

# 25. Disability & Secondary Conditions

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## ***Goal:***

**Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the Alaska population.**

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Health Goal for the Year 2010: Promote the health of people with disabilities, prevent secondary conditions, and eliminate disparities between people with and without disabilities in the Alaska population.					
	Indicator	Alaska Data Source	U.S. Baseline	Alaska Baseline	Alaska Target Year 2010
1	Include in the BRFSS questions that identify "people with disabilities".	BRFSS	Available 2002	Available 2002	Module continued every other year
2	Reduce the number of days adults aged 18 years and older with disabilities report being sad, blue or depressed.	BRFSS	Available 2002	Available 2002	
3	Reduce the number of days adults aged 18 years or older with disabilities report they have a hard time doing their usual activities, such as self-care, work, or recreation.	BRFSS	Available 2002	Available 2002	
4	Increase the proportion of children and youth aged 6 to 21 years with disabilities who spend at least 80% of their time in regular education programs.	DEED Division of Teaching & Learning Support	45% (1995-96)	60% (1999-2000)	70%
5	Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed.	BRFSS (potential)	Developmental (NHIS)	Developmental	

**BRFSS** - Alaska Behavioral Risk Factor Surveillance System. All U.S. BRFSS data are age-adjusted to the 2000 population; the Alaska BRFSS data have not been age adjusted, so direct comparisons are not advised. See Technical Notes.

**NHIS** - National Health Interview Survey

**DEED** - Alaska Department of Education and Early Development

### Overview

Because disability status has been traditionally equated with health status, the health and well-being of people with disabilities has traditionally been addressed in a medical care, rehabilitation, and long-term care financing context. Four main issues emerge from this approach:

- The belief that all people with disabilities automatically have poor health.
- The belief that preventing disabling conditions should be the major focus of public health.
- The lack of a crosscutting, standard definition of “disability” or “people with disabilities” for public health.
- The absence of discussion about the role of the environment in the disabling process.

Many people with disabilities reject the “medical model” of disability, which treats them as dependent patients rather than as self-directed individuals fully capable of autonomy. The “independent living” model was established in the early 1970s as a reaction to the medical model. It holds that individuals with disabilities have the right to live with dignity and with appropriate support in their own homes, fully participate in their communities, and to control and make decisions about their lives. It further holds that the inability to do so lies not within the individual with a disability, but within societal attitudes and environmental barriers.

Understanding these issues will help to clarify the health status of people with disabilities and address the attitudes and barriers that undermine their health, well-being, and participation in life activities. People with disabilities often have great difficulty gaining access to adequate primary and secondary health care. There are several reasons for this lack of access.

As a group, people with disabilities have higher-than-average health care costs and are therefore considered a high-risk group. Many insurance policies systematically attempt to exclude them or to reduce the value of their benefits through preexisting condition clauses, coverage exclusions, and benefits caps.

Many health care providers are not adequately familiar with the health needs of people with disabilities and are therefore not equipped to meet their needs. Under-emphasis on health promotion and disease prevention activities targeting people with disabilities may

increase the occurrence of secondary conditions (e.g., medical, social, emotional, family, or community problems).

Environmental factors affect the health and well-being of people with disabilities in several ways. For example, medical offices and equipment may not be adapted or adaptable, and fitness centers may not be staffed or equipped for people with disabilities. Compliance with the Americans with Disabilities Act (ADA) would help overcome some of these barriers. Although the ADA was not designed to resolve the major health care problems experienced by people with disabilities, it was intended to address some key access problems.

Over the past 15 years, several historic pieces of legislation related to disability policy have been enacted, including the ADA, the Assistive Technology Act, several re-authorizations of the Individuals with Disabilities Education Act and the Rehabilitation Act, and the Ticket to Work and Work Incentives Improvement Act. These bills all promote social change designed to eliminate disability-based discrimination and create opportunities for people with disabilities to participate in their communities.

Historians and disability experts feel that these legislative changes have brought a new era in the disability movement. This new era is broadly referred to as the “disability culture movement,” which is aimed at encouraging pride in one’s ability, creating positive self-images, and building a society that accepts and celebrates difference. People from many diverse backgrounds are reaching past their own individual perspectives to raise public awareness, promote full equality for all, and replace barriers to opportunity with policies and programs that empower and include all people.

The ADA ensures equal access to employment, state and local government, private businesses that offer goods, services and activities to the public, transportation, and telecommunications for people with disabilities. In passing the ADA with overwhelming bi-partisan support, Congress identified the full participation and inclusion of people with disabilities into society as a national goal.

