

The Surgeon General's

Call to Action to Improve the Health and Wellness of Persons with Disabilities 2005

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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Message from Michael O. Leavitt

Secretary of Health and Human Services

Individuals with disabilities are newborn infants, children, teens, working-age adults and older adults of all races and ethnicities. They live in towns, cities and rural areas. They attend schools and places of worship, vote, marry, have children, work and play. They also need health care and health promotion programs for the same reasons we all do: to stay well, to be active and to participate in community life.

This Surgeon General's *Call to Action to Improve the Health and Wellness of Persons with Disabilities* emphasizes the centrality of health to the quality of our lives. Developed by the Surgeon General in collaboration with the Department's Office on Disability, it describes the particular challenges to health and well-being faced by persons of all ages with disabilities. It places their health squarely among the public health issues at the forefront of research, service delivery, financing, training and education and health care policy today. It also builds upon the Nation's efforts to promote wellness and disease prevention in all persons, including those with disabilities, as called for in the President's HealthierUS Initiative.

Just as the Americans with Disabilities Act of 1990 and President George W. Bush's New Freedom Initiative have opened doors for persons with disabilities through equal access and inclusion, the overarching principle of this *Call to Action* recognizes that with good health, persons with disabilities have the freedom to work, learn and engage actively in their families and their communities. In other words, health and wellness is a key component to realizing the central principles of the NFI—the assurance of educational opportunity, workforce engagement and full access into daily community life.

It will take effort by all members of society to achieve this principle. Everyone has a role to play in improving health and wellness, from health care and service support providers, training institutions, federal, state, local and tribal governments, the private sector and the media, to persons with disabilities and their families and community groups nationwide.

I wholeheartedly endorse this *Call to Action*. I encourage you to join me in making a healthier U.S. for all of us.

Foreword

*from the Surgeon General,
U.S. Department of Health and Human Services*

Since 1900, the nation has witnessed unprecedented improvement in the health of its people thanks, in large part, to the public health movement that works to prevent disease and its spread, and to promote mental, physical and emotional well-being. As a result of a century of public health initiatives, such as vaccinations, improved nutrition and sanitation, and new treatments to combat acute illnesses, millions of people have led longer, healthier lives. As a result, the emphasis of the nation's work in public health has shifted from a focus solely on acute illnesses to a more balanced approach that has added attention to chronic medical conditions and the factors that cause them.

The perception of disability—a condition of the body, mind, or senses of a person of any age that may affect the ability to work, learn or participate in community life—also is in transition. With the recognition that disability is not an illness, the emphasis increasingly is on continuity of care and the relationship between a person with a disability and the environment at the physical, emotional and environmental levels. This approach is based on the knowledge that good health means the same thing for everyone, and that the best possible health status and quality of years of life should be a goal for everyone, whether experiencing a disability or not.

Today, 54 million Americans—more than one fifth of us—are living with at least one disability. Some individuals are born with a disability; others acquire disabilities over the course of their lifetime. At any time, each of us is at risk for acquiring a disability, whether through an illness, an injury, genetics, or any number of other causes. With the “baby boom” generation approaching later life, there will be increased numbers of persons with or at risk for a disability. The sheer numbers of persons with disabilities today and tomorrow mean that disability is an issue for the nation as a whole, not just for those of us concerned about public health.

This *Call to Action to Improve the Health and Wellness of Persons with Disabilities* is built on the need to promote accessible, comprehensive health care that enables persons with disabilities to have a full life in the community with integrated services, consistent with the President's New Freedom Initiative. Persons with disabilities must have accessible, available and appropriate health care and wellness promotion services. They need to know how to—and to be able to—protect, preserve and improve their health in the same ways as everyone else. This *Call to Action* encourages health care providers to see and treat the whole person, not just the disability; educators to teach about disability; a public to see an individual's abilities, not just his or her disability; and a community to ensure accessible health care and wellness services for persons with disabilities.

This volume provides a roadmap for change. It delineates the challenges and strategies to address this critical public health concern. Because it is based on input not only from health specialists in the disability field, but also from individuals with disabilities and their family members, this *Call to Action* presents not just a scientific perspective on disability, but also the reality experienced by those living daily with disabilities.

This *Call to Action* can, and must, resonate with community leaders in both the public and private sectors (including employers and the media) and with policymakers who craft or influence the creation of community programs. The principle and goals of this document can both incentivize and yield dividends for employers of persons with disabilities, including greater productivity and lower overall health costs by preventing illnesses and injuries secondary to a disability. Advocates for persons with disabilities can use this *Call to Action* to promote the involvement of individuals with disabilities as equal partners in all aspects of American life. With concerted action—undertaken through public-private partnerships spanning all levels of government and all service, education and research systems—the full potential of legal, health policy and health program initiatives to improve access to health and wellness services by persons with disabilities can be realized.

Richard Carmona, M.D., M.P.H., F.A.C.S.
Surgeon General

I. Introduction

Today, approximately 54 million individuals of all ages, races, ethnicities, socioeconomic status and educational attainment in the United States live with at least one disability (McNeil 2001; 1997) (See Figure 1). Disabilities have been defined in many ways. In general, however, disabilities are characteristics of the body, mind, or senses that, to a greater or lesser extent, affect a person’s ability to engage in some or all aspects of day-to-day life. Some disabilities are visible; others are not. Some are physical, some visual or auditory, some developmental or cognitive, and some mental or behavioral. Some persons are born with one or more disabilities; others acquire a disability during the course of a lifetime. Most individuals in the United States will experience a disability of some duration at some point in their lives.

Different kinds of disabilities affect people in different ways. No single disabling condition necessarily affects one person in exactly the same way as it does another. Yet, persons with disabilities of all kinds share many of the same challenges when it comes to their own health and well-being.

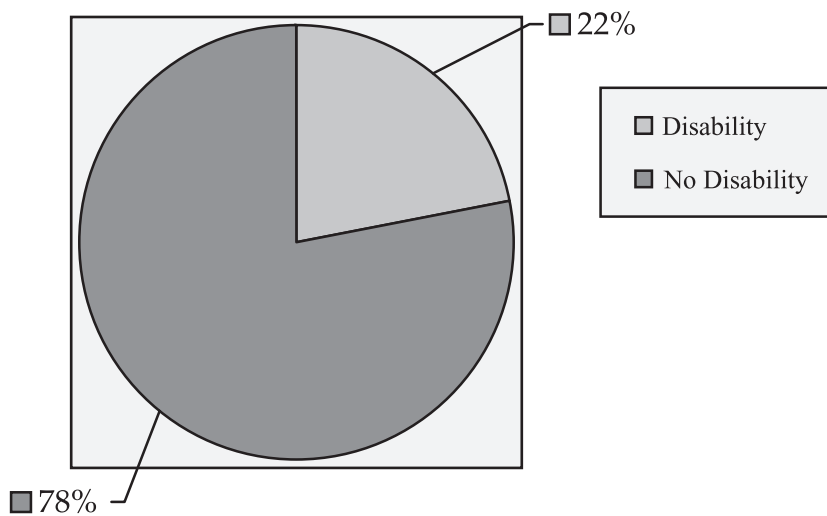
Disability is not an illness. The concept of health means the same for persons with or without disabilities: achieving and sustaining an optimal level of wellness—both physical and mental—that promotes a fullness of life (Krahn 2003). For persons with disabilities, as for

those without disabilities, to be healthy, it means having the tools and knowledge to help promote wellness and knowing the risk factors that can promote illness and the protective factors that can prevent it. For persons with all kinds of disabilities it also means knowing that conditions secondary to a disability—from pain to depression and from urinary tract infections to heightened susceptibility to acute illnesses—can be treated successfully. Health also means that persons with disabilities can access appropriate, integrated, culturally sensitive and respectful health care that meets the needs of a whole person, not just a disability.

When it comes to focusing attention on meeting those health care challenges for persons with disabilities, Clancy and Andresen (2002) assert that “healthcare delivery has been slower to come to the fore than other areas.” Thus, while much has been accomplished through such efforts as the Americans with Disabilities Act (1990), the President’s New Freedom Initiative, his HealthierUS initiative, and the U.S. Department of Health and Human Services’ Healthy People, much more remains to be done. Challenges to the health and wellness of persons with disabilities continue, as does the need to meet those challenges and overcome them.

Some of the challenges arise from insufficient knowledge and awareness; some arise from provider and community attitudes and behaviors. Some chal-

Figure 1: Percentage of Americans With Disabilities (based on McNeil 2001)



lenges are the result of inadequate access to information and opportunities for appropriate health care and wellness promotion. Still others are the product of service systems that do not always make use of innovative and creative approaches to enhancing the health and wellness of persons with disabilities.

This *Call to Action* responds to those challenges. It is based on a simple principle: good health is necessary for persons with disabilities to secure the freedom to work, learn and engage in their families and communities. The *Call to Action* further delineates four specific goals:

GOAL 1: People nationwide understand that persons with disabilities can lead long, healthy, productive lives.

GOAL 2: Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.

GOAL 3: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.

GOAL 4: Accessible health care and support services promote independence for persons with disabilities.

This *Call to Action* helps identify barriers to overcome and suggests direction to improve the health and wellness of persons with disabilities and to promote their engagement in school, in work, in worship, in family and in the overall fabric of life in ways unimagined a century ago. It sets forth a vision for the future and challenges America to action. The work to achieve the vision of this *Call to Action*, however, must take place at the federal, state, tribal and community levels in policy and programs; in infrastructure and education; and in the hearts, minds and actions of persons with disabilities and their families, health care providers—including paraprofessionals and professionals—in the health care system, and a concerned, informed public.

The *Call to Action* was developed by the Surgeon General in collaboration with the Department's Office on Disability. In order to ensure input from the disability community, a focus group was held in October of 2004 in which nine individuals of varying disabilities were invited to participate. The focus group received a

A Personal Story—Access Ignored

I was so frustrated at having to tell the people in the emergency room "I can't get up on the gurney; I can't stand up to do this; you're going to have to get someone to help me get on this examination table" ... and they just look at you like, "Hey, what's the problem?"

presentation on the report from the Office on Disability. Overall, participants had a favorable reaction to the draft and their additional comments and suggestions were incorporated into the final version of the *Call to Action*.

II. Understanding Disability

Challenges to a person's health can happen to anyone, at any age and at any time as a result of any number of different causes. When limitations related to a medical condition arise and begin to have a negative effect on essential life functions, such as walking, talking, seeing, hearing, or working (functions often referred to as "Activities of Daily Living" (ADLs), a person is said to have a disability. When it comes to health and wellness of persons with disabilities, in many ways, each of the individuals described here and in the personal stories throughout this *Call to Action* faces a comparable challenge. It is the challenge to be seen, acknowledged and heard as a whole person with a range of health service and wellness promotion needs and not to be viewed solely through the prism of disability.

No one is immune from the potential onset of a disability: An infant can be born with profound deafness; a child can become paralyzed from a playground injury; a young adult can develop depression and drug abuse; a woman in her early 30s can be diagnosed with multiple sclerosis; a man in midlife can develop Type II diabetes; and an older adult can lose vision because of glaucoma.

It is important to recognize that disability is not an illness. Just as health and illness exist along a continuum, so, too, does disability. Just as the same illnesses can vary in intensity from person to person, so, too, can the same condition lead to greater or lesser limitation in activity from one person to another. Some persons with disabilities never perceive themselves as being disabled. Some medical conditions might more likely be accompanied by limitations or changes in activity. According to a report based on data from the 1999 Survey of Income and Program Participation (Centers for Disease Control and Prevention 2001), a broad array of conditions led to disability among adults living in the community:

- Arthritis or rheumatism (17.5%)*
- Back or spine problems (16.5%)
- Heart trouble/hardening of the arteries (7.8%)
- Lung or respiratory problems (4.7%)
- Deafness or hearing problems (4.4%)
- Limb or extremity stiffness (4.2%)
- Mental or emotional problems (3.7%)

- Diabetes (3.4%)
- Stroke (2.8%)
- Blindness or vision problems (3.4%)
- Broken bone or fracture (2.1%)
- Intellectual disability (mental retardation)** (2.0%)
- Cancer (1.9%)
- High blood pressure (1.7%)
- Head or spinal cord injury (1.1%)

According to the 2002 National Health Interview Survey (Centers for Disease Control and Prevention 2004), some 28.3 million adults nationwide report difficulty of some sort in physical functioning; and 4.9 million children, 3 through 17 years of age, were told at some point that they had a learning disability. Not all of these issues necessarily result in significant disability for any one person, but each has that potential.

Some disabilities are relatively limited in duration; others can extend across a lifetime. Some children are born with disabilities, whether as the result of genetics, *in utero* infection (for example, rubella), trauma, exposure to drugs or alcohol, or the birth process itself (Luckasson and Borthwick-Duffy 2002). As a result of advances in neonatal clinical care, high-risk infants are surviving in far greater numbers, despite the likelihood of disabilities that can extend across their lifetimes.

Some disabling conditions are more likely to arise at different times in the life span (Pope and Tarlov, 1991), for instance, cerebral palsy at birth, spinal cord injury-related paralysis during late adolescence and early adulthood, and Alzheimer's disease in later life. As individuals age, many experience multiple disabling conditions simultaneously, often accruing over time (Calkins et al 1999), among them, chronic medical conditions, genetic predispositions to late-onset illnesses; sensory disorders; and disabilities from problems secondary to other medical conditions (e.g., amputations or vision deficits secondary to diabetes. Because the population as a whole is aging (DeJong et al 2002; LaPlante and Kay 1998), the absolute number of persons with disabilities is growing.

