This chapter is dedicated to the concept that people with disabilities must be recognized as whole and healthy beings. Living with a disability is a unique experience, one that cannot be fully understood until it is experienced. Disability is a natural part of the human experience that does not diminish the right of the individual to enjoy the opportunity to live in and contribute to the mainstream of American society.

Disability encompasses a wide range of experiences. A disability can begin anytime during one's life span: at conception, during pregnancy, at birth, during childhood or adulthood, or as the result of aging. It may affect one or more areas of a person's functions -- mobility, personal care, communication, or learning. A disability can be hidden, as with dyslexia, or obvious, as with a spinal cord injury or Down syndrome. It may be mild or severe, or it may be progressive, chronic, or intermittent, as in the beginning stages of multiple sclerosis.

A disability is rarely static; instead it will likely fluctuate during the course of a person’s life. The same disability may manifest itself differently in two individuals, as is often the case with cerebral palsy. Disability may result from genetic abnormalities, trauma, illness, chemical imbalances, or conditions usually associated with aging. Some disabilities can now be prevented; others cannot.

There are many different types of disability: physical, cognitive, psychiatric, behavioral, or sensory. However, it is not the "diagnosis" that makes a condition a disability. People with disabilities do not need to have their disability removed or fixed to be whole and contributing members of society. Often, whether or not a person with a disability participates in and contributes to society is determined by that individual's access to society's goods and services, and the availability of individualized, "consumer-controlled" services and supports. For a person with a disability, services and supports must include health promotion, primary and specialized health care, transportation, assistive technology (devices which help the disabled person to function), personal assistance, and peer support.

For far too long, society has considered the concepts of good health and disability to be contradictory. In fact, good health has been considered to be synonymous with the absence of disability and has been assumed to be beyond the reach of people with disabilities. Such assumptions are not necessarily true. Most people with disabilities have the potential to lead healthy and productive lives if given the opportunity to attain good health and fully participate in society.

Attaining and maintaining good health for people with disabilities, like all people, is a process that must focus on maximizing functioning and well being throughout the life of the disabled person. Because the nature of the process that leads to good health is interactive and involves considerations other than biology, prevention must deal with traditional health issues as well as social, educational, spiritual, and environmental factors that ultimately help to determine quality of life.

Health promotion for people with disabilities includes:

- Promotion of healthy lifestyles and a healthy environment.
- Prevention of health complications and further disabling conditions.
- Preparation of the person with a disability and his or her family to understand and monitor personal health and healthcare needs.
- Promotion of opportunities for participation in commonly-held life activities.

People with disabilities particularly need quality health promotion and rehabilitative services and long-term services and supports. Having a disability is not an immunization against developing the same chronic conditions as the rest of the population, including, high blood pressure, heart disease, cancer, diabetes, and substance abuse. People with disabilities are susceptible to the same health conditions and, in some cases, may be at increased risk. The Healthy People 2010 Chapter on Disability and Secondary Conditions notes that when compared with people without disabilities, those with disabilities have higher rates of chronic conditions, e.g., diabetes, depression and sadness, elevated blood pressure and blood cholesterol, obesity, tooth loss, vision and hearing impairments. They also have lower rates of recommended health behaviors, e.g., cardiovascular, strengthening, and flexibility activities, and no cigarette smoking. A number of studies have also shown that people with a traumatic brain injury have higher than average rates of substance abuse.

Prevention including self-care and counseling, screening for early detection, appropriate and timely treatment, and early recognition and reduction of known risks, are as important for people with disabilities as they are for everyone else. Much of the health promotion developed to reduce the risk of illness in the general population can be adapted for use with people with disabilities.
population can be used directly with people with disabilities. In some cases, however, new strategies will need to be developed or adapted for people with disabilities and tested in inclusive, community-based settings.

People with disabilities also are at risk of developing certain secondary conditions (conditions directly related to their primary disability) that may add to their level of disability and negatively affect their independence and quality of life.

These conditions may range from chronic pain, drug interactions, contractures, skin breakdown or injuries to psychosocial problems, such as communication difficulties or depression-related conditions due to their isolation in society. One Iowa specific study, the University of Iowa College of Public Health Prevention of Secondary Conditions Study of Iowans with Mobility Impairments, found higher than usual rates of drug interactions among both adults and elders with mobility impairments. That same study also noted significant rates of depression about adults with mobility impairments. In addition, many people with disabilities, particularly those with mobility impairments, report they experience one or more conditions generally associated with aging (pain, fatigue, loss of function, and loss of independence) beginning as early as their twenties.

