid, and private health plans employ outdated policies for covering assistive technologies and services.

## **DISABILITY MONITORING**

A number of federal agencies are involved in disability monitoring, including the National Center for Health Statistics, the Census Bureau, and the Bureau of Labor Statistics. The new report encourages these agencies to adopt the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) as their conceptual framework. Using the ICF would help standardize how agencies describe and measure different aspects of disability, which would improve the clarity and comparability of research findings and strengthen the base of scientific knowledge that guides public policies and health practices.

This report reiterates the absence of a comprehensive disability monitoring system, first noted in the 1991 IOM report, and recommends creating one. This will help the United States to more accurately monitor disability and provide information important to policymakers.

## **DISABILITY RESEARCH**

Despite the personal and societal impact of disability, funding for the National Institute on Disability and Rehabilitation Research, the National Center for Medical Rehabilitation Research, and the Veterans Health Administration Rehabilitation Research and Development Service has increased only modestly since the 1997 IOM report. The current report recommends increasing public funding to support a program for research in these and other agencies that is commensurate with the need. Additionally, the visibility of federal rehabilitation and disability research within federal research agencies should be enhanced. Both the 1997 and 2007 reports recommend elevating the National Center for Medical Rehabilitation Research to the status of a full institute or free-standing center within the NIH.

Agencies already engaged in disability research should coordinate their activities in order to reduce wasteful duplication of effort and identify neglected research issues. In particular, federal funding agencies should invest more in the development, testing, and dissemination of promising interventions that will help people maintain their independence and ability to function in community life.

## **ACCESS TO HEALTH CARE AND SUPPORT SERVICES**

Health plan policies that limit coverage for assistive technologies and services are a major obstacle for people with disabilities. The report recommends that policymakers eliminate or modify the “in-home-use” requirement in the Medicare statute and regulations. This provision keeps many from obtaining scooters and wheelchairs that would allow them to navigate reliably and safely outside the home. Criteria for covering technologies should consider their effects on an individual’s participation in the community, including employment. The Department of Justice should strengthen enforcement of the ADA and offer providers better guidance about their responsibilities under the ADA.

The report also notes that most working-age people who qualify for Social Security Disability Insurance (SSDI) must wait 24 months after the start of SSDI benefits before they are eligible for Medicare; many have no health insurance during this period. Congress should reduce or eliminate this waiting period. In addition, Congress and administrative agencies should 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.

Moreover, young people with disabilities face many challenges when they move from pediatric to adult health care. Promoting further development of the medical home and chronic care models of care, including changes in Medicaid and the State Child Health Insurance Program, would help ease this transition and improve the quality of care throughout people's lives.

## **PUBLIC AND PROFESSIONAL EDUCATION**

Although people with disabilities often receive care from rehabilitation specialists, they also depend on other health care professionals for primary care and services unrelated to their specific conditions. These professionals are not necessarily well-informed about proper primary care for people with disabilities, the problems these people face as they age, the barriers that our current health care system creates, and the ways that assistive technologies can enhance people's independence and productivity. Educators, practitioners, and consumers should develop curricula and competency standards to better prepare professionals to care for people with disabilities.

In addition, federal agencies should launch a major public information campaign to increase professional and consumer awareness and acceptance of assistive and accessible mainstream technologies that could benefit people affected by a range of limitations. To increase professional and consumer awareness of aging with disability and secondary health conditions, the Agency for Healthcare Research and Quality should take the lead in developing evidence reviews that could be used as the basis for professionals, consumer organizations, and others to collaborate in developing clinical practice and consumer guidelines.

All of these recommendations reflect the mounting evidence that much disability results from societal decisions and is avoidable. Ultimately, the future of disability in America rests with Americans.

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### **FOR MORE INFORMATION...**

Copies of *Future of Disability in America*, are available from the National Academies Press, 500 Fifth Street, N.W., Lockbox 285, Washington, DC 20055; (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area); Internet, <http://www.nap.edu>. The full text of this report is available at <http://www.nap.edu>.

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