Critically, whatever the age of onset of disability, one point is unassailable: increasing numbers of persons with disabilities that once resulted in premature death now live for or exceed the life span for the average

* Percentage represents proportion of persons with disabilities for whom the particular condition is the factor leading to their disabilities; percentages do not total 100% since only selected conditions leading to disability are listed

** Intellectual disability is the term preferred, since it lacks the stigmatizing label of "mental retardation."

American of over 76 years. (Panko Reis et al 2004). For persons with disabilities, when their comprehensive health needs go unaddressed, secondary conditions, such as decubitus ulcers, lower immune function, depression, among others, can result. Equally important from the public health perspective, many persons with disabilities can, and do, lead normal, healthy lives *when they can access appropriate care to support their ongoing health and wellness needs.*

Defining Disability

Disability has been defined in a variety of ways for both program and policy purposes. It is specifically defined in law (see box below) and also is used variously in other contexts. For example, the term has been used to describe “limitations in physical or mental function, caused by one or more medical conditions, in carrying out socially defined tasks or roles” (Pope and Tarlov 1991). Such a disability, or limitation in personal or societal functioning, occurs when a person interacts with his or her environment (Brandt and Pope 1997).

This *Call to Action* emphasizes the importance of a biopsychosocial approach to disability in which disability arises from a combination of factors at the physical, emotional and environmental levels. This approach diverges sharply from the “illness” model under which disability historically had been defined and approached. That illness model approaches disability from the perspective of diagnosing, treating and discharging (Zola 1982). In contrast, the biopsychosocial approach focuses on three interrelated concepts that extend beyond the individual: (1) *impairments*, which are problems, changes, or losses in body function or structure (whether physical, neurological, mental, sensory, or cognitive); (2) *activity*: the performance of a task or action by an individual; and (3) *participation* within the context of the environment (Iezzoni 2003).

Who Are Persons With Disabilities?

Approximately 54 million persons (one in five) in the United States are living with disabilities of all kinds (McNeil 2001, 1997). (Figure 1) According to the most recent (2000) census data, around 52 million of them reside in the community (U.S. Census Bureau 2002). The Government Accountability Office has estimated that at least 1.8 million individuals with disabilities are being served in institutional settings, including 1.6 million in nursing facilities. McNeil (2001) reported that age-specific rates range from a low of 7.8 percent for those

Definitions of Disability

A recent report to the Interagency Committee on Disability Research has found that 67 separate laws define disability for federal purposes alone (CESSI 2003).

Programs such as maternal and child health programs, Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, have adopted a definition that encompasses person, physical surroundings, and social environment. Each of these programs defines a person with a disability as someone who

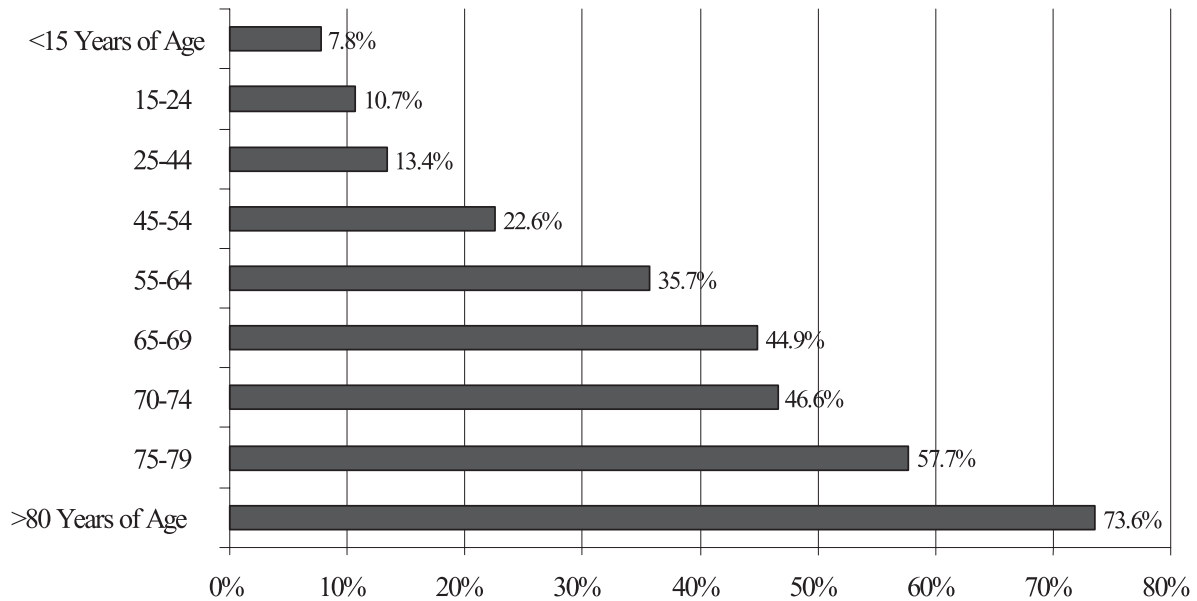
- (1) Has a physical or mental impairment that substantially limits one or more “major life activities”;
- (2) Has a record of such an impairment; or
- (3) Is regarded as having such an impairment.

From a legal, benefit, and social program perspective, however, disability often is defined on the basis of specific activities of daily living, work and other functions essential to full participation in community-based living. Thus, to be found disabled for the purpose of Social Security's Supplemental Security Income or Social Security Disability Insurance benefits, individuals must have a severe disability (or combination of disabilities) that has lasted, or is expected to last, at least 12 months (or to result in death), and which prevents working at a “substantial gainful activity” level.

younger than 15 years of age to a high of 73.6 percent for those 80 years of age or older (Figure 2).

Disability spans age, race, ethnicity, socioeconomic status and education level. In earlier life (ages 5 to 15 years) males tend to have higher rates of disability than females; the rates reverse subsequently. (U.S. Census Bureau 2002). (Table 1) According to the Census, 7.3 million individuals with disabilities, ages 15–64, are of racial or ethnic minorities (U.S. Census Bureau 2002). Rates of disability rise with age consistently across all racial and ethnic groups (Table 2). Overall, Asian Americans and Whites, 5 years of age or older, have lower rates of disability than other racial and ethnic groups. American Indian and Alaska Native and Black or African-American populations experience the highest rates, five percent above rates of disability among White

Figure 2: Prevalence of Disability by Age Group, 1997*



*As reported by McNeil, 2001. Disability was defined as anyone who: (a) used a wheelchair, cane, crutches or walker; (b) had difficulty with one or more functional limitations; (c) had difficulty with one or more activities of daily living; (d) had one or more specified conditions; (e) had any other mental or emotional condition that seriously interfered with everyday activities; (f) had a condition that limited the ability to work around the house; (g) if 16–67 years of age, had a condition that made it difficult to work at a job or business; or (h) received federal benefits based on an inability to work.

Table 1: Population with Disability by Age

Characteristic	Male #	%	Female #	%
Population, Age 5 and over	124,636,825	100.0	132,530,702	100.0
With any disability	24,439,531	19.8	25,308,717	19.1
Population, Ages 5-15	23,135,324	100.0	22,008,343	100.0
With any disability	1,666,230	7.2	948,689	4.3
Population, Ages 16-64	87,570,583	100.0	91,116,651	100.0
With any disability	17,139,019	9.6	16,014,192	17.6
Population, Age 65 and Over	13,940,918	100.0	19,405,708	100.0
With any disability	5,634,282	40.4	8,343,836	43.0

Source: U.S. Census Bureau, Census 2000 Summary File 3 (adapted from Panko Reis et al 2004)

Table 2: Percentage of Disability in the Civilian Non-institutionalized Population Over 5 Years of Age, 2000

Ethnicity	Total Population	≥ 5 Years	5–15 Years	16–64 Years	≥ 65 Years
White alone	195,100,538	18.5	5.6	16.8	40.6
Hispanic or Latino (of any race)	31,041,269	20.9	5.4	24.0	48.5
White alone, not Hispanic or Latino	180,151,084	18.3	5.7	16.2	40.9
Black or African American alone	30,297,538	24.3	7.0	26.4	52.8
American Indian and Alaska Native alone	2,187,597	24.3	7.7	27.0	57.6
Asian alone	9,455,058	16.6	2.9	16.9	40.8
Native Hawaiian and Other Pacific Islander alone	337,996	19.0	5.1	21.0	48.5
Some other race alone	13,581,921	19.9	5.2	23.5	50.4
Two or more races	6,206,804	21.7	7.1	25.1	51.8
Total	257,167,527	19.3	5.8	18.6	41.9

Source: U.S. Census Bureau, Census 2000 Summary File 3 (adapted from Panko Reis et al 2004)

populations. Hispanic/Latino Americans, the fastest growing racial or ethnic population in the country, have a disability rate that falls between that for White and Asian American populations, but lower than among American Indian/Alaska Native and Black/African-American populations. (Table 2)

Yamaki and colleagues (2003) reported a 16 percent increase in the prevalence of disability from 1983 through 1996. In part, this increase is explained by the ongoing rise in life expectancy, including increased longevity for persons with disabilities. The population of elderly persons with disabilities grew in absolute size from about 6.2 million persons in 1984 to about 6.8 million in 1999, since the total population of persons aged 65 and over grew fast enough to offset the decline in overall disability rates during the same period (Federal Interagency Forum on Age-Related Statistics 2004). The older adult population is expected to keep growing, from around 35 million in 2000 to as many as 80 million in 2040 (Federal Interagency Forum on Age-Related Statistics 2004). As the baby boom generation reaches later life in the coming decade, so, too, will the absolute numbers of adults with disabilities (See Figure 2 and Table 3).

The increase in the prevalence of disability also is a product of advances in preventing infant and child mortality from both the birth process and trauma-related impairments. Children and youth—from birth to 18 years of age—represent one fourth of the total United States population. The 2000 National Survey of Children with Special Health Care Needs (Centers for Disease

Control and Prevention 2000) found that 12.8 percent (9.4 million) of children nationally have special health care needs. This population includes children whose disabilities could have been prevented altogether, such as those with Fetal Alcohol Syndrome, a constellation of neurological, behavioral and physical disabilities, resulting from the use of alcohol by a mother during pregnancy.

As children and youth with disabilities of all kinds live longer, they will contribute to growing rates of disability in each age group to which they advance over the years. For example, in 1929, the average life span of a person with Down syndrome was 9 years of age. Today, it is common for a person with Down syndrome to live to 50 years of age and beyond (National Institute of Child Health and Human Development 2004). In fact, since 1983 alone, the average life span of a person with Down syndrome has doubled (Yang et al 2002). Individuals with cystic fibrosis, for whom the average life expectancy was around 18 years in 1985, today are living roughly twice as long, on average around 34 years (National Heart, Lung and Blood Institute 1995). Further, a 40-year-old person who survives the first year after an injury causing paraplegia can be expected to live to nearly 70 years of age, only around 8 years fewer than the average person who has not had such an injury (National Spinal Cord Injury Statistical Center 2001).

Consideration of the impact of this expanding population on the health system is critical to ensure the nation's public health. Development of health policy, health programs and health financing must address the

Table 3: Population by Age and Disability

Characteristic	Total	Total %
Population, Age 5 and over	257,167,527	100.0
With any disability	49,746,248	19.3
Population, Ages 5–15	45,133,687	100.0
With any disability	2,614,919	5.8
Sensory	442,894	1.0
Physical	455,461	1.0
Mental	2,078,502	4.6
Self-care	419,018	0.9
Population, Ages 16–64	178,687,234	100.0
With any disability	33,153,211	18.6
Sensory	4,123,902	2.3
Physical	11,140,365	6.2
Mental	6,764,439	3.8
Self-care	3,149,875	1.8
Difficulty going out	11,414,508	6.4
Employment disability	21,287,570	11.9
Population, Age 65 and Over	33,346,626	100.0
With any disability	13,978,118	41.9
Sensory	4,738,479	14.2
Physical	9,545,680	28.6
Mental	3,592,912	10.8
Self-care	3,183,840	9.5
Difficulty going out	8,795,517	20.4

Source: U.S. Census Bureau, Census 2000 Summary File 3 (adapted from Panko Reis et al 2004)

need for access to services and supports for persons with disabilities.

Historical Perspective

The need to ensure health and wellness for persons with disabilities has not always been recognized in health care policies and programs, funding, or training. Similarly, the overall health and well-being of persons with disabilities have not always been acknowledged as a public health issue. A century ago—even 35 years ago—little research was conducted on disability; little mention was made of the individuals who were born with or acquired a disability; little attention was paid to how they or their family fared. Most often, at best, individuals with disabilities received acute care services; some might have received brief rehabilitation services. Some individuals with disabilities associated with considerable stigma, such as mental illnesses, neurological

disorders, or developmental challenges, were closeted in institutions; others with visible physical impairments remained at home on front porches or in back bedrooms. Most were pitied; some were feared; few were expected to play an active role in the life of the community.

As a result of advances in public health and the imperative of the Americans with Disabilities Act, the landscape has been changing. Increasingly, research and health care are being directed toward preventing conditions that can give rise to disability in the first place and toward increasing access to health and wellness services for individuals already living with a disability. Part of the new focus is evidenced by such public health initiatives as the U.S. Department of Health and Human Services’ Healthy People 2010 Initiative and the Administration’s HealthierUS Initiative.

Several decades of advances in science and services coupled with the civil rights movement, the deinstitutionalization movement and other human rights and

health policy initiatives of the 1960s and 1970s, have helped catalyze the disability rights movement. In turn, the voices of advocates for persons with disabilities have become more powerful in the drive for a more level playing field for persons with disabilities, in education, in jobs, in health care and in all aspects of community life (Braddock and Parish 2002; Parish 2002; West 1991; Shapiro 1994; Pelka 1997; Francis and Silvers 2000).