Although more research is needed to understand the incidence, cause and prevention of certain secondary conditions, a number of studies have identified specific secondary conditions that are preventable or manageable. One study of 40 common secondary conditions in people with mobility impairments reported that participants had an average of 13 secondary conditions during the previous year. This study also found that 11 of the 15 conditions with the highest incidence and severity involved environmental, behavioral, and psychosocial factors that could be prevented.

Disparity issues related to disability are both complex and unique. People with disabilities, like other groups that historically have been disadvantaged, have higher rates of unemployment, lower incomes, fewer educational opportunities, fewer living options and face an ongoing struggle for inclusion. Although the Americans with Disabilities Act (ADA), which became law in 1990, was created to address many of the barriers to participation in society, full implementation has not yet been realized.

People with disabilities also encounter significant structural, financial, and personal barriers that limit their access to health and health-related care. Those who are elderly or members of minority groups face additional barriers. Our healthcare system does not foster the inclusion, integration, and independence of people with disabilities. Instead, services are often fragmented, frequently inadequate in addressing the constellation of needs of people with disabilities, and many times inaccessible.

Structural barriers, such as the unavailability of services and the lack of accessible transportation, buildings, and programs are a major concern for people with disabilities. A number of services needed by people with disabilities, such as specialty medical care, rehabilitation, and long-term services and supports, are not universally available and are particularly lacking in rural areas. Other services may be available but physically inaccessible. For example, women with disabilities are concerned about the high incidence of false negative mammograms due to equipment that is not properly adapted or technicians who do not know how to properly position women with disabilities.

Data show that women with severe physical disabilities are significantly less likely to receive regular pelvic examinations. And one study found that physically disabled women are at the same risk for physical and sexual abuse as able-bodied women but experience abuse over longer periods because they lack access to resources to help them leave abusive environments.

Personal barriers, including attitudes, knowledge, and communication, also influence access to care for people with disabilities. Consumers report that many healthcare providers focus on their disabilities and fail to deal with critical primary-care issues. They also indicate that they lack important information about maintaining their health and managing their disability -- information that is vital to helping them attain and maintain their health and independence.

There are numerous complaints that health education materials are not available in accessible formats and that healthcare providers lack the knowledge and time to communicate in an effective manner. Communication with people with disabilities may involve adapting the content or print size of written materials, using interpreters, working with special communication devices or recording instructions.

And finally, people with disabilities face a number of financial barriers in accessing services. Obtaining adequate private insurance can be particularly difficult due to restrictions on pre-existing conditions, caps on the amount or cost of services, benefit packages that do not cover needed services, and the affordability of the package.

Affordability is a particularly important issue in a rural state like Iowa where significant numbers of people with disabilities work for small employers who do not pay for healthcare benefits. As a result, many people with disabilities who cannot obtain adequate coverage through their employers or cannot afford to buy it are forced to
forego working or limit themselves to part-time employment to maintain government health insurance.

As of 1994, some 47 million Americans (nearly one in every five people) were considered to be "functionally disabled." Around one in every ten Americans experienced a disability so severe that the person required the assistance of another person or a special device to perform everyday activities.

A person is considered to have a "functional disability" if he or she has difficulty:

- Performing certain functions, such as seeing, hearing, talking, or walking.
- Performing activities of daily living.
- Assuming expected social roles, such as doing school work, working at a job, or doing household chores.

Disability affects not only the person with the disability but the person’s family. Studies show that about 80% of primary helpers are relatives and nearly half of them live with the person with the disability. Over 30% of American families have a member limited in a life activity. Unless there is adequate support, care giving for a family member with a disability can result in significant stress and affect the caregivers health.

The effects of disability in Iowa are only now beginning to be understood. Although a comprehensive, coordinated state data system does not yet exist, data available begin to provide a picture of the scope and influence of disability for Iowa's citizens. For instance, over 10% of the state's school-age children routinely receive special education or related services due to some type of disabling condition.

Some data about the effects of disability on the adult population in the state are becoming known. In 2003, some 375,000 non-institutionalized Iowa adults (17.1% of the designated population) reported having activity limitations according to Iowa's Behavioral Risk Factor Surveillance System survey. About 34,000 of those surveyed in 2002 reported they needed assistance with personal care and 88,500 reported needing assistance with routine needs, such as household chores, shopping or getting around.