However, despite advances, many people with disabilities continue to report barriers to full participation in community life. Full participation cannot be achieved without eliminating environmental and attitudinal barriers, such as architectural barriers,

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organizational policies and practices, discrimination, and social attitudes. Thus, public health agencies need to measure not only the nature and extent of disability in Alaska, but also the extent to which environmental and attitudinal factors enhance or impede participation.

About 17 percent of United States children under 18 years of age have a developmental disability. Developmental disabilities are a diverse group of physical, cognitive, psychological, sensory, and speech impairments that begin anytime during development up to 18 years of age. In most instances, the cause of the disability is not known. It is important to understand what factors increase the chance that a child will have a developmental disability and what can be done to prevent the condition. Approximately 2 percent of school-aged children in the United States have a serious developmental disability, such as mental retardation or cerebral palsy, and need special education services or supportive care. State and federal education departments spend about \$36 billion each year on special education programs for individuals with developmental disabilities who are 3 to 21 years old.<sup>1</sup>

Few health surveillance and health promotion programs target people with disabilities. The needs of caregivers should also be addressed by public health activities. In a 1997 telephone survey conducted by the American Association of Retired Persons, 23 percent of all United States households included at least one caregiver.<sup>2</sup> Whether caring for infants, children, seniors, or adults with disabilities, the caregiver is crucial to health.<sup>3</sup>

### Disparities

Although disability is a universal phenomenon anyone can experience, people with disabilities as a group are generally less visible than other sub-populations. The disabled may be the nation's single largest minority group, but it differs from others in that people with disabilities are not homogeneous. Variations in type, severity, and cause of disability result in different concerns. For example, the needs of someone who is blind are different from those of an individual with spinal cord injuries. The needs of someone who is hard of hearing are different from those of someone who is deaf. Not all people with disabilities see themselves as having a disability; they may just have difficulty getting around. Some people deny their disability because of the stigma that accompanies the label.

Few data systems identify people with disabilities as a sub-population. As a potentially underserved minority group, people with disabilities generally experience disadvantages in health and well-being compared with the general population. Possible differences in disability prevalence by race, age and sex, as well as the possible geographic differences associated with where care or accessible work and educational opportunities exist, will need to be studied over the decade.

### Issues and Trends in Alaska

The Current Populations Report estimated that nearly 20 percent of the United States population lives with disabilities. Using that basis for estimation, about 124,400 Alaskans experience some degree of disability, of whom 25 percent experience significant limitations in their daily activities. Less than 15 percent of people who experience disabilities were born with them. Furthermore, disabilities occur with greater frequency as we age. It is a minority that we all may join if we live long enough.

People with disabilities report significantly lower levels of social participation (such as volunteering, shopping, going to the movies, attending sporting events) compared with people without disabilities. Alaskans with disabilities have identified a number of reasons for this discrepancy, including:

- needs for physical accessibility, accessible transportation and assistive technologies,
- a general lack of public awareness about the abilities, needs, rights and responsibilities of people who experience disabilities, and
- limited incomes, which further prevent their full participation in community life.

More and more Alaskans with severe disabilities are living in their own homes or with their families. Alaska is the first state in the country to have eliminated public and private institutions for people with developmental disabilities. However, there are still a number of individuals with disabilities who must live in nursing homes to get the services and supports they need.

Several recent legislative, regulatory, and judicial events have resulted in the most federal policy activity to date on long-term services and supports for people with disabilities. Community-based, long-term supports and services are now seen as valid and preferred alternatives to congregate care services. Only 32 percent of working age people with

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disabilities are working, compared to 81 percent of working age people without disabilities. There are a number of reasons for this disparity including:

- fear of losing health benefits that may depend on disability status
- financial disincentives
- fragmented systems
- lack of comprehensive vocational services
- lack of knowledge about or use of existing work incentive programs
- limited work opportunities.

Individuals with disabilities, state agencies and service providers are working together through the Alaska Works initiative to address these barriers in a comprehensive way.

A priority for Alaska is to reduce the proportion of adults with disabilities who report feelings such as sadness, unhappiness or depression that prevent them from being active or participating in activities within their communities. Disability may involve a number of physical, mental or sensory losses, or environmental, economic or attitudinal barriers which may lead to psychological stress. Children and adults with disabilities and their families face issues of coping, adapting, adjusting, and learning to live well with the disability -- a dynamic, ongoing process.