The result has been the adoption of laws, policies, programs and regulations intended to ensure and protect the rights of persons with disabilities, including prohibiting discrimination in health care. Among the most significant are:

- *Section 504 of the Rehabilitation Act of 1973* that specifically prohibits discrimination against a class of individuals—persons with disabilities—by agencies, organizations and employers that either are part of the federal government or receive federal funding. Section 504 specifically requires equal opportunity to persons with disabilities who otherwise would qualify to participate in, receive benefits from and be free from discrimination by any programs conducted or supported by federal dollars. These include programs related to housing, employment, health care and education, among others. Sections 501 and 503 of the same act prohibit discrimination against persons with disabilities in federal employment practice and by federal contractors, respectively.
- *The Americans with Disabilities Act of 1990 (ADA)* (P.L. 101-336) that provides comprehensive civil rights protections to individuals with disabilities in the areas of employment; state, tribal and local government services (including those of public health agencies and health or wellness programs); public accommodations (including health care facilities and offices as well as exercise and wellness programs and facilities); transportation; and telecommunications. The ADA does not cover the executive branch of the federal government, since its anti-discrimination rules are contained in the previously described Rehabilitation Act of 1973. Indeed, the 1973 act served as a model for the ADA.
- *The Olmstead v. L.C. and E.W. decision of 1999* in which the Supreme Court interpreted Title II of the ADA and its implementing regulations as requiring states to administer their services, programs and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities” where professionals have determined place-

ment is appropriate, the person does not object, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with disabilities. The Court held that unjustified isolation and segregation of individuals with disabilities, primarily in institutions, constitute discrimination based on disability. The decision further recognized that such confinement both perpetuated unwarranted assumptions that people with disabilities were incapable or unworthy of participating in community life and severely curtailed everyday life activities, such as family relations, social contacts, work, educational advancement and cultural enrichment.

- *The 2001 New Freedom Initiative (NFI)*, announced by President Bush in 2001, is a comprehensive plan to help remove barriers to community living for persons with disabilities. Focusing on six areas (education, housing, employment, transportation, assistive technologies and access), the NFI is helping to ensure that all Americans have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives and participate fully in community life.
- Both private health insurance and federal and state health and supportive benefits programs, including the Medicaid and Medicare programs, that serve as a vital source of health insurance for persons with disabilities, older persons and children and mothers; the Supplemental Security Income program that provides a safety net for persons with disabilities who are economically impoverished; and the Social Security Disability Insurance program that cushions the economic impact on workers who become disabled.

While statutes, regulations, court decisions and programs have mandated equal opportunity and equal access for persons with disabilities, alone they cannot necessarily mandate improved quality of life for persons with disabilities. The challenge today and tomorrow is not only to build on what has come before, but also to ensure that disability is understood within the context of health and wellness by providers, educators, policymakers and the public.

Costs of Disability

The annual direct and indirect costs associated with disability among persons of all ages were estimated over a decade ago to be more than \$300 billion—

upward of 5 percent of the gross domestic product. This includes \$160 billion in medical care and \$155 billion in lost productivity (1994 dollars) (Brandt and Pope 1997). Another \$195 billion in earnings and taxes are lost each year by persons with disabilities because of unemployment (American Association of People with Disabilities 2004).

Additionally, the costs of inattention to the health and wellness services for persons with disabilities extend beyond the economics of lost productivity and health care dollars to human costs as well.

Federal, state and local government, and private payments to support persons with disabilities of employable age who do not have jobs are estimated at \$232 billion a year. In 2000 alone, over 6.9 million adults with disabilities received Medicaid services, at a combined federal and state cost of \$72.7 billion. Private insurance is estimated to contribute \$6 billion; persons with disabilities or long-term illnesses and their families pay \$34 billion out-of-pocket (Hough 2000; Leigh et al 1997).

With the aging of the population, the projected increases in the numbers of persons with disabilities of all ages, the higher costs of new medications and treatments, and the overall rise in health care costs, these commitments are certain to rise.

III. Health and Wellness for Persons with Disabilities Today

The principle underlying this *Call to Action* is that, with good health, persons with disabilities have the freedom to work, learn and engage actively in their families and their communities. Health and wellness are not the same as the presence or absence of a disability; they are broader concepts that directly affect the quality of a person's life experience. Research and clinical experience have shown that persons with disabilities can be both healthy and well (Krahn 2003). And good health opens the door to employment and education for persons with disabilities, just as it does for persons who do not have disabilities.

This *Call to Action's* goals and strategies for action, too, are based on a growing body of scientific knowledge and evidence-based practice about disability, health and wellness. They also recognize the costs of inaction in both human and economic terms. The impetus for this *Call to Action* has been the recognition that health is a key to realizing the goals of the President's New Freedom Initiative (NFI) for persons with disabilities. Only with accessible, comprehensive health care and wellness promotion services can all persons with disabilities enjoy the intent of the NFI: full, engaged and productive lives in their communities.

Surveys have found that a substantially lower percentage of persons with disabilities than those without disabilities report their health to be excellent or very good (28.4% versus 61.4%) (Centers for Disease Control and Prevention 2004a). While at risk for the same ailments and conditions as people in the general population (for example, injury, obesity, hypertension and the common cold), persons with disabilities also are at specific risk for secondary conditions that can damage their health status and the quality of their lives (Kinne et al 2004; Rimmer et al 1996; Hough 1999; Simeonsson and Leskinen 1999). Yet, particularly when it comes to access, many health and wellness programs do not address the needs of persons with disabilities.

Healthy People 2010, the national health promotion agenda, has included health indicators designed to measure how America is promoting the health of persons with disabilities, to prevent secondary conditions and to eliminate health disparities that now affect persons with disabilities. It identified four main misconceptions that continue to plague how disability status has been perceived: (1) disability is equated with poor health status; (2) public health should focus only on preventing disabling conditions; (3) no standard definition of dis-

ability is needed for public health purposes; and (4) the environment is not a factor in the genesis of disability.

These Healthy People 2010 goals are reflected in those of the *Call to Action*, which calls for: (1) public knowledge and understanding about disability, (2) provider training and capacity to see and treat the whole person and not just a person's disability, (3) health and wellness promotion for persons with disabilities, and (4) access to needed health care services for persons with disabilities. The balance of this section discusses these goals.

GOAL 1: People nationwide understand that persons with disabilities can lead long, healthy, productive lives.

Despite progress in science, technology and advocacy, disabilities of all kinds are still equated—incorrectly and by too many people—with ill health, incapacity and dependence. Welner and Temple (2004) point out that the misperception remains that “only a person who is physically agile and neurologically intact can be considered healthy.” Similarly, with regard to individuals with mobility difficulties, Iezzoni (2003) has observed that “much of society still holds persons with mobility difficulties individually responsible for problems....” Early disability advocate and sociologist Irving Zola (1982) suggested some believe that mobility difficulties are a weakness or personality defect to be overcome. Age-old perceptions, misunderstandings and fears, while still prevalent, are far from the reality of disability today.

The reality is that with accommodations and supports, ample access to health care, engagement in wellness activities and the impetus that comes from support-

A Personal Story—Ignorance

When my son, who has cerebral palsy (CP), was around 2 years of age, I took him to visit an old college friend who had a child the same age. We hadn't been in touch for a while; she didn't know my son had CP. The visit was brief. When I called her to plan another play date for the boys, she told me that she didn't think we could do that because she didn't want her son to “catch” my son's CP. I hung up and cried.

A Personal Story— Disability Isn't Inability

Children from across the United States and Europe compete in the National Junior Disabled Sports Championships. Many travel long distances with coaches, teams and parents. Just like other Olympians-in-training, many train year round as athletes. They set personal bests, captured medals and set new benchmark records, just as other amateur and professional athletes have done.

But the reporters often don't "get it." The Headlines: "Disabled boy sets records...suffers from spina bifida.... An athlete who suffers from cerebral palsy.... Another who suffers from a severed spinal cord.... Children afflicted with a disability...."

When one boy saw the newspaper headline about his achievements—Disabled boy sets records—he was devastated. He called his father at work: "Guess what they called me? They called me a disabled boy." He never felt the only thing important about him was that he was disabled. It was part of him, but never all of him.

ive friends and families, persons with disabilities can—and do—lead long, productive, healthy lives. Issues about disability and the lives of persons with disabilities increasingly are becoming part of the American consciousness and are beginning to be addressed.

A recent Henry J. Kaiser Family Foundation survey (2004) found that a majority (82%) of those surveyed thought that persons with disabilities overall have "better lives today than they had 50 years ago"; however, almost two thirds believed that at least some discrimination continues against persons with disabilities. Around 40 percent believed that the health care system treats persons with physical disabilities unfairly. The survey also found that over half (58%) of all people surveyed had read, seen, or heard about the Americans with Disabilities Act of 1990 (ADA). When told the specific content, an overwhelming majority said they supported its key provisions. Large majorities indicated support for health reforms to benefit persons with disabilities.

When not specifically mentioned, disability was rarely identified as a concern by persons without disabilities. It became a concern only when it was posed as an issue on which to voice an opinion. One of the challenges, then, is to identify ways in which the health and

wellness of persons with disabilities can be brought to the consciousness of the American public as an issue warranting effective action and ongoing attention.

Challenging the misconceptions about persons with disabilities—and elevating the importance of their health and wellness in the public consciousness—are steps that can begin to help improve the health status of persons with disabilities. At the same time, changing attitudes toward persons with disabilities can help the public recognize and address the environmental, social and economic barriers that undermine the ability of persons with disabilities to become and remain full participants in community life.

GOAL 2: Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.

Health care providers and their staff may harbor many of the same misconceptions about persons with disabilities as are found in the general public. Too often, health care service programs and personnel have not adopted the biopsychosocial approach to disability. Reports from persons with disabilities suggest that health care providers often focus on their disabling condition rather than on other health issues that might be of concern to the individual (Panko Reis 2004). In part, this is the product of the historical "compartmentalization" of health care education and training.

As a result, individuals with disabilities often encounter professionals unprepared to identify and treat their primary and secondary conditions and any other health and wellness concerns. For example, when it comes to persons disabled by mental illness, health care providers need to be aware of and respond to the

A Personal Story— Sensitivity Training Needed

I was referred to a specialist for treatment of chronic asthma. Because I'd never been to that doctor's office before, I was asked to complete a standard medical questionnaire. It was standard until it asked, "Do you have a history of insanity?" The term is not used today in medical treatment or education. As a middle-aged woman in recovery from schizophrenia, I found the questionnaire language insensitive and stigmatizing. Was this a potential indication about the sensitivity of the practitioner, too? I hoped not and told him so.

full array of medical, physical, psychosocial, cultural and spiritual issues associated with—and separate from—an individual's mental disorder. They need to recognize that mental illnesses, as other disabling conditions, need to be treated within the larger context of the individual, including the range of other health care needs that might require medical attention (U.S. Department of Health and Human Services, 2000; U.S. Department of Health and Human Services 2003).

When visiting a health care provider, a person, without regard to disability status, should reasonably expect that the provider has expertise and knowledge about health care and wellness promotion, the ability to hear and respond to articulated health concerns, the ability to communicate clearly, culturally and directly, and the willingness to spend the time necessary to be fully responsive (Kaplan and Sullivan 1996; Iezzoni 2003; Welner and Temple 2004). Unfortunately, this is not always the case.

Still other health care providers seem to believe it is the job of a person with a disability, not of a health care professional, to work to overcome provider and service limitations. Others are willing to be responsive to the comprehensive health needs of an individual with disabilities, but have trouble creating the kind of provider-patient partnership needed to promote optimal health. Iezzoni (2003) describes how persons with mobility disabilities characterize some of their health care professionals, suggesting that some “just don't listen”; some “don't think”; some “just say you have to live with it”; and still others just “rush in and rush out,” often as the result of patient load and cost-efficiencies. Some individuals with disabilities suggest that some doctors, under the misguided belief that the only acceptable outcome of treatment should be cure, distance themselves from their patients with disabilities because they represent treatment failures in some way (Iezzoni 2003; Barnard 1995). Further, when it comes to early detection and prevention of health problems, Krahn (2003) has reported that both adult and pediatric primary care providers tended not to refer their patients with disabilities for such services unless they are directly related to their individual disabilities.

Frequently, health care providers do not recognize individuals with disabilities as either knowledgeable partners in discussing care options or as “experts” with respect to their own medical conditions. In some cases, persons with disabilities believe they do not receive sufficient information from their health care providers—most often primary care providers—to play an informed role in their own health care decisions (Masuda 1999). In other cases, effective communication is frustrated due to the limited availability of assistive supports, such as the

use of interpreters for persons who are deaf or hard of hearing. In still other cases, persons with disabilities are excluded from discussions about their health issues altogether, by being treated in much the same way as children are excluded from the conversation between pediatrician and concerned parent (Iezzoni 2003; Welner and Haseltine 2004).

These issues seem to be exacerbated for individuals with sensory disabilities—hearing loss, deafness, blindness and low vision—that center around the key issues of respect, physical access, communication and inaccessible information formats (O'Day et al 2004; Iezzoni et al 2004). While assistive devices and technologies (including interpreters for signing) can improve communication between such individuals and their health care providers, their availability and use are limited and not always best adapted for all patients, such as older adults with late life onset of limited vision, blindness, or deafness whose experience with adaptive methodologies, such as signing, might be scant.

Further, persons with disabilities have noted that, when they find a physician or other health care provider willing to engage them as partners in care, considerable time needs to be spent educating the health care provider both about the disability and about the nature of the often unrelated health concern that brought them to the provider in the first place. A survey by the Henry J. Kaiser Family Foundation (2003) disclosed that among nonelderly persons with disabilities, 25 percent reported that they had difficulty finding a doctor who “understands my disability.”

This finding is not entirely surprising because many physicians have had limited experience during medical training in treating patients with disabilities. As a result, many are unable to meet the full range of health care needs presented by a person with a particular disabling condition, much less to evaluate and treat that individual in a culturally appropriate and sensitive manner. This compounds the need for physicians and other health care providers to receive ongoing training and education on a discipline-by-discipline basis about the health care challenges of persons with disabilities and on current and promising best practices in care. Until health care provider training curricula and continuing education practices change, when confronted by a health care provider lacking sufficient skill to serve an individual with a particular disability, a person with a disability should seek another practitioner more sensitive and well-trained in the needs of persons with disabilities.