There has been significant growth in the rate of disability in America in the last quarter century. The percent of the population with at least one activity limitation grew from 11.7% in 1970 to 16% to 18% in 1994. This growth is attributed to a gradual long-term increase because of the aging of the population and a short-term increase concentrated in the younger populations.

The long-term increase is expected to continue if not accelerate in the coming decades. The percent of the total population 65 years old or over is projected to increase from 12% to 20% in the next 30 years. This means that even if the rate of disability in the older age group remains constant, the actual number of people with disability will increase substantially. This trend supports the need for a public-health approach to prevention and participation.

Before 1990, disability rates for both children and younger adults had held steady for nearly two decades. Since 1990, dramatic changes have been noted in the rate of disability for both groups. Between 1990 and 1994, the disability rate increased by 16% among younger adults aged 18 to 44, and by 40% for boys and 33% for girls under the age of 18. Similar increases have been noted in recent studies of work disability and personal-assistance needs in the same age groups. Although speculation is rife, the reasons behind these increases are not yet fully understood.

Among adults ages 18 to 44, increases have been noted in the rates of orthopedic impairments and mental and nervous disorders. In children under age 18, rate changes may be partly due to recent improvements in health care. As a result of improved health care, some 95% of children with disabilities and severe chronic health conditions now reach adulthood. National data have found increases in the prevalence of severe asthma, mental disorders (including attention deficit disorder), mental retardation, and learning disabilities in children. Because about 70% of the population is under age 45, these increases are responsible for the recent rise in the proportion of the population with disabilities.

The likelihood of having a disability increases with age. The elderly experience disability at roughly twice the rate of those in the older working ages (45-64) and three times the rate of the younger working-age group (18-44). A still smaller fraction of children have disabilities.
According to the 1994 National Health Interview Survey on Disability, nearly two-thirds of the population with functional disabilities and half of those with long-term care needs were under the age of 65. These numbers, taken with the length of time younger people will live with their disability, shows the importance of including the younger populations with disabilities in public-health policy and program planning.

People in the United States with disabilities include:
- 6.1 million children under 18.
- 25.7 million adults aged 18-64.
- 15.8 million adults 65 and over.

Although age appears to be the main factor affecting the likelihood of having a disability, there are some differences by race and ethnicity. Nationally, the rate of disability reported by people in different ethnic groups varies from a low of 9.9% for Asian and Pacific Islanders to a high of 21.9% for Native Americans. The rate for Hispanics is 15.3%, for whites 19.7%, and for blacks 20%.

The only way to eliminate years of disparity for people with disabilities is to recognize them as full participants in diverse, tolerant, and inclusive communities. Using inclusion as a guiding principle in developing its approach, the chapter committee determined that, whenever possible, the health-promotion and preventive-service needs of people with disabilities should be addressed within each individual chapter of Healthy Iowans 2010. Toward this end, the committee developed and distributed to other chapter committees a white paper on crosscutting access issues and a set of guiding principles for serving people with disabilities. The guiding principles are presented here at the end of the introduction.

This thinking is supported by the June, 1999 U.S. Supreme Court Olmstead decision that held that discrimination on the basis of disability was illegal. The decision further stated that people with disabilities have the right to services provided in the most integrated setting appropriate to their needs. In February 2003, Governor Vilsack signed Executive Order 27, which called on Iowa to “move purposefully to swiftly implement the Olmstead decision” and coordinate a comprehensive effort by state agencies to “reshape the structure and nature of community-based services”.

Covered within this chapter's action plan are broad prevention concerns for people with disabilities, including significant infrastructure questions and concerns about the promotion of opportunities for participation in common life activities. Many of the goals and action steps in this chapter reflect a vision of what must be accomplished for Executive Order 27 to be carried out. Within this framework, the committee has chosen to organize the action plan into five sections: Health Care Information and Empowerment; Health, Wellness and Disability; Professional Training; Participation in Society; and, Individual and Community-Based Services and Supports. Even if all the plan's goals are met by the year 2010, Iowans with disabilities will still face many areas of disparity.

People with disabilities must be recognized as people first. They share the same hopes and dreams and have the same expectations as all members of society. They expect to:
- Attain economic self-sufficiency, live independently, enjoy good health, and fully participate in all aspects of life.
- Live, work, recreate, and learn in the communities of their choice.
- Be active, valued, and contributing members of their communities and society.