Good mental health, including refusal to internalize the social stigma of disability and developing a positive attitude and strong self-esteem, is a key ingredient to overcoming these issues. Improving mental health status among people with disabilities and their families will help address psychological barriers and enhance their ability to participate fully in society. Barrier-free environments also help, as do information, coaching, listening, referring, teaching, and modeling from nonprofessionals who have a disability.

A second priority is to increase the proportion of adults with disabilities reporting sufficient emotional support in their lives. Emotional support often is derived from a person's social supports. Being involved in the community often increases feelings of connectedness and decreases feelings of isolation, both among people with and without disabilities. The lack of encouragement from community organizations is a major factor holding people with disabilities, particularly those with severe disabilities, from participating more, which suggests that these organizations need to take a concerted approach to reaching out to them. Targeting increased participation

in such regular social activities as traveling, socializing with friends and family, attending church or community events, and voting can result in improved functional status and well-being.

Satisfaction with life is associated with the more general term "quality of life," which is a personal evaluation of one's own position in numerous dimensions of life, including physical, emotional, social, spiritual, level of independence, and environmental support. Monitoring the life satisfaction of people with disabilities, as well as that of the broader population, allows an opportunity to evaluate society's progress in including people with disabilities.

### *Current Strategies and Resources*

Several studies have demonstrated that health promotion programs focused on improving functioning across a spectrum of diagnoses and a range of age groups are effective in reducing secondary conditions and outpatient physician visits among people with disabilities. For example, a focus on improving muscle tone, flexibility, and strength can benefit people who use wheelchairs and people with arthritis. People with sight impairments can have access to readable job applications, food labels, and medications. People with hearing impairments can have access to televised or videotaped exercise programs that are captioned or signed by interpreters depicted within an inset of a video screen. Often, the most effective interventions are environmental rather than medical.

Many health promotion interventions already in place for the population at large may be easily adapted to the needs of people with disabilities. New strategies can be influenced by results from studies that describe risk factors for secondary conditions or protective factors against additional impairments. For example, the results of investigations of secondary osteoporosis already influence health promotion strategies among able-bodied women; similar investigations can augment the development of health promotion strategies among women with disabilities. Cost-effective, evidence-based health promotion and disease prevention programs can be developed, implemented, and evaluated to target the health and injury disparities between people with and without disabilities.

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Training for the medical community may be expanded to include a disability perspective. This training could equip health professionals with the information, tools, insight, and resources they need to provide quality customer service and care to individuals with disabilities. For example, the Disability Rights Education and Defense Fund is developing a disability rights curriculum for the Center for Disability Issues and the Health Profession at Western University of Health Sciences to introduce a non-medical disability paradigm to medical practitioners. Changes in attitudes of health care providers may result in better health care. For example, people with psychiatric disabilities frequently report that health care professionals disregard or discount reports of physical illnesses, as if their disabilities disqualify their knowledge of their medical needs.

The internet is having a positive impact on the quality of lives of people with disabilities. Specifically, it allows people with disabilities to be better informed and more connected to the world around them. It also puts them in touch with people who have similar interests and experiences.

Parents of students with disabilities have found that their children make greater gains academically and socially in inclusive regular classrooms than they did in segregated classrooms. Both parents and students feel that inclusion helps students without disabilities become more understanding of students with disabilities. Several studies have demonstrated that inclusion does not interfere with the ability of students without disabilities to learn. However, in order for inclusion to work, an investment needs to be made in training, planning time, and supports for regular educators, including adequate staff and technological assistance.

For people with disabilities to have the opportunity for healthy lives, both physically and emotionally, programs and facilities that offer wellness and treatment services must be fully accessible. Effective enforcement of the ADA can improve services for people with disabilities and help prevent secondary disabilities.

For many people with severe disabilities, assistive technology changes the most ordinary of daily activities from impossible to possible. Although the inability to pay for needed technology is the main reason why people with disabilities do not have the

technology they need, there are three other major barriers. They are:

- lack of awareness and expertise
- lack of accessible product development and deployment
- limited research, development and technology transfer.

Assistive Technologies of Alaska is charged with building capacity statewide, meeting market needs, utilizing existing funding sources wherever possible, and creating systems change to open new markets and funding sources. The ultimate outcome of this process is to have in place across Alaska, a sustainable system of assistive technology, which is being developed by the Assistive Technology Library of Alaska.