Secondary Conditions

The presence of a particular disability is not the only factor a health care provider should consider when working to meet ongoing, quality health and wellness needs of a person with a disability. Rather, the health care provider should also pay close attention to the person's full range of health concerns, including the onset of possible secondary conditions. These are medical, social, emotional, family, or community problems for which a person with a primary disabling condition is at increased risk (Marge 1988; Simeonsson and Leskinen 1999; Krause and Bell 1999; McMillen et al 1999; Wilber et al 2002).

Some have suggested that the high direct health care costs of disability are a result of insufficient attention early on to secondary and other health needs of individuals with disabilities. The result is increasing numbers of persons with multiple, complex and often preventable, chronic conditions and a health care system insufficiently prepared educationally, structurally and economically to recognize and address those needs (Panko Reis et al 2004; U.S. Department of Health and Human Services 2003; Institute on Disability and Development 2003). The vast majority of these secondary conditions can be mitigated with early intervention; many can be prevented altogether.

Some individuals with disabilities develop no specific secondary health issues related directly to the condition or conditions accompanying their disabilities. Rather, they require only a routine regimen of ongoing health care. However, many persons with disabilities experience secondary conditions directly related to their disability.

A recent Centers for Disease Control and Prevention-supported study by Kinne and colleagues (2004), the first population-based prevalence study of its kind, suggests why clinical attention to secondary conditions among persons with disabilities is a critical element in the quality-of-life equation. They found that 87 percent of persons with disabilities reported experiencing a secondary medical condition.

Persons of all ages with disabilities are susceptible to secondary conditions. For example, unrecognized and untreated *depression* coupled with another kind of disability potentially places children at risk for poor school performance, developmental delay lost potential as adults in the workforce and community, and suicide (U.S. Department of Health and Human Services 2003). Depression also is not an uncommon secondary condition among adults with such potentially disabling illnesses as diabetes, arthritis and heart disease. In persons of all ages, mobility limitations can lead to decubitus

A Personal Story—Doing It Right

Jim was diagnosed with cystic fibrosis at 3 months of age. One of the first questions the diagnosing doctor asked his mother was "Where do you want your son to be in 20 years?" Forced to think about a future for a child just diagnosed with a genetic disorder that, at the time, had an average life expectancy of 14 years, she articulated her hope that her son could go to college. Together, the physician and Jim's mother began planning for his future and for college. Part of that thinking was finding ways to help Jim learn to assume responsibility for his own health care—and not just for the management of his cystic fibrosis.

By 2-½ years of age, Jim was encouraged to ask questions about his health. Jim says, "I was never looked down on because I was younger or sick. I was always asked the most serious questions about my health. And they valued what I had to say."

Throughout his childhood, with the support of his family, school and health care providers, Jim was able to take on increasing levels of responsibility for his own health care for his cystic fibrosis and for other routine health problems, such as flu, colds and sprained ankles. He also learned skills to promote his wellness—exercise, healthy diet and avoiding alcohol and tobacco.

Today, Jim is 24, recently married, working, and preparing to buy a home. He believes he has been able to enjoy a full life with—not despite—his increasingly disabling cystic fibrosis, thanks in large part to a doctor who treated him as a person with a future, not just a disability, from the day he was diagnosed.

ulcers (pressure sores), lost muscle tone and gait instability. Substance use disorders occur more often in persons with a disability than in the general population. This includes problems related to the abuse of prescription medications as well as illicit drugs (Moore and Li 1998; Heinemann et al 1991; Fann et al 1995). Moreover, an injury such as a hip fracture, may give rise to fears about loss of independence, triggering depression, lowered immune function and factors that can exacerbate or increase the risk for still other secondary conditions. These issues take on particular significance for older adults, who run a greater-than-average risk of multiple

disabling conditions than do younger individuals (National Institute of Mental Health 1999).

Campbell and colleagues (Centers for Disease Control and Prevention 2002) reported that a substantially higher percentage of persons with disabilities experienced obesity than did persons without disabilities. Similarly, a person who depends on a wheelchair for mobility might experience other medical conditions beyond obesity that are related to that limited mobility, such as osteoporosis, loss of muscle tone and bowel dysfunction. It has been observed that children with certain developmental disabilities tend to be predisposed to pulmonary infections, emotional disturbance and obesity secondary to their developmental disability. A person with a spinal cord injury might have secondary conditions such as decubitus ulcers, infections and osteoporosis. Persons with conditions that affect the ability to feel pain, such as spinal cord injury or diabetes, unknowingly can injure themselves and develop life-threatening infections. Persons with disabilities, regardless of whether their disabilities are visible to others, are all susceptible to equally “invisible” health concerns such as clinical depression, substance use disorders and the risk for suicide. In fact, Moore (2002) estimates that as many as 1.5 million individuals with disabilities may need substance use disorder treatment in any given year.

On the positive side, both research and clinical efforts to help prevent—or at least reduce—the incidence of secondary conditions are ongoing (Hough 1999; Simeonsson and Leskinen 1999).

GOAL 3: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.

Healthy living is a positive concept—a concept that has been highlighted through health promotion and disease prevention efforts for people of all ages, from smoking cessation to obesity control, from the value of exercise to the benefits of mental health. Maintaining good health by adopting healthy lifestyle choices, both physical and mental, is a key component of a satisfying life. It is a goal of the U.S. Department of Health and Human Services, and embodied in both its HealthierUS Initiative and the objectives for Healthy People 2010.

When it comes to persons with disabilities, healthy behaviors and a drive toward positive health across the life span need be no different than it is for persons who do not experience disabilities. Indeed, for persons with disabilities, health promotion efforts can be of critical importance. Studies have shown that individuals with

A Personal Story—Taking Control

To me, recovery means I try to stay in the driver’s seat of my life. I don’t let my mental illness run me. Over the years, I have worked hard to become an expert in my own self-care. Being in recovery means I don’t just take medications; rather, I use medications as part of my recovery process. Over the years, I have learned different ways of helping myself. Sometimes, I use medications, therapy, self-help, and mutual support groups, friends, my relationship with God, work, exercise, spending time in nature—all these measures help me remain whole and healthy—even though I have a disability.

disabilities can run a higher-than-average risk for such preventable chronic problems as osteoporosis, obesity, diabetes and heart disease (Center et al 1998; Walsh et al 2001; Coyle and Santiago 2000; Nosek 2000; Pitetti and Tan 1990; Rimmer et al 1993; Rimmer et al 1996). Similarly, research has shown that by engaging in healthful behaviors such as exercise, persons with disabilities can lower the risk of these common chronic problems. Further, they can prevent additional disability-related losses (for example, muscle tone, bone density and dexterity) and increase overall mental and physical wellbeing (Compton et al 1989; Janssen et al 1994; Santiago et al 1993; Thomas 1999).

Both the 1996 Report of the Surgeon General on Physical Activity and Health: Persons with Disabilities and the subsequent Closing the Gap: A National Blueprint for Improving the Health of Individuals with Mental Retardation (2002) emphasized that individuals with disabilities should engage in health promotion and wellness activities. Both underscored the importance of individual responsibility for healthy behaviors by per-

A Personal Story—Exercise at Any Age

For several years, I was unable to stand up or stretch my arms above my head. I had to use a walker. At the age of 74, I had lumbar spinal fusion to correct this problem. But I eventually had to rely on a walker again. At the age of 77, my wife and I joined a fitness club. We started doing cardiovascular conditioning and strength building. Now, at the age of 80, I can once again maintain an erect posture and stretch my arms over my head—great for putting dishes in cupboards.

sons with disabilities to help prevent the occurrence of secondary conditions.

However, significant data suggest that persons with disabilities do not participate in wellness programs or health screening activities at the same level as do persons without disabilities. For example, Healthy People 2010 has indicated that, while 68 percent of women who are older than 40 years of age and who do not have disabilities have had a mammogram, the percentage drops to 54 percent among women with disabilities (U.S. Department of Health and Human Services 2000). The 2000 National Health Interview Survey similarly found that the percentage of nonelderly adults with mobility limitations who received preventive health services, including cholesterol screening and blood pressure checks, was considerably lower than that of persons without disabilities in the same age range (Centers for Disease Control and Prevention 2004).

Persons with disabilities generally are not benefiting from health promotion screening and wellness programs because the focus of health care professionals often remains on their disabilities alone, and not the needs of the whole person. Further, health promotion and illness prevention information, programs and activities often are not tailored to the needs of individuals with particular disabilities (Welner and Temple 2004). Programs for screening, behavior change and exercise, for example, need to be highlighted and encouraged by primary care providers, perhaps working with health clubs and others to meet the individual needs of persons with disabilities. Thierry and Cyril (2004) note that persons with disabilities, particularly women, need health promotion efforts that address such issues as physical activity, clinical prevention and access to care. Such programs also should promote healthy lifestyles (for example, diet, smoking and alcohol consumption), with specific reference to data reflecting the rates of untoward health effects for individuals with disabilities.

Because health care and health promotion providers alike often focus solely on a person's disability rather than on the full range of health and wellness needs of each person as an individual, they may fail to communicate health promotion messages that are given routinely to persons who are not disabled (Coyle and Santiago 2000). This counseling is necessary to empower individuals to take personal steps to improve their health and wellness. Data from the 2002 Behavioral Risk Factor Surveillance System (Centers for Disease Control and Prevention 2004), which provides health indicator data for all 50 states, the District of Columbia, tribal governments and U.S. Territories, found that a higher percentage of persons with disabilities were obese, were current daily smokers and were physically inactive (Table 4). Moreover, while a large percentage of individuals with disabilities reported engaging in some type of physical activity in their leisure time, a high percentage reported greater obesity and adverse effects from stress compared with persons who do not have disabilities. The higher prevalence of risk factors among disabled individuals suggests that counseling about good health practices can be increased above its current rates. (Branigan et al 2001) (Table 5).

Health communication materials that target individuals with disabilities are scant (Thierry and Cyril 2004), despite growing recognition that health communication represents a significant arena in which public health initiatives can promote knowledge and foster adoption of beliefs, attitudes and behaviors that promote overall health for persons with disabilities.

Health promotion and wellness services and materials often are not adapted for use by persons with disabilities. Similarly, most health promotion resource professionals—such as wellness counselors and trainers—lack the knowledge of both how best to communicate with individuals with disabilities and how to work with them to meet their often specialized wellness goals. For example:

Table 4: Prevalence of Risk Factors in Persons with Disabilities and Persons without Disabilities

	Persons With Disabilities	Persons Without Disabilities
Current smoker	30.2%	21.7%
Physically inactive	25.3%	13.4%
Obese	20.5%	18.6%

Source: Behavioral Risk Factor Surveillance System, CDC, 2004

Table 5: Percentage of Counseling/Inquiries Made at Last Health Maintenance Examination for Persons with Disabilities

Counseling/Inquiry Topic	Inquiry made (%)
Changes in functional status	38.3
Emotions	41.8
Diet	35.3
Exercise	38.8
Smoking	15.4
Alcohol consumption	13.4
Sleep	41.3
Pain	46.3
Sunscreen use	11.9
Sexuality (ever discussed)	28.4

Source: Adapted from Branigan et al 2001

- Health promotion instructions might be written at too high a reading level for a person with an intellectual disability; they also might be unavailable in formats accessible to persons with visual impairments (e.g., Braille or interactive technology).
- Screening programs might not be equipped to examine persons with disabilities appropriately (e.g., lack of universal equipment and screening devices) and screening facilities might not be accessible for examinations.
- Exercise facilities might not have adaptive equipment.
- Health care and wellness providers might not know how to educate persons who have disabilities that compromise mobility, vision, sensation or cognition about how best to perform breast self-examinations or self-assessments for skin cancer.

For all of these reasons, increased counseling by health care and wellness service providers and accessible information about preventable risk factors (e.g., smoking, diet, inactivity, etc.) that can lead to secondary health problems would likely provide persons with disabilities with tools they need to help improve their health status.

Equally daunting is the fact that many individuals with disabilities do not recognize their need to become advocates for their own wellness activities because they simply do not “see” or know about materials and messages about health promotion directed toward them.

A Personal Story—Exercise Opens Doors

With a combination of autoimmune disorders, my body fights itself daily. Juvenile rheumatoid arthritis, fibromyalgia and scleroderma leave me exhausted and in ongoing pain. Combined with increasing degeneration and deformity of my joints, my wheelchair isn’t just helpful any more; it’s become a necessity.

The result was mobility, but at the price of substantial weight gain and decreased muscle tone. Both added to the burden of disability I experienced. A hip fracture woke me up. Even though I sit in a wheelchair, I can be fitter and lighter by adopting a healthy lifestyle tailored just for me. Every day, I eat carefully and healthfully. I balance how much I eat against my body’s ability to use it. I exercise portion control, which helps me keep meal planning simple. And I’ve found ways to exercise physically, too. It doesn’t matter what your disability is; there is a way to be more physically active than you are today. I can’t do weight-bearing exercise, but I can do aqua exercise, and I skipper a modified sailboat. The best news is that I don’t just look better; I feel better and am more involved in my world, too.

- Literature, videos, presentations and materials found on the World Wide Web primarily show images of persons who do not have disabilities engaging in healthy behaviors.
- Programs that promote exercise rarely show individuals with mobility impairments involved in physical activity.
- Few, if any, programs, literature or products designed to promote healthy diet mention persons with disabilities as a target population, include one or more person with a disability in visuals, or otherwise suggest that diet needs to be a concern to this population.
- Few wellness seminars routinely include discussions to motivate or instruct individuals with disabilities toward resources they can use best. At most, a separate concurrent session might be offered, removing those individuals with disabilities from mainstream discussion and participation.