People with disabilities must be given the information and respect necessary to make their own decisions. They must also be equal partners in conceptualizing, developing, directing, and evaluating policies, programs, and services that affect them.

Traditional health services and systems must be adapted to foster the inclusion and independence of people with disabilities. Specifically, they must:
- Provide information and training to help people with disabilities make their own healthcare decisions and choose their own healthcare plans and providers.
- Emphasize prevention and wellness to promote independence and personal responsibility.
- Deal with chronic health conditions and enhanced functioning and receive acute and episodic care.
- Allow the appropriate use of specialty and rehabilitative care.
- Facilitate transportation and provide physical access to buildings, programs, and services.
- Promote coordination and continuity of care between healthcare providers and health and human-service systems.

Public and private-sector healthcare financing must assure equity in access to health care, promote the development of a seamless system of care, and develop policies that are responsive to the needs of diverse populations, including people with disabilities. Specifically, such mechanisms need to:
• Eliminate discrimination on the basis of pre-existing conditions.
• Support a consumer-driven, risk-neutral system that covers everyone.
• Provide broad-based benefits that adequately meet individual needs.
• Provide access to affordable health care.
• Eliminate disincentives for people to pursue employment and economic self-sufficiency because of their inability to obtain health coverage.

Prevention efforts for people with disabilities need to address not only traditional health issues but the social, educational, spiritual, and environmental factors that maximize functioning and independence, and ultimately determine quality of life. Toward this end, long-term services and supports for people with disabilities must:
• Promote the use of individual and in-home services as the first option and out-of-home placement as the last resort;
• Be individually designed to meet the needs of the individual and the family in which he or she lives;
• Be provided for in inclusive, community-based settings.
• Be coordinated through service teams that are directed by people with disabilities and their families who have choice and flexibility in the services and supports they receive.

Health promotion must include assurance of access to places, buildings, and services for people with disabilities to participate in commonly held activities, including: regular and higher education, employment, housing, religion, and recreation.

Progress Report

Since the disability plan was unveiled in 2000, a number of products have been developed and objectives achieved. Guidelines of healthcare professionals for communicating with Iowans with disabilities were created. A “Consumer Report Card” provided comparisons between Health Management Organizations and organized delivery systems. The “Living Well” and “Continuing to Live Well with a Disability” classes have been conducted at a number of sites around the state. An arthritis program has been established. Training related to making services physically accessible has been conducted. Workshops related to “fair housing laws” were held. Objectives concerning reducing unemployment barriers to employment were achieved. Several goals related to enhancing transportation for Iowans with disabilities were also reached. Informational sessions regarding assistive technology were conducted.

Several goals were not achieved because of limited resources. The plan to visit all state offices to assess physical barriers is not possible because of lack of available staff. However, an ADA compliance survey is available free of charge upon request. The fulltime state ADA coordinator position was eliminated because of funding cuts. ADA compliance information is now provided by staff from the Commission on Persons with Disabilities. The proposal to establish a statewide, consumer-controlled personal assistance service program was not funded because of budget shortfalls.

Many of the objectives and action steps contained in the updated version of chapter four represent a continuation of objectives that have been attained; for example, from “establishing a statewide arthritis program” to “maintaining a statewide arthritis program.” Updated data were used throughout the document. New issues such as the Olmstead decision will have a profound affect on service delivery and are also incorporated.

Goal Statements and Action Steps

4-1 Goal Statement

Develop and distribute disability-related healthcare information to twenty-five service providers in Iowa and teach Iowans with disabilities how to evaluate information by June 2005.

Rationale

Empowerment means being able to make informed choices. Maintaining and improving health depends on the person’s ability to access and use healthcare information. To make effective choices, information on the following is essential: 1) services and support networks; 2) disability-specific signs and symptoms which require evaluation and intervention by medical and allied healthcare providers; 3) basic human rights related to use of health care; and 4) current disability research.

With the advent of electronic information processing, the amount of information on health care and disabilities in all formats has increased greatly. However, there is no integrated or readily accessible, comprehensive system of information dissemination in Iowa. Designing an infrastructure that enhances the availability and accessibility of healthcare information for people with disabilities and their support persons will greatly facilitate their participation in healthcare decisions.

4-1.1 Action Step
Appoint a statewide coalition of resource persons on specific disabilities, services, and assistive technologies (Iowa Abilities Network (IANet) to make an agenda for the review of healthcare and consumer information and its use by people with disabilities by 2001. (An Iowa Department of Public Health and Prevention of Disabilities Policy Council action step.)