### Data Issues and Needs

The call for statistics on people with disabilities is longstanding and increasing. To remedy these gaps, survey questions have been developed and tested to identify individuals with varying degrees of disability in terms of activity limitations. These survey questions are now included as a rotating core of the Behavioral Risk Factor Surveillance System (BRFSS). Once collected, these data will help government policymakers, consumers and advocates, researchers, and clinicians make better-informed choices to promote the health status and well-being of people with disabilities.

### Related Focus Areas

A variety of objectives in other *Healthy Alaskans* chapters will have an impact on promoting the health of people with disabilities and on preventing secondary conditions.

- *Physical Activity*
- *Maternal, Infant and Child Health*
- *Mental Health*
- *Injury Prevention*
- *Violence and Abuse Prevention*
- *Occupational Safety and Health*
- *Vision and Hearing*
- *Heart Disease and Stroke*
- *Arthritis*

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Physical activity can improve the health and well-being of people with disabilities. Exercise decreases depression. People with disabilities who have sufficient emotional support and report being happy and not depressed are less likely to develop mental health problems. Maternal and infant health programs that prevent birth defects and provide for early diagnosis and treatment of developmental problems have a critical role in preventing disabilities and preventing secondary conditions.

*Disability and Injury Prevention* are related, because reducing injuries will reduce the number of people with disabilities. A decrease in violence will decrease the number of people with disabilities, also relating it to the *Disability* chapter. Many disabilities including some osteoarthritis cases are caused by occupational injuries. Prevention of blindness and deafness decreases the number of people living with these disabilities, linking to the *Vision and Hearing* chapter. High blood pressure can be a serious limitation or disability for many people, thus connecting *Heart Disease and Stroke* to *Disability and Secondary Conditions*. Finally, arthritis and osteoporosis are both disabling conditions and thus related to the chapter on disabilities.

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### Endnotes

<sup>1</sup> Summary of the Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda [www.surgeongeneral.gov/cmh/default.htm](http://www.surgeongeneral.gov/cmh/default.htm), [www.cdc.gov/ncbddd/dd/default.htm](http://www.cdc.gov/ncbddd/dd/default.htm).

<sup>2</sup> National Alliance for Caregiving and the American Association of Retired Persons. Family Caregiving in the U.S.: Findings from a national survey. Bethesda, M.D.: The American Association of Retired Persons, Washington, DC, June 1997

<sup>3</sup> Pugliese, J.M.; Ingram, T.O.; and Edwards, G. Stability of Employment Status of Caregivers Who Have a Child with a Disability. Birmingham, AL: United Cerebral palsy of Greater Birmingham, Inc., February 1, 1998.

### References and Sources

#### Alaska

Alaska Division of Vocational Rehabilitation	<a href="http://www.labor.state.ak.us/dvr/home.htm">www.labor.state.ak.us/dvr/home.htm</a>
Alaska State ADA Coordinator	<a href="http://www.labor.state.ak.us/ada/home.htm">www.labor.state.ak.us/ada/home.htm</a>
Alaska State Independent Living Program	<a href="http://www.labor.state.ak.us/silc/index.htm">www.labor.state.ak.us/silc/index.htm</a>
Assisstive Technology Library of Alaska, Disability Resources - Alaska	<a href="http://www.alaska.net/~atla/">www.alaska.net/~atla/</a> <a href="http://www.disabilityresources.org/ALASKA.html">www.disabilityresources.org/ALASKA.html</a>
Parents, Inc. Families Assisting Families of Children with Disabilities	<a href="http://www.parentsinc.org/">www.parentsinc.org/</a>
Special Education Service Agency	<a href="http://www.sesa.org/index.html">www.sesa.org/index.html</a>

#### National

Council for Disability Rights	<a href="http://www.disabilityrights.org/">www.disabilityrights.org/</a>
DisAbility and Health National Center on Birth Defects and Developmental Disabilities	<a href="http://www.cdc.gov/ncbddd/dh/">www.cdc.gov/ncbddd/dh/</a>
Disability Rights and Education Defense Fund	<a href="http://www.dredf.org/">www.dredf.org/</a>
US Department of Justice ADA Home Page	<a href="http://www.usdoj.gov/crt/ada/adahom1.htm">www.usdoj.gov/crt/ada/adahom1.htm</a>
Disability Rights Commission	<a href="http://www.drc-gb.org/drc/default.asp">www.drc-gb.org/drc/default.asp</a>
New Freedom Initiative	<a href="http://www.hhs.gov/newfreedom/">www.hhs.gov/newfreedom/</a>

# *Chapter Notes*