However, the critical need for individuals with disabilities to engage in health promotion is grounded in Tables 4 and 5 (above). Perhaps most important, studies have shown that health promotion programs that focus on improving functioning across a spectrum of diagnoses and a range of age groups can reduce secondary conditions and visits to health care providers. For example, a focus on exercise to improve strength, flexibility and muscle tone can help avoid some secondary conditions for persons who are mobility impaired (Melnikova et al 1998).

Achieving optimal health is a goal for everyone. The notion of health promotion for persons with disabilities is a new and emerging area in research and prevention programming. Health disparities—many mitigated by environmental factors—exist for persons with disabilities, in part due to insufficient information about and available services for wellness promotion. Fortunately, many health promotion interventions already in place could be adapted easily to the needs of persons with disabilities.

GOAL 4: Accessible health care and support services promote independence for persons with disabilities.

Without regard to the number and types of health care issues facing an individual with disabilities, access to the full range of all health care and services to meet his or her specific needs is a key factor that can affect his

A Personal Story— Battlefield to Playing Field

While serving in the Military Police in Iraq, Steve was severely injured in a roadside bomb attack. Despite 15 operations at Walter Reed to save his badly damaged leg, it was amputated in January 2005. He was fitted with a prosthesis and given physical therapy. Thanks to a rehabilitation sports program, not only was he skiing again in 6 months, but he also runs and rides a bicycle. Steve observed that getting involved in sport has decreased his recovery time because “I stay more active and try new, more challenging activities.” He tells newly wounded soldiers that the need to understand that “a tragic injury does not have to be the end of their world. Functionality, mobility and independence happen on many different levels.... Sports rehab programs give soldiers a renewed sense of the person that they used to be” in both body and mind.

or her health throughout a lifetime. It is clear that, at present, existing health care and wellness systems—including the providers who staff them, as noted earlier—are not sufficiently responsive to the needs of these individuals. In part, this may be the product of gaps in training and education. As a result, access to prevention, screening, diagnosis, treatment and services for both disability- and nondisability-related health care can be limited, incomplete, or misdirected.

The literature has reported numerous impediments to maintaining good health for persons with disabilities. For example, to get care from a physician or other health care provider, an individual with a disability must be able to make an appointment; get to the clinical care setting or office; get into the building and office; be able to communicate health needs and health history; have access to the appropriate facilities and equipment to receive care; and be able to spend sufficient time and to communicate clearly with the clinician to resolve the one or more health concerns to be addressed (Allen and Mor 1997; Branigan et al 2001; Jones and Tamari 1997; Nosek 2000).

More simply stated, the barriers relate primarily to accessibility. They include such factors as transportation to get to the health care site, access to the building and the necessary health facilities in the building, access to the health care provider and staff for sufficient time and with sufficient supports to promote clear and complete communication. (Table 6) Jackson (2004) refers to these

Table 6: Access to Care for Persons with Disabilities: Challenges and Consequences

Challenges when attempting to access health care	
Transportation problems	Inaccessible, untimely and inconvenient, particularly in rural areas.
Inaccessibility of facilities or services	Physical accessibility of health care provider offices, examination rooms and equipment; and both personnel untrained to communicate with and absence of translators for persons with hearing and visual disorders.
Lack of provider knowledge about disability	Limited skills set to address the comprehensive health care and health promotion needs of persons with disabilities, including medical conditions either unrelated to or secondary to the disabilities.
Untimely appointments	Delays with referral process and scheduling.
Consequences of delayed or denied access to care	
Physical	Declining condition, energy and mobility; inability to engage in community life, work and activities of daily living; increased secondary medical conditions.
Psychological	Compromised emotional well-being, reduced self-esteem, depression and stress.
Economical	Increased time off from work amounts to reduced income; need for more health care leads to increased costs; reduced income leads to reduced consumer opportunity
Social	Relationships and social roles strained, restricted or limited participation in family and social activities.
Independence issues	Decreased independence due to combination of any or all of the previously mentioned issues.

*Adapted from a qualitative survey conducted by the National Rehabilitation Hospital, Center for Health and Disability Research

A Personal Story: Too Far from Home

Carol was born both blind and deaf. She lived with her family on a remote reservation in Montana, and neither assistive technology nor appropriate health and support programs were available to her. To help her get the services she needed, she was sent away to a school for the deaf and blind, located over 350 miles from her home. She lost all but brief contact with her family and friends; the distance was too great for visits. She was unable to engage in either tribal ritual or cultural activities. She felt as if she had lost connection to who she was; Carol missed her family and her home community. As a result, she became depressed, withdrawn, and found herself unable to participate fully in her school.

concepts as: “getting there”; “getting in”; clarifying needs; the doctor’s clock; and overcoming attitudes.

Iezzoni and colleagues (2002) reported that costs of care were a source of particular dissatisfaction by persons with disabilities. Nearly 30 percent of nonelderly adults with disabilities reported that they were “dissatisfied” with the costs of their care, compared with 17.6 percent of nonelderly adults who did not have disabilities.

Physical barriers are another common impediment to getting care. Frequently cited physical barriers include issues related to getting to a treatment site in the first place and, once there, getting in and getting treatment. Making an appointment is the first potential hurdle. For persons with hearing loss, telephone access to make an appointment can be complicated if TTY, TDD, or other assistive technology is not available for use in making appointments, or if staff are trained insufficiently in receiving relay calls or making arrangements for auxiliary aids and services. For some persons with mental and developmental disabilities, the logistics of traveling to a health care provider are difficult, if not impossible, to negotiate. Remembering routes, bus times, transit payments and the location of the treatment program can be challenging. Challenges of accessible transit for persons with limited mobility, communication difficulties for individuals with sensory impairments and sheer distance for anyone with any kind of disability can complicate access to care. The last challenge is particularly acute for individuals with disabilities who live in rural areas (Branigan et al 2001; Jones and Tamari 1997; Nosek 2000; Iezzoni et al 2002).

A Personal Story—It’s a Cold

Once I had a doctor’s appointment at 9 in the morning with a family practitioner. I was in my wheelchair. The nurses moved some of the other patients ahead of me. They wanted to get them taken care of first, because they thought it would take the doctor more time with me. They really didn’t know what my complaint was; all they saw was my wheelchair and made an assumption about my health needs. I could have had a common cold.

Once at a health care facility, other potential physical barriers arise. Accessibility remains an issue for some facilities. To raise awareness about the ADA, the Office for Civil Rights in the U.S. Department of Health and Human Services and the U.S. Department of Justice have engaged in a number of education and technical assistance activities. Both also have investigated a number of complaints about accessibility and secured relief where violations have been found. Panko Reis and colleagues (2004) have observed that, despite the legal ramifications and sanctions that can be imposed by the ADA, most offices of health care providers remain insufficiently accessible. This trend continues despite the fact that the U.S. Department of Justice has sought remedy for ADA violations on behalf of individuals with disabilities. Indeed, Panko Reis and colleagues (2004) suggest that health care providers “who serve patients in private offices appear to have little awareness of the ADA, particularly of their obligation to determine if a patient with a disability requires an accommodation and to provide that accommodation if possible.” To raise awareness about the ADA, the Office of Civil Rights in the U.S. Department of Health and Human Services and the Civil Rights Division in the U.S. Department of Justice engage in education and technical assistance activities, investigate complaints about accessibility, and secure relief where violations are found.

Frequently, treatment sites do not have adaptive equipment that can meet the needs of individuals with disabilities, from changing rooms with narrow doorways to examination tables too high or too flat for comfort, and from a lack of staff with sign language capability to communicate with a patient who has a hearing deficit to toilets that are not accessible to wheelchairs or scooters. These physical barriers to care alone can reduce the likelihood that persons with disabilities will receive timely and appropriate services.

For example, the quality and scope of a full gynecological examination for a woman with a mobility dis-

ability requiring the use of a wheelchair could be compromised in the absence of a universally adaptable examination table. Without appropriate equipment, a full examination might not be possible. Few, if any, women without mobility disabilities would be asked to remain seated in a chair for a comparable examination. The result for a woman with a mobility disability can be more than discomfort; the result might well be an incomplete, potentially inaccurate, examination. Over time, the result could lead to the development of a secondary condition that might have been prevented had it been found earlier during a complete, thorough examination using adaptable, accessible equipment. Women with disabilities are largely underexamined, underdiagnosed and undermanaged (Welner et al 1999, Welner and Haseltine 2004).

Thus, the consequence of failing to receive appropriate, coordinated care as the result of access difficulties alone can result in poor health and increased secondary conditions. Consequences also can resonate in other aspects of life: lost productivity, lost wages, increased health care costs and compromised overall quality of life.

However, models exist that seek to reduce problems with coordinated, appropriate health care with the potential to improve the ways in which health care providers approach their patients with disabilities. Among them are efforts to identify and test promising practices in community-based care, such as those now underway at the Centers for Medicare and Medicaid Services and other agencies in the U.S. Department of Health and Human Services that focus on service delivery and best practices in health care. Other efforts are working to assess best ways to integrate care across health and service needs.

IV. Vision for the Future

Principle

Good health is necessary for persons with disabilities to secure the freedom to work, learn and engage in their families and communities.

Goals

GOAL 1: People nationwide understand that persons with disabilities can lead long, healthy, productive lives.

GOAL 2: Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.

GOAL 3: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.

GOAL 4: Accessible health care and support services promote independence for persons with disabilities.

The health and wellness of persons with disabilities today is a matter of public health concern. As this *Call to Action* suggests, what is called for are better approaches to new knowledge, new technologies and new systems of services that emphasize a team approach and partnerships with persons with disabilities themselves. What is needed are health care providers who see and treat the whole person, educators willing to teach about disability, a public that sees beyond the disability to see a whole person, and a community that provides accessible health and wellness services for persons with disabilities.

With the four goals as a guide, this section of the *Call to Action* identifies specific challenges that must be overcome to realize the principle that with good health, persons with disabilities have the freedom to work, learn and engage actively in their families and their communities. The challenges are present in all aspects of

health care and service delivery for persons with disabilities. They include such concerns as an inadequately trained and educated health care and services workforce, and a health care and health promotion service system that is limited in access or availability to persons with disabilities.

This section also suggests strategies for action and research priorities that can lead to improved interaction, communication and cooperation of the health care system and related services with persons with disabilities. Taken together, they represent ways in which the individual objectives and, ultimately, the goal of this *Call to Action* can be realized for 54 million Americans who, today, are living with a disability.

<p>GOAL 1: People nationwide understand that persons with disabilities can lead long, healthy, productive lives.</p>

Challenges

- Misperceptions persist that disability is the equivalent of poor health.
- The lack of uniformity in the use of the term “disability” affects public knowledge and understanding about the health and wellness needs of persons with disabilities.
- This incomplete public understanding of disability often means that the needs of persons with disabilities are often overlooked when decisions about community adaptations, health and service delivery and public policy are made.

Strategies

- Promote the use of language to describe persons with disabilities that emphasizes the individual, not the disability first. This use of “people first” language that refers to persons with disabilities recognizes that individuals with disabilities are—first and foremost—persons with inherent value, individuality, dignity and capabilities and helps raise

awareness of and reduce stigma and discrimination against persons with disabilities.

- Consider health literacy when making health and wellness information about persons with disabilities available to the public.
- Enhance understanding and acceptance of persons with disabilities of all ages nationwide by improving the content and dissemination of educational information in community programs, schools, faith-based programs, workplaces and at home about how persons with disabilities can lead long, healthy lives.
- Encourage the entertainment industry to increase its portrayal of realistic characters with disabilities and their challenges and successes in maintaining good health.
- Encourage the print and electronic media to increase coverage of disability-related issues and expand current health and wellness reporting to include ramifications for persons with
- Continue to include age and specific disability status as demographic indicators in health surveys or surveillance systems.
- Encourage persons with disabilities to join as partners in public health initiatives and include them on advisory committees as services are being planned by federal, state, tribal and local governments.

GOAL 2: Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.

Challenges

- Due to insufficient ongoing education and training for health care professionals and wellness service providers, the needs of persons with disabilities are often overlooked when decisions about community

adaptations, health and service delivery and health care policy are made.

- Health and other community-based support services are insufficiently integrated to meet the needs of the ‘whole person’ and not just the disabling condition.
- Insufficient attention is paid by the health care system on the prevention of secondary conditions in persons with disabilities, specifically the prevention of important conditions such as obesity, type II diabetes, depression and substance abuse.

Strategies

- Encourage health care and wellness service providers to relate to persons with disabilities in ways that recognize their value, dignity and capabilities, whether communicating in person, electronically, or in writing.
- Educate health care providers of persons with disabilities in an ongoing manner about state-of-the-art health services and supports that should be available to the patients with disabilities.
- Ensure that both clinical and health services research include persons with disabilities across the life span, particularly in areas in which health disparities in risk, access and outcome exist
- Increase in an ongoing manner health care provider awareness of and compliance with laws designed to protect the rights of individuals with disabilities.
- Identify currently available disability-oriented training curricula and programs for health care providers, assess if the training curricula are evidence-based and delineate the next steps necessary to advance the adoption of evidence-based training curricula focused on persons with disabilities in professional and other service provider training and continuing education.
- Promote development and use of medical equipment and devices that allow universal access to all recommended screening and diagnostic tests and treatments.
- Enhance and broaden the content and expand the use of educational and training materials for health

care providers that focus on the health care and wellness needs of persons with disabilities, including secondary conditions

- Create a series of provider handbooks that include best practices and current resources to educate health professionals and service providers about the value of wellness promotion for persons with disabilities.
- Promote practical experiences with persons with disabilities in health and service provider training and continuing education. Include in this training information regarding civil rights and disability, including the health care ramifications of the Americans with Disabilities Act.
- Promote researcher experiences with persons with disabilities in health care research training programs.
- Promote the development of research to enhance the evidence base for best practices in clinical service delivery for persons with disabilities.
- Promote interdisciplinary collaboration in scientific pursuits and to improve clinical research networks to advance better prevention, early diagnosis and treatment of disabilities and secondary conditions.
- Analyze the content and diffusion of information about persons with disabilities that is used in health care settings.