**4-1.2 Action Step**
Locate a system to identify gaps and repetition of resources in Iowa that produces, collects, or disseminates healthcare information, or provides training on use of such information or services for persons with disabilities; examine the use (how obtained, source, format, how used, health topics) of healthcare information by persons with different types of disabilities in the summer of 2001. (An Iowa Net action step.)

**4-1.3 Action Step**
Develop guidelines in 2002 for the accessibility of disability healthcare and related information (readability, presentation format, location, modes of distribution, cultural sensitivity, age and gender appropriateness) to be disseminated by 2003. (An Iowa Net action step.)

**4-1.4 Action Step**
Identify service providers and distribute material by October 2004. (An Iowa Department of Public Health action step.)

**4-1.5 Action Step**
Identify during 2005 funding resources and develop a web site for coordination and dissemination of specific disability health care and related information with links to web sites on education, service provision, funding resources, technology, support groups or persons, disabilities research, speakers, chat rooms and other appropriate computer sites. (An Iowa Department of Public Health action step.)

**4-1.6 Action Step**
Identify funding sources and develop a pilot project to teach people with disabilities and others to evaluate printed and electronic healthcare and related information and to use this information in health care decision-making during 2005. (An Iowa Department of Public Health, Center for Disabilities and Development and Child Health Specialty Clinics action step.)

**4-2 Goal Statement**
Develop and distribute a comparison of health care plans and initiate a curriculum that helps people with disabilities to select the best health insurance plan for them.

**Rationale**

Managed care has brought a proliferation of healthcare plans and a corresponding need for persons with disabilities and their support persons to become discriminating consumers. Material describing such plans is often difficult to interpret and may not readily convey to people with chronic healthcare needs what is covered by the plan and often does not provide opportunities for consumer input.

The development of guidelines for the presentation of plan information to persons with disabilities would greatly enhance their ability to participate as informed consumers. Educational opportunities encouraging the development of self-advocacy and negotiating skills are also important to active consumer participation.

**4-2.1 Action Step**
Invite stakeholders in healthcare reimbursement and consumers with chronic health needs to a forum to discuss what and how information enhances individual understanding of healthcare plans, consumer choice, and control by 2001. (An Iowa Department of Public Health Prevention of Disabilities Policy Council, and insurance industry action step.)

**4-2.2 Action Step**
Develop guidelines by 2002 that assist people with disabilities to make informed choices. (An Iowa Department of Public Health and the Center for Disabilities and Development action step.)

**4-2.3 Action Step**
Disseminate in 2003 guidelines to public and private health insurers on providing consumer-friendly information on selecting and using healthcare plans. (An Iowa Department of Public Health and the Center for Disabilities and Development action step.)

**4-2.4 Action Step**
Identify in 2005 funding to develop and pilot a curriculum that teaches people with disabilities how to choose their healthcare team members, plan visits with providers, understand their rights as consumers, and negotiate with providers and payers. (An Iowa Department of Public Health, Center for Disabilities and Development, and Child Health Specialty Clinics action step.)

**4-3 Goal Statement**
Assure by 2010 that each Healthy Iowans 2010 chapter assess the health issues and potential treatment available for people with disabilities and incorporate appropriate goals and action steps within each chapter’s action plan to help eliminate health disparities for the disabled.

**Rationale**

People with disabilities are susceptible to the same chronic health conditions as the general population and sometimes are at increased risk. They are also at risk for
secondary conditions that can increase their disability and decrease their quality of life. For these reasons, health promotion and prevention, promotion of self-care and counseling, screening for early detection and treatment, and early recognition and reduction of known risks are particularly important to people with disabilities.

Despite this situation, anecdotal and study data suggest that people with disabilities receive fewer health-promotion and preventive services than the population as a whole. The action steps outlined under this goal are intended to create an infrastructure that will capture the data necessary for state and community health providers to initiate effective health promotion and prevention for this population.

4-3.1 Action Step
Initiate a system to collect, track and analyze disability data within all health-department systems during 2008. (An Iowa Department of Public Health action step.)

4-3.2 Action Step
Establish a way to collect information about health issues and effective prevention for people with disabilities nationally and in Iowa. Identify resources to assist state and community groups in planning and initiating appropriate health promotion and prevention for this group during 2004. (An Iowa Department of Public Health and Prevention of Disabilities Policy Council action step.)

