

## Current Research

### **Healthy People Two Thousand National Health Promotion and Disease Objectives:**

#### **People with Disabilities**

**An Address on January 23, 1997**

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I bring you greetings from the Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS), Judy Heumann. Judy and I want to take this opportunity to express our appreciation to Dr. Phil Lee and members of the Healthy People 2000 Working Group on People with Disabilities for their work. OSERS and the National Institute on Disability and Rehabilitation Research (NIDRR) have a keen interest in and involvement with this Progress Review of the Healthy People 2000 disability objectives and in setting the stage for development of the 2010 objectives. These objectives are a bridge to the 21st century.

#### Paradigm Change

Within the disability community both consumers and researchers have struggled with a linear model in which impairment is assumed to cause disability with resulting disadvantages. This is a limited and static view of health

which suggests the absence of disease or, at best, the prevention of disease. However the reality of disability is often that people with disabilities enjoy good health, but live in a hostile environment. I cannot use the telephone without assistance; thus, I have one IADL; the Assistant Secretary has more. Using a dynamic and more ecologically informed model of health will permit us to work within the new paradigm. Health objectives for people with disabilities will include personal assistance and technological applications in personal devices, housing, communications, and transportation.

Many of you have been engaged in the development of the paradigmatic change in which an individual with disability is viewed not simply in reductive terms of impairment, but in holistic terms, much like other people. This view incorporates medical factors with psychosocial and environmental factors. The new paradigm has been referred to as an integration paradigm, a civil right paradigm, an independent living paradigm, and a socio-political paradigm. The integrative paradigm recognizes that disability is a relationship between impairment and the environment. Whatever the new paradigm is called, there is no doubt that it serves as the beacon of information to guide Disability Policy.

#### Partnership between Individuals with Disabilities, Researchers and Providers

The new paradigm was developed by people with disabilities and researchers and providers who recognize the impacts on disability of the extraordinary advances in medicine and engineering. Many individuals with disabilities live the issues, including the relationship between aging with a disability and cardiac arrest. In the last two years, a number of disability leaders, such as Ed Roberts and Irv Zola, have died from cardiac arrest in middle age. From the standpoint of the mortality norm, they died early; from the standpoint of the 19th century, they had long lives. For the twenty-first century, more people will live longer with disabilities and use

supports. The joint efforts of health care professionals and those who walk and roll the talk does and will result in a more robust and legitimate set of health objectives.

Today, NIDRR/OSERS, CDC, ASPE, HCFA, ADD, and other health-related agencies are working more closely together to address issues areas such as managed care, secondary conditions, exercise regimes and disability statistics. The disability community has articulated its concerns about these issues and, I believe, supports research and demonstrations to further them. Healthy People 2000 is on target here. But there are many challenges in identifying and addressing issues using the organizational framework of the new paradigm. For example, measurement of secondary conditions, such as decubitus ulcers, must include factors such as wheelchair seating and positioning.

#### The Challenge to Healthy People 2000 Working Group

Lack of independence in home management and self care activities does not automatically mean disability in other important life activities. Some people who need assistance in IADL or ADL can work. Such limitations may be offset by personal assistance, assistive technology, and environmental accommodations required by civil rights legislation. How are disabling conditions affected by the use of assistive technology, and rehabilitation and medical engineering interventions? How are the Healthy People 2000 and 2010 objectives affected by these and do you have the flexibility to modify these objectives as needed? How do you measure the use of hearing aids, eyeglasses, computers, communication boards, new medication techniques, wheelchair design, and ADA worksite accommodations? How can you incorporate assistive technology and personal assistance into the objectives? How can you show improvement if you do not incorporate assistive technology and personal assistance into the objectives?

To build a bridge to the 21st century we would be remiss if we did not recognize and apply our formidable energies to incorporating the products of bioengineering, rehabilitation, and assistive technology into our measures and to incorporate the values of the Americans with Disabilities Act. While the field of health must be joined with medicine, it also must keep pace with a society in which so much change is generated by technological applications and civil rights. Indeed, these objectives must be sensitive to the differences between those with chronic illness and those with disabilities.

We are among the bridge builders as well as a part of the crowd crossing the bridge. Should the bridge support a broad range of abilities among the multitudes who cross, we can take quiet pleasure in our accomplishments.

NIDRR/OSERS looks forward to these challenges and to working with other agencies and the disability community to develop and implement futuristic and dynamic health objectives for the Third Millennium.

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