GOAL 3: Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.

Challenges

- Misperceptions exist regarding the positive role wellness promotion can play for persons with disabilities.
- Policy and infrastructure emphasis continues to be placed on both acute illness and on the acute ele-

ments of disability rather than on prevention and health maintenance for persons with disabilities.

Strategies

- Conduct health research to identify and support effective health promotion programs for persons with disabilities.
- Educate persons with disabilities, their families and advocates in an ongoing manner about state-of-the-art wellness and prevention activities.
- Consider health literacy when making health and wellness information accessible to persons with disabilities.
- Provide increased health promotion and wellness training opportunities specifically for persons with disabilities, their family members, personal attendants and advocates, ensuring that both focus on the whole individual and not just the disability.
- Encourage health systems to use all media, computer-based, internet and other adaptive or assistive technologies when planning and developing health information for persons with disabilities. Encourage them to include materials that will be accessible to individuals with limited English proficiency.
- Include persons with disabilities in all stages of health care and wellness promotion communication research, including formative research, message development and testing, identification of appropriate communication strategies and channels and evaluations of effectiveness.
- Identify evidence-based best practices for health promotion among persons with disabilities by developing, implementing, evaluating and disseminating strategies to translate into practice the results of research.

GOAL 4: Accessible health care and support services promote independence for persons with disabilities.

Challenges

- Persons with disabilities may have difficulty getting to health care providers, getting in and getting around the service setting, being able to benefit from health care equipment in the service setting, and communicating with the health care provider and staff about their health needs and concerns.
- Insufficient numbers of health care services programs have the tools, skills and capacities to meet the full range of health care and wellness needs of persons with disabilities.

Strategies

- Develop and implement surveys to assess the full range of health needs of persons with disabilities, including whether and how those needs are being met by providers and facilities in communities nationwide
- Advance accountability by all health service delivery programs, including clinical and community preventive services, to ensure that persons with disabilities have full access to their services.
- Bring inventors, clinicians and industry together through more effective incubator and development programs to collaborate efficiently and effectively to enhance research and development of assistive technology for all types of disabilities.
- Encourage research efforts that collaborate and partner with integrated community-based provider networks to include individuals with disabilities in those efforts.
- Continue to develop community-based, public-private partnerships to facilitate coordinated, integrated care of persons with disabilities. Include collaboration with transportation, education and wellness providers. Include communication between all

providers and the disability community about the benefits of wellness resources.

- Encourage the development of integrated, multidisciplinary service teams to provide one-stop health care for persons with disabilities.
- Encourage or develop partnerships to facilitate coordinated, integrated care for populations identified as traditionally underserved, including persons with disabilities who are members of racial or ethnic groups.
- Promote and disseminate the adoption of new treatments, models of care and adaptive or assistive technologies (for example, making available specialized, adaptive cognitive and psychiatric research applications of assistive technology for individuals with communication deficits as well as a mental disorder).
- Identify key elements of best practices in health service delivery for persons with disabilities and, among existing health service delivery programs for this population, identify highlighted models that are using the key element and assess why they are successful.
- Identify and implement in community-based care evidence-based best practices in health service delivery for persons with disabilities.

V. Advancing the Call Nationwide

This *Call to Action* is designed to expand knowledge, understanding and action by a broad range of individuals, groups and organizations. Each has a role to play in advancing the principle that good health is necessary for persons with disabilities to secure the freedom to work, learn and engage actively in their families and their communities. While all disabilities are as different as the individuals who experience them, the challenges and opportunities for persons with disabilities often are similar.

Health, Wellness and Service Professionals

Health care providers, service support systems and the programs that train and educate them can gain from this *Call to Action*. Old attitudes about the relationship between disability and health can be changed; opportunities for better ways for health care providers to work with individuals with disabilities can be identified; and partnerships in treatment, education and health promotion can be forged.

Community Leaders and Influencers

This *Call to Action* can, and should, resonate with community leaders in both the public and private sectors (including employers and the media) and persons who craft or influence the creation of community programs. The goal and objectives, and how they are implemented as strategies at the community level, can both incentivize and yield dividends for employers of persons with disabilities, including greater productivity and lower overall health costs due to secondary illnesses. Advocates for persons with disabilities can use this *Call to Action* to promote the involvement of individuals with disabilities as equal partners in all aspects of American life.

The Media and Entertainment Industries

The media and entertainment industries can help educate persons with disabilities about ways to meet their own health and wellness needs by enabling individuals with disabilities to see, hear and read about “persons just like them” in electronic, print and audio media. All forms of broadcast and print media, and all forms of public entertainment can be used to further

needed public education to open minds about individuals with disabilities of all kinds.

Policy Makers and Administrators

Policy makers in both the public and private sectors can foster collaborations, partnerships and approaches to accessible, integrated services that span federal, state, tribal and local governments to improve access to and affordability of health and wellness services for persons with disabilities. This *Call to Action* can point to new directions in both policies and programs that will yield savings in both economic and human terms, from changes in how programs address the whole individual and not just a person’s disabilities, to ways to remove impediments to wellness promotion for persons with disabilities across the life cycle.

The Public

This *Call to Action* is about the education of America to the reality that persons with disabilities are just like everyone else. Their health and wellness needs are much the same as those of individuals without disabilities, although sometimes more difficult to achieve. Their disabilities are just one aspect of their lives and should not define who they are or what they can become.

Persons with Disabilities, Families and Advocates

Individuals of all ages with disabilities, their families and the organizations that represent them can translate the objectives in this *Call to Action* using the strategies for action recommended in the “Vision for the Future” section in the conduct of their daily lives. These same strategies can be applied as well to the places where they live, work, play and learn. Some strategies might present opportunities for personal growth. Others might provide impetus for local coalition building to respond to the health and wellness needs of persons with disabilities and for advocacy to ensure that these needs are met.

VI. The *Call to Action* at a Glance

About 54 million Americans of all ages, races, ethnicities, socioeconomic status and education levels are living with at least one disability. That is more than 20 percent of the people in the United States. A disability may affect the body, mind or senses and can limit a person from taking part in day-to-day life. People may be born with or acquire a disability, and most people in the United States will have a disability at some point in their life.

Health and illness exist at different levels; so, too, does disability. *However, disability is not an illness.* Illnesses can vary in degree from person to person. The same is true for disabilities. The same disability may affect one person in a different way than it does another. This is particularly true if someone cannot get needed treatment or services.

Persons without disabilities do not always understand what life is like for persons with disabilities. This is something that needs to be changed. To do this, it is important to make everyone aware of the barriers that may prevent persons with disabilities from becoming and remaining active in their community.

The principle on which this *Call to Action* is based is: Good health is necessary for persons with disabilities to have the freedom to work, learn and engage actively in their families and their communities.

To make this happen, this *Call to Action* looks to reach the following goals:

- People nationwide understand that persons with disabilities can lead long, healthy, productive lives
- Health care providers have the knowledge and tools to screen, diagnose and treat the whole person with a disability with dignity.
- Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.
- Accessible health care and support services promote independence for persons with disabilities

These will not be easy tasks. Many barriers stand in the way. For example, more research needs to be done about disability, health care providers need to be better educated and trained, and health care and services for persons with disabilities need to be easier to access.

This *Call to Action* is based on what is known and what has been observed about disability, health and wellness. It touches on the costs of inaction, in both human and dollar-and-cent terms. However, its main focus is on the need to put complete health care within the reach of persons with disabilities. Thus, person with disabilities will be able to lead a full life in their community.

This *Call to Action* is important for leaders in both the public and private sectors and for people who make or have input to community programs. The goals, put into action, can help employers of persons with disabilities increase work output and lower total health care costs. People who work with and for persons with disabilities can use this *Call to Action* to make others aware that persons with disabilities can be equal partners in all aspects of American life.

The health and wellness for persons with disabilities today is a matter of public health concern. Everyone needs to be made aware of the health issues for persons with disabilities. Swift action needs to be taken to ensure that these matters are brought to the attention of those who can help. Without such action, the quality of life for 54 millions Americans will be lessened. To that end, the principle and goals that define this Call to Action must be acted upon. Barriers must be identified and solutions must be found and, more importantly, set into motion.

This *Call to Action* provides a blueprint for these solutions. It clearly states the challenges, strategies and research priorities that are required. These four areas were crafted with input not only from health specialists in the disability field, but also with input from members of the disability community. Therefore, it is not just the science side of disability that is presented, but also the reality of living with disability by those who do it daily.

The cost of disability to the nation is measured not only in dollars, but in human lives. When a person with a disability is “lost” because the existing health care system cannot provide the needed level of care, it is a loss for everyone. Understanding the health and wellness of persons with disabilities is the first step to help change that situation. That is what this *Call To Action* is all about; that is why disability is a critical public health issue today.

VII. Appendices

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Richard H. Carmona, M.D., M.P.H., FACS
Surgeon General, United States Public Health Service
Office of the Surgeon General, Office of the Secretary
Washington, D.C.

Cristina V. Beato, M.D.
Acting Assistant Secretary for Health
Office of Public Health and Science, Office of the Secretary
Washington, D.C.

Margaret Giannini, M.D., FAAP
Director
Office on Disability, Office of the Secretary
Washington, D.C.

Kenneth P. Moritsugu, M.D., M.P.H.
Deputy Surgeon General, United States Public Health Service
Office of the Surgeon General, Office of the Secretary
Washington, D.C.

Robert C. Williams, P.E., DEE
Chief of Staff
Office of the Surgeon General, Office of the Secretary
Washington, D.C.

Jennifer Cabe, M.A.
Writer
Office of the Surgeon General, Office of the Secretary
Washington, D.C.

The editors of the report were

Scientific Editor

Margaret Giannini, MD, FAAP
Director
Office on Disability
Office of the Secretary
Washington, DC

Managing Editors

Edward Brann, MD, MPH
Director
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, GA

Eileen Elias, MEd
Deputy Director
Office on Disability
Office of the Secretary
Washington, DC

Scientific Writers

Theodora Fine, MA, ABD
Senior Policy and Public Affairs Specialist
Office on Disability
Office of the Secretary
Washington, DC

JoAnn M. Thierry, PhD, MSW
Behavioral Scientist
Disability and Health Team
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, GA

Technical Editors

Jameta Barlow, MPH
Program Analyst
Office on Disability
Office of the Secretary
Washington, DC

Connie L. Whitehead
Senior Writer-Editor
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, GA

Federal Contributors

Kari Benson
Policy Analyst
Administration on Aging
Washington, DC

Linda Bergofsky, MSW, MBA
Disability, Aging and Long-Term Care Policy
Office of the Assistant Secretary on Planning
and Evaluation
Washington, DC

Vincent A. Campbell, PhD
Associate Director for Science
Division of Human Development and Disability
National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, VA

John E. Crews, DPA
Lead Scientist
Division of Human Development and Disability
National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, GA

Robin C. Deykes
Investigator
Civil Rights Division
U.S. Department of Justice
Washington, DC

H. Stanley Eichenauer, MSW, ACSW
Senior Advisor to the Administrator for
Mental Health System Transformation
Substance Abuse and Mental Health Services
Administration
Rockville, MD

Monique Fountain, MD, MPH, MBA
Director, Medical Home and Healthy Ready to
Work Initiatives (HRTW)
Maternal and Child Health Bureau
Health Resources and Services Administration
Rockville, MD

M. Leonard Genova
Division of Partnership Development
Centers for Medicare and Medicaid Services
Baltimore, MD

Susan N. Hill, MPA
Senior Policy Advisor
Disabled and Elderly Health Programs Group
Center for Medicaid and State Operations
Centers for Medicare and Medicaid Services
Baltimore, MD

Chris Kochtitzky, MSP
Deputy Director
Division of Human Development and Disability
National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, GA

Diana Lawry, MEd
Aging Service Program Specialist
Administration on Aging
Washington, DC

Alan Levine
Senior Program Specialist
Office of Evaluation and Inspections
Office of the Inspector General
Washington, DC

Marianne Hamilton Lopez, MPA
Emerging Leaders Program
National Institutes of Health
Bethesda, MD

Saralyn Mark, MD
Senior Medical Advisor
Office on Women's Health
Office of the Secretary
Washington, DC

Merle McPherson, MD
Director, Division of Services for Children with
Special Healthcare Needs
Maternal and Child Health Bureau
Health Resources and Services Administration
Rockville, MD

Jeanne McDowell
Equal Employment Opportunity Staff
Center for Devices and Radiological Health
Food and Drug Administration
Rockville, MD

Taya McMillan, MPH
Service Fellow
Office of Women's Health
Office of the Secretary
Washington, DC

Daniel Morales, MPSA
Acting Director of Communications, Office of
Public Health and Science
Office of the Secretary
Washington, D.C.

Ruby Neville, MSW, LGSW
Public Health Advisor
Center for Substance Abuse Treatment
Substance Abuse and Mental Health Services
Administration
Rockville, MD

Allan S. Noonan, MD, MPH
Scientific Editor
Office of the Surgeon General, Office of the
Secretary
Washington, D.C.

Delores Parron, PhD
Scientific Advisor for Capacity Development
Office of the Director
National Institutes of Health
Bethesda, MD

Jon Perez, PhD
Director, Division of Behavioral Health
Indian Health Service
Rockville, MD

Latonya Phipps, Esq
Emerging Leader
Office of Equal Opportunity and Diversity
Management
National Institutes of Health
Bethesda, MD

Louis Quatrano, PhD
National Center on Medical Rehabilitation
Research,
National Institute of Child Health and Human
Development
National Institutes of Health
Bethesda, MD

Juliette Rizzo, MJ
Special Assistant/Senior Public Affairs Specialist
Office of Internal Communications
U.S. Department of Education
Washington, DC

Margaret Schaefer, MA
Program Specialist
Administration on Developmental Disabilities
Administration for Children and Families
Washington, DC

Peggy Schmidt, MEd
Civil Rights Analyst
Office for Civil Rights
Office of the Secretary
Washington, DC

Curt Shannon, BA
Writer-Editor
National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention
Atlanta, GA

Craig Stevens, MA
Director of Communications
Office of the Surgeon General, Office of the
Secretary
Washington, D.C.