4-3.3 Action Step
Disseminate the health data and information about effective strategies and resources to each chapter team facilitator by 2004. (An Iowa Department of Public Health action step.)

4-3.4 Action Step
Assess the health issues and potential treatment available for people with disabilities and amend chapter action plans to initiate effective health promotion and prevention measures for this group by 2005. (A Healthy Iowans 2010 Chapter Committees action step.)

4-3.5 Action Step
Establish a method to continuously collect information about effective prevention activities and resources and to disseminate the information gathered to key Healthy Iowans 2010 leaders through 2010. (An Iowa Department of Public Health and Prevention of Disabilities Policy Council action step.)

4-4 Goal Statement
Identify questions in the BRFSS that are disability-related and fund via the CDC disability grant by 2005.

Rationale
The Iowa Department of Public Health, Prevention of Disabilities Policy Council, and University of Iowa are conducting a statewide survey to identify the secondary conditions and risk factors of Iowans with mobility impairments. However, these surveys are time-limited. The state needs an ongoing data system that can track changes in secondary conditions and their risk factors over time. Such a system will identify important trends and aid in the evaluation of potential treatments.

4-4.1 Action Step
Analyze responses to the statewide survey of secondary conditions and revise it to facilitate development of an ongoing data collection system by 2001. (An Iowa Department of Public Health, University of Iowa College of Public Health, Prevention of Disabilities Policy Council action step.)

4-4.2 Action Step
Identify during 2001 a funding source to initiate and maintain an ongoing information system on secondary conditions associated with mobility impairments. (An Iowa Department of Public Health, University of Iowa College of Public Health, and Prevention of Disabilities Policy Council action step.)

4-4.3 Action Step
Identify questions in the BRFSS that are of interest and incorporate of a request to fund in the CDC disability grant in 2005.

4-4.4 Action Step
Begin compiling and disseminating the collected data to interested disability groups and to state and local policy makers, health planners, and service providers in 2006. (An Iowa Department of Public Health, University of Iowa College of Public Health, and Prevention of Disabilities Policy Council action step.)

4-5 Goal Statement
Establish a baseline and conduct a pilot study of selected interventions to increase the percentage of people with mobility impairments who engage in appropriate healthcare practices.

Rationale
Through funding from the Centers for Disease Control and Prevention (CDC), Iowa has the opportunity to select and study potential interventions intended to increase the percentage of people with mobility impairments who engage in appropriate healthcare practices. The study will be designed by grant participants, based on information from the secondary-conditions survey discussed earlier.

4-5.1 Action Step
Define "appropriate health practices" and establish baseline rates for them by June 2000. (An action step of the Iowa Department of Public Health, University of Iowa College of Public Health, Prevention of Disabilities Policy Council, and Center for Disabilities and Development and the Blue Ribbon Panel on Secondary Conditions action step.)

4-5.2 Action Step

4-5.3 Action Step
Conduct a pilot study of the selected interventions, and evaluate the results during 2005. (An Iowa Department of Public Health, University of Iowa College of Public Health, and Prevention of Disabilities Policy Council action step.)

4-5.4 Action Step
Continue to review intervention options and design additional interventions for testing through 2010. (An Iowa Department of Public Health, Prevention of Disabilities Policy Council, Center for Disabilities and Development and Blue Ribbon Panel on Secondary Conditions action step.)

4-6 Goal Statement
Establish a proven physical activity program for people with physical disabilities in at least 10 Iowa communities during 2003.

Rationale
The Iowa Department of Public Health has piloted an effective physical activity program for people with physical disabilities in one urban Iowa area. Preliminary evaluation has been very encouraging. The program now needs to be copied and evaluated in other Iowa communities.

4-6.1 Action Step
Develop a strategy for marketing this physical activity program for people with disabilities in other Iowa communities during 2000. (An Iowa Department of Public Health and Prevention of Disabilities Policy Council action step.)

4-6.2 Action Step
Compile program information into a format suitable for use by community sponsors and develop any necessary informational and promotional materials on physical activity programs for people with disabilities during 2001. (An Iowa Department of Public Health action step.)

4-6.3 Action Step
Implement during 2003 the marketing plan and provide technical assistance to Iowa communities interested in developing a similar program. (An Iowa Department of Public Health action step.)

4-7 Goal Statement
Establish a way to identify new funding and develop collaborative applications that will expand health promotion and prevention for Iowans with disabilities by 2004.

Rationale
Current research is identifying effective health promotion and prevention for people with disabilities