Bonnie Strickland, PhD
Chief, Integrated Services for Children with
Special Health Needs
Maternal and Child Health Bureau
Health Resources and Services Administration
Rockville, MD

Charlene Tusan
Staff Attorney
Office of the General Counsel
Office of the Secretary
Washington, DC

Janet Valluzzi, MBA, OTR/L
Service Fellow
Center for Financing, Access, and Cost Trends
Agency for Healthcare Research and Quality
Washington, DC

Edwin Woo
Acting Associate General Counsel
Civil Rights Division
Office of the General Counsel
Office of the Secretary
Washington, DC

Private Sector Contributors

David B. Gray, PhD
Associate Professor of Neurology and Associate
Professor
Occupational Therapy Program in Occupational
Therapy
Washington University School of Medicine
St. Louis, MO

Nancy Lee Head
Mental Health Consumer, Retired Program
Director
National Alliance for the Mentally Ill, District of
Columbia Chapter
Arlington, VA

Lisa Iezzoni, MD, MSc
Professor of Medicine, Harvard Medical School
Division of General Medicine and Primary Care
Beth Israel Deaconess Medical Center
Boston, MA

John D. Kemp, JD
Powers, Pyles, Sutter & Verville, L.C.
Washington, DC

Maggie Nygren
Technical Assistance Director
Association of University Centers on Disability
Silver Spring, MD

Marcie Roth
Parent of children with disabilities
Executive Director, National Spinal Cord Injury
Association
Bethesda, MD

Clifford Thorne
Chairperson
District of Columbia State Rehabilitation
Council
Washington, DC

Steven Towle
Washington Liaison
National Association of Alcohol, Drugs and
Disability
Rockville, MD

MEDICARE AND MEDICAID

Many persons with disabilities rely on the federal-state Medicaid program and the federal Medicare programs of the Centers for Medicare and Medicaid Services (CMS) to assist with their health care needs. Both provide a public safety net for persons with disabilities; historically, both also have limitations (e.g., biases toward acute and institutional care and against preventive or home health care). In the past, people have been forced to “follow the money” to more expensive—often less appropriate—care. However, recent innovations are helping states to promote individual choice and community-based alternatives.

Medicaid

Home and community-based services are being provided by growing numbers of states through the CMS *home-and community-based services program* (HCBS) and through Independence Plus waivers. Information about these programs is available on-line, respectively at < www.cms.hhs.gov/medicaid/1915c/design.asp> and < www.cms.hhs.gov/independen-ceplus/>.

- *Medicaid Real Choice System Change Grants for Community Living* are helping states rebalance their programs to provide meaningful health care choices to enable individuals with disabilities and long-term illnesses to lead meaningful lives in the community. While states determine the areas on which to focus, the program is yielding results in such areas as:
 - Consumer direction and control of medical and other services—including eliminating barriers, creating individualized budgets, promoting transitions and selecting services needed;
 - Consumer access to community-based, long-term care and supports, including workforce availability and single point of consumer entry;
 - State budgeting and reimbursement that provide optimum flexibility to meet individual consumer needs (for example, personal care attendants); and
 - Quality assurance in service provision, including consumer feedback to promote continuous quality improvement.
 - Integration of multiple service systems to focus on the needs of individuals making states’ long-term support systems more efficient, effective and responsive to individual choices.

The *Medicaid Buy-In Program*, authorized by Congress under the Ticket to Work and Work Incentives Improvement Act of 1999, recognizes that eliminating barriers to health care and creating incentives to work can greatly improve the financial independence and well-being of beneficiaries with disabilities. The program, adopted at state option, allows people to go to work while retaining essential Medicaid health care benefits.

Medicare

The *Medicare Modernization Act* includes a number of specific provisions that focus on the needs of individuals with disabilities who qualify for Medicare coverage:

- The *Chronic Care Improvement Program* is a new demonstration program for people with multiple chronic conditions. Under the program, CMS will contract with private organizations to offer self-care guidance and support to chronically ill beneficiaries, helping beneficiaries manage all aspects of their health, adhere to their physicians’ plans of care and ensure that they seek or obtain medical care that they need to reduce their health risks. Participation by Medicare beneficiaries will be voluntary; participants will not have to change plans or providers, or to pay extra to participate. They will be able to stop participating at any time.
- A new demonstration project in Missouri, Colorado and Massachusetts is assessing a new definition of “homebound” that removes the limitation based on actual time spent away from home, eliminating concern among many homebound persons that they will lose access to home-based care if they engage in any activities beyond their homes.
- New preventive services will become available in 2005, including an initial physical for new beneficiaries, coverage for cardiovascular screening blood tests for all beneficiaries and diabetes screening for high-risk beneficiaries.

These services come on top of the new Medicare Part D prescription drug benefit that will allow Medicare beneficiaries to enroll in drug coverage through a prescription drug plan or Medicare health plan with Medicare paying for 75% of the premium. Additional benefits for Medicare beneficiaries who have limited means will cover, on average, 95% of their drug costs. All the new Medicare benefits are voluntary; beneficiaries may choose to keep their existing traditional coverage. Until that program is in effect (2006), individuals with disabilities and older adults will be able to use new medication discount cards to garner savings of about 10 to 15% on their total drug costs, with savings of up to 25% or more on individual prescriptions.

Speedier Medicare Appeals can help ensure that individuals with disabilities are able to resolve appeals for Medicare benefits more quickly and efficiently as the result of a new Medicare-related program set in place by the Centers for Medicare and Medicaid Services.

Glossary of Terms

1973 Rehabilitation Act: A federal law that prohibits discrimination on the basis of disability in programs conducted by federal agencies (Section 504), in programs receiving federal funding (Section 504), in federal employment (Section 501), and in the employment practices of federal contractors (Section 503). Section 508 of the Act requires federal electronic and information technology to be accessible to persons with disabilities. This means it must be able to be operated in a variety of ways and not rely on a single sense or ability of the user.

1999 Olmstead Decision: A decision by the U.S. Supreme Court that interpreted Title II of the Americans with Disabilities Act (ADA) and its implementing regulations to require states to administer services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities,” a setting that “enables individuals with disabilities to interact with persons with no disabilities to the fullest extent possible.” Settings may range from home or community-based settings to residential care settings (such as assisted living) to institutional settings. Paramount is the opportunity for persons with disabilities to participate in community life, including everyday life activities, such as family relations, social contacts, work, educational advancement, and cultural enrichment.

Accessibility: The degree to which an environment (physical, social, or attitudinal) makes appropriate accommodations to eliminate barriers or other impediments to equality of access to facilities, services, and the like, for persons with disabilities.

Activities of Daily Living (ADL): Basic tasks of everyday life or personal functional activities required for continued well-being, including eating or nutrition, mobility (such as walking and getting in and out of a chair or bed), and personal hygiene (such as bathing or showering, dressing, and using the toilet).

Adaptive or Assistive technology: Any item, piece of equipment, product, or system (whether off-the-shelf, modified, or customized) that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.

Americans with Disabilities Act of 1990 (ADA): A federal law (P.L. 101-226) that prohibits discrimination on the basis of disability in employment, in public accommodations, in commercial facilities, in transportation, in telecommunications, and by state, tribal, and local government. Under the act, persons with disabilities are to receive “reasonable accommodations” — adjustments or modifications provided by an employer—that enable each individual with a disability to enjoy equal employment opportunities.

Accommodations vary based on the needs of the individual applicant or employee. Not all people with disabilities (or even all people with the same disability) will require the same accommodation; each must be accommodated based on his or her individual needs.

Attitudinal barrier: Negative viewpoints, behaviors, or actions by individuals or groups that limit another person's ability to function in the environment, leading to the state of disability.

Attitudinal impediment: See *Attitudinal barrier*.

Behavioral factors: Individual responses or reactions to internal stimuli and external conditions. Social and physical environmental conditions and situations, many of which are not under an individual's personal control, can exert a positive or negative effect on an individual or group.

Behavioral disorder: A condition characterized by displaying behaviors that significantly deviate from socially acceptable norms for the individual's age and situation over a long period of time. This term generally is used to avoid the stigma of the term “mental illness” when describing these conditions in children and youth.

Behavioral health: An integrated, interdisciplinary system of care related to mental health and substance use disorders that approaches individuals, families, and communities as a whole and addresses the interactions between psychological, biological, sociocultural, and environmental factors.

Behavioral Risk Factor Surveillance System (BRFSS): A national telephone survey conducted by the Centers for Disease Control and Prevention that monitors state-

level prevalence of major behavioral risks among adults for death and disability. The survey collects these data to help plan, initiate, and evaluate federal and other health promotion and disease prevention programs.

Built environment: Any structures, spaces, and products that are created, modified, and used by people, such as buildings, parks, businesses, schools, and road systems.

Caregiver: An individual, not necessarily a family member, who provides assistance to another person who experiences limitations in activities of daily living (ADLs) or instrumental activities of daily living (IADLs), or both.

Chronic condition: Conditions lasting at least 3 months that, once acquired, currently are not able to be cured.

Chronic illnesses: See *Chronic condition*.

Cognitive impairment: A loss or abnormality in the various mental processes that underpin an individual's ability to think or reason.

Cultural competence: The provision of services, supports, or other assistance in a manner responsive to and respectful of the beliefs, interpersonal styles, attitudes, languages, and behaviors of individuals receiving these services, supports, or assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation.

Deinstitutionalization movement: An effort that began in the late 1950s to shift individuals with physical or mental illnesses or disabilities from institutional to community-based care settings.

Developmental disability: A severe, chronic disability of an individual attributable to a mental or physical impairment or combination of impairments that (a) manifests before the individual attains 22 years of age; (b) is likely to continue indefinitely; and (c) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency, and the continuous need for individually planned and coordinated services.

Direct cost: The economic cost incurred as a direct result of the presence of a disability.

Functioning: An umbrella term referring to an individual's capacity related to body functions, activities, and participation in aspects of individual, family, and community life. It includes the positive aspects of the interaction between an individual and that individual's environment.

Genetic predisposition: Susceptibility to a disease that is related to a genetic mutation, which might or might not result in actual development of the disease.

Health literacy: The ability to comprehend basic concepts and tasks related to health. Health literacy programs include information on how to read prescription labels, consent forms, and communicate effectively with health care providers.

HealthierUS Initiative: A White House initiative with the goal of helping Americans lead longer, better, and healthier lives by promoting physical activity, preventive screenings, balanced nutrition and healthy choices. *Steps to a HealthierUS* was established by the U.S. Department of Health and Human Services to advance the larger initiative. It targets public education and community-based grants to reduce the burden of diabetes, overweight, obesity, and asthma, and to address three related risk factors—physical inactivity, poor nutrition, and tobacco use.

Healthy People 2010: A decade-long set of national disease prevention and health promotion objectives for America designed to identify and respond to the most significant preventable threats to individual health. It provides a snapshot of the nation's health at the beginning of the decade, establishes national goals and targets to be achieved within the decade, and monitors progress over time.

Instrumental Activities of Daily Living (IADL): Skills and abilities related to independent living related to home, work, and the social environment. In the home, this can include but is not limited to the ability to engage in such activities as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone without the need for assistance from others.

Impairment: A loss, abnormality, or deficit in body structure or physiological function (including mental functions). Abnormality refers to significant variation from a population mean within measured standard norms.

Indirect costs: The economic cost incurred collateral to, but not directly related to, the presence of a disability.

Institutional setting: A facility in which an individual lives, often on a long-term basis, to receive services, often for a particular health problem. Such settings stand in contrast to community settings, where services are available as part of the area or neighborhood in which one lives.

Intellectual disability: Once referred to as “mental retardation,” an impairment of thinking abilities that generally results in an intellectual quotient (IQ) equivalent that is two or more standard deviations below the average, or 70 or lower when the mean is 100. Intellectual disability often is a component of a developmental disability arising in an individual before he or she is 22 years of age.

Interdisciplinary: Collaboration involving two or more academic, scientific, or artistic disciplines working together toward a single purpose.

International Classification of Functioning, Disability, and Health (ICF): A classification of health, impairment, and disability created by the World Health Organization. The ICF is structured around three broad components: (1) body functions and structure; (2) activities (related to tasks and actions by an individual) and participation (involvement in a life situation); and (3) additional information on severity and environmental factors. Functioning and disability are viewed as a complex interaction between the medical condition of the individual and the contextual factors of the environment, as well as personal factors. The picture produced by this combination of factors and dimensions is of “the person in his or her world”. The classification treats these dimensions as interactive and dynamic rather than linear or static. It allows for an assessment of the degree of disability, although it is not a measurement instrument. It is applicable to all people, whatever their medical condition. The language of the ICF emphasizes function rather than condition or disease. It also is designed to be relevant across cultures, as well as age groups and sex.

Major life activity: Activities an individual needs to be able to perform to function adequately during the conduct of daily life. These include self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.

Medical home: An approach to providing health care in a high-quality, cost-effective manner in which families and individuals receive health care from a physician they know and trust. When a child is the patient, the parents and physician partner to identify and access all the medical and nonmedical services needed to help the child and family achieve maximum potential.

Mental disorder: A clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (for example, a painful symptom) or disability (that is, impairment in one or more important areas of functioning) or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom. In addition, this syndrome or pattern must not be a culturally sanctioned response to a particular event (for example, the death of a loved one). Whatever its cause, it must currently be considered a manifestation of a behavioral, psychological, or biological dysfunction in the individual.

Mental illness: See *Mental disorder*.

New Freedom Initiative: A 2001 presidential initiative designed to help eliminate barriers to equality for many individuals with disabilities. Programs and proposals developed through the initiative are designed to (1) increase access to assistive and universally designed technologies; (2) expand educational opportunities; (3) promote homeownership; (4) integrate Americans with disabilities into the workforce; (5) expand transportation options; and (6) promote full access to community life.

National Health Interview Survey (NHIS): A multi-purpose, questionnaire-based health survey conducted by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS) to provide national estimates for a broad range of health measures for the U.S. civilian adult noninstitutionalized population.

Noninstitutionalized population: The population of civilians who are not residing in institutions. Institutions include, but are not necessarily limited to correctional facilities, detention homes, and training schools for juvenile delinquents; homes for the aged and dependent (for example, nursing and convalescent homes); homes for dependent and neglected children; homes and schools for persons with mental or physical disabilities; and long-term and residential treatment centers.

People-first language: The practice of reshaping common language to refer to persons with disabilities in a manner that is more respectful and inclusive. By placing the “person” descriptor before the “condition” descriptor (for example, a woman who is deaf or a child with a developmental disability) people-first language recognizes that individuals with disabilities are first and foremost persons with inherent value, individuality, dignity, and capabilities.

Prevalence: The number of cases of a disease, number of infected persons, or number of persons with another quantifiable attribute at a particular point in time or during a particular period of time. Prevalence most often is expressed as a rate (for example, the prevalence of diabetes per 1,000 persons during a particular 12-month period).

Protective factor: Personal, family, and community elements that can improve a person's response to an environmental hazard resulting in an adaptive outcome. Such factors do not necessarily foster normal development in the absence of risk factors, but they can help mitigate the influence of risk factors.

Quality of life: The relative degree of happiness and satisfaction with both one's life and environment. It encompasses health, recreation, culture, rights, values, beliefs, aspirations, and the conditions that promote a life containing these elements. Health-related quality of life specifically refers to an individual's sense of physical and mental health and well-being, and the ability to respond to the physical, social, and behavioral environment.

Rehabilitation: Comprehensive program to reduce or overcome deficits following injury or illness, or to assist the individual to attain an optimal level of mental and physical ability. Rehabilitation is seen as a process leading to recovery of capacity, albeit not nec-

essarily at a level that preceded the illness or injury that led to the impairment.

Respite care: A short time of rest or relief for a person who acts as a caregiver for an individual with a disability. It allows the caregiver a break from day-to-day duties while the person with a disability receives care from another qualified individual or individuals. Such care can be provided in a home, community organization, or residential facility; for part of the day, evening, or overnight; by paid staff, volunteers, family, or friends; and occasionally or on a regular basis.

Secondary condition: Medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences. Common secondary conditions include pressure sores, urinary tract infections, and depression; from a social perspective, such secondary conditions also can include decreased social participation and unemployment.

Secondary medical condition: See *Secondary condition*.

Social Security Disability Insurance: A federal program, financed through Social Security taxes, providing wage replacement income for individuals with disabilities who also meet Social Security Administration disability rules. To be eligible, an individual (including disabled workers, widows, widowers, or children or adults disabled since childhood) must be unable to engage in any substantial gainful activity (SGA) due to any medically determinable physical or mental impairment(s) that can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. In addition to being unable to perform his or her previous work, the person cannot, considering age, education, and work experience, engage in any other kind of SGA in the national economy.

Substance use (or abuse) disorder: The misuse, dependence, and addiction to alcohol, or legal or illegal drugs, or both. The term encompasses a range of severity from “problem” through dependence and addiction.

Supplemental Security Income Program: A program, administered by the Social Security Administration (SSA) since 1972, that enables eligible persons of low income and few resources who also are 65 years of age or older, blind, or disabled to receive monthly benefit payments. To be eligible based on a disability, an indi-

vidual must meet the SSA definition of disability: unable to engage in any “substantial gainful activity” (SGA) due to any medically determinable physical or mental impairment(s) that can be expected to result in death or that has lasted or can be expected to last for a continuous period of not less than 12 months.

Universal design: The creation of goods, products, and physical environments that are, to the greatest extent possible, both accessible and usable by all persons without the need for adaptation or specialized design.

1998 Workforce Investment Act: A law that offers a comprehensive range of workforce development activities through state, tribal, and local organizations. Available workforce development activities provided in local communities are intended to benefit job seekers, including persons with disabilities. The goal is to promote an increase in the employment, job retention, earnings, and occupational skills improvement by participants, thereby improving the quality of the workforce, reducing welfare dependency, and improving the productivity and competitiveness of the nation as a whole. Title IV of the act further reauthorizes programs under the Rehabilitation Act and links these programs to state, tribal, and local workforce development systems.

Resources

Federal Departments, Agencies, and Offices

Administration on Aging
U.S. Department of Health and Human Services
<http://www.aoa.gov>

Administration on Developmental Disabilities
Administration for Children and Families
U.S. Department of Health and Human Services
<http://www.acf.gov>
<http://www.acf.dhhs.gov/programs/add/index.htm>

Center for Financing, Access and Cost Trends
Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
<http://www.ahrq.gov>

Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
<http://www.cms.hhs.gov>

Clearinghouse on Disability Information
Office of Special Education and Rehabilitative Services
U.S. Department of Education
<http://www.ed.gov>

Department of Defense
<http://www.defenselink.mil>

Department of Homeland Security
<http://www.dhs.gov>

Department of Housing and Urban Development
<http://www.hud.gov/groups/disabilities.cfm>

Department of Labor
DisabilityInfo.gov
<http://www.disabilityinfo.gov>

Disability Rights Section
Civil Rights Division
U.S. Department of Justice
<http://www.usdoj.gov/crt/drs/drshome.htm>

Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities

Centers for Disease Control and Prevention
U.S. Department of Health and Human Resources
<http://www.cdc.gov>

Federal Transit Administration
U.S. Department of Transportation
<http://www.ftadot.gov/>

Health Resources and Services Administration
U.S. Department of Health and Human Services
<http://www.hrsa.gov>

Indian Health Service
U.S. Department of Health and Human Services
<http://www.ihs.gov>

Interagency Committee on Disability Research (ICDR)
<http://icdr.us/>

National Center on Medical Rehabilitation Research
National Institute of Child Health and Human
Development
National Institutes of Health
U.S. Department of Health and Human Services
<http://www.nichd.nih.gov>

National Council on Disability
<http://www.ncd.gov>

National Institute on Deafness and Other
Communication Disorders
National Institutes of Health
U.S. Department of Health and Human Services
<http://www.nih.gov/nidcd>

National Institute on Disability and Rehabilitation
Research
U.S. Department of Education
<http://www.ed.gov>

Office for Civil Rights
U.S. Department of Health and Human Services
<http://www.hhs.gov/ocr/>

Office of Disability Employment Policy
U.S. Department of Labor
<http://www.dol.gov/odep>

Office of Equal Opportunity and Diversity
Management
National Institutes of Health
U.S. Department of Health and Human Services
<http://nih.hhs.gov>

Office of Public Health Emergency Preparedness
U.S. Department of Health and Human Services
<http://www.hhs.gov/ophep/>

Office of Special Education and Rehabilitative Services
U.S. Department of Education
<http://www.ed.gov>

Office of the President's Council on Physical Fitness
and Sports
U.S. Department of Health and Human Services
<http://www.fitness.gov>

Office on Disability
U.S. Department of Health and Human Services
<http://www.hhs.gov/od/>

Office on Women's Health
U.S. Department of Health and Human Services
<http://www.4woman.gov>

President's Committee on Persons with Intellectual
Disorders, Agency for Children and Families
U.S. Department of Health and Human Services
<http://www.acf.hhs.gov/programs/pcpid/>

The President's Challenge Physical Activity and Fitness
Awards Program
<http://www.presidentschallenge.org>

Social Security Administration
<http://www.ssa.gov>

Substance Abuse and Mental Health Services
Administration
U.S. Department of Health and Human Services
<http://www.samhsa.hhs.gov>

Private Resources

*[This list is not all inclusive; inclusion neither represents
nor otherwise suggests endorsement by the U.S. Department
of Health and Human Services.]*

AARP (American Association of Retired Persons)
<http://aarp.org>

ADAPT
<http://www.adapt.org>

Alliance Project (special education)
<http://www.alliance.org>

Alliance for Technology Access
<http://www.atacess.org>

American Academy of Pediatrics
<http://www.aap.org>

American Academy of Physical Medicine and
Rehabilitation
<http://www.aaprm.org>

American Alliance for Health, Physical Education,
Recreation, and Dance
<http://www.aahperd.org>

American Association for Geriatric Psychiatry
<http://www.aagpgpa.org>

American Association for Homecare
<http://aahomecare.org>

American Association of Mental Retardation
<http://www.aamr.org>

American Association of Occupational Therapy
<http://www.aota.org>

American Association of People with Disabilities
<http://www.aapd.com>

American Association on Health and Disability
<http://www.aahd.us>

American Council of the Blind
<http://www.acb.org>

American College of Sports Medicine
<http://www.acsm.org>

American Foundation for the Blind
<http://www.afb.org>

American Health Care Association
<http://www.ahca.org>

American Indian Rehabilitation Research and training
Center
<http://www.nau.edu/ihd/airrtc>

American Physical Therapy Association
<http://www.apta.org>

American Society on Aging
<http://www.asaging.org>

American Speech-Language-Hearing Association
<http://www.asha.org>

American Therapeutic Recreation Association
<http://www.atra-tr.org>

ANCOR
<http://www.ancor.org>

Arc of the United States
<http://www.thearc.org>

Asian Community Mental Health Services
<http://www.igc.apc.org/acmhs>

Association of Maternal and Child Health Programs
<http://www.amchp.org>

Association of University Centers on Disability
<http://www.aucd.org>

Breast Health Access for Women with Disabilities
<http://www.bhawd.org>

Center for Medicare Advocacy
<http://www.medicareadvocacy.org>

Center for Research on Women with Disabilities
<http://www.bcm.edu>

Center for Universal Design
<http://www.design.ncsu.edu/cud>

Child Welfare League of America
<http://www.cwla.org>

Christopher and Dana Reeve Paralysis Resource Center
<http://www.paralysis.org>

Council for Exceptional Children
<http://www.cec.sped.org>

Disabled American Veterans
<http://www.dav.org>

Diabetes Research and Wellness Foundation
<http://www.diabeteswellness.net>

Disability Service Providers of America
<http://www.dspofamerica.org>

Disabled Sports USA
<http://www.dsusa.org>

Disabled Women's Alliance
<http://www.disabilityhistory.org>

Easter Seals
<http://www.easterseals.com>

Educational Resources Information Center on
Disabilities and Gifted Education
<http://www.ericec.org>

Epilepsy Foundation
<http://www.epilepsyfoundation.org>

Exceptional Parent
<http://www.eparent.com>

Family Voices
www.familyvoices.org

Federation of Families for Children's Mental Health
<http://www.ffcmmh.org>

Georgetown University Center for Child and Human
Development
<http://gucchd.georgetown.edu>

Goodwill Industries International
<http://www.goodwill.org>

Howard University Research and Training Center for
Access to Rehabilitation and Economic Opportunity
<http://www.law.howard.edu/hurtec/hurtec.html>

International Center for Bioethics, Culture and Disability
<http://www.bioethicsanddisability.org>

Kids Enjoy Exercise Now (K.E.E.N.)
<http://www.keenusa.org>

March of Dimes
<http://www.marchofdimes.com>

National Adult Day Services Association
<http://www.nadsa.org>

National Alliance for Accessible Golf
<http://www.accessgolf.org>

National Alliance for Hispanic Health Centers for Providers
<http://www.hispanichealth.org>

National Alliance for the Mentally Ill
<http://www.nami.org>

National Asian Pacific Center on Aging
<http://www.napca.org>

National Association of Alcohol, Drugs and Disability
<http://www.naadd.org>

National Association of Protection and Advocacy Systems
<http://www.napas.org>

National Association of State Alcohol and Drug Abuse Directors
<http://www.nasadad.org>

National Association of State Directors of Special Education
<http://www.nasdse.org>

National Association of State Medicaid Directors
<http://www.nasmd.org>

National Association of State Mental Health Program Directors
<http://www.nasmhpd.org>

National Association of State Units on Aging
<http://www.nasua.org>

National Catholic Partnership on Disability
<http://www.ncpd.org>

National Center for Disability Services
<http://www.business-disability.com>

National Center on Physical Activity and Disability
<http://www.ncpad.org>

National Clearinghouse on Managed Care and Long-term Support and Services for People with Developmental Disabilities and Their Families
<http://www.mcare.net>

National Council on the Aging
<http://www.ncoa.org>

National Information Center for Children and Youth with Disabilities
<http://www.nichcy.org>

National Industries for the Severely Handicapped
<http://www.nish.org>

National Limb Loss Information Center
<http://www.amputee-coalition.org>

National Mental Health Association
<http://www.nmha.org>

National Organization on Disability
<http://www.nod.org>

National Rehabilitation Association
<http://www.nationalrehab.org>

National Rehabilitation Information Center (NARIC)
<http://www.naric.com>

National Resource Center on AD/HD: A program of CHADD
<http://help4adhd.org>

National Spinal Cord Injury Association
<http://www.spinalcord.org>

Native American Training and Research Center
<http://www.ahsc.arizona.edu/nartc>

Paralyzed Veterans of America
<http://www.pva.org>

Parent Advocacy Coalition for Educational Rights
(PACER)
<http://www.pacer.org>

Programs and Services Center of Minority Research in
Special Education (COMRISE)
<http://www.curry.ed.school.virginia.edu/go/comrise>

Rehabilitation Engineering and Assistive Technology
Society of North America
<http://www.resna.org>

Special Olympics
<http://www.specialolympics.org>

Spina Bifida Association of America (SBAA)
www.sbaa.org

United Cerebral Palsy Association
<http://www.ucp.org>

United Spinal Association
<http://www.unitedspinal.org>

Veterans of Foreign War
<http://www.vfwdc.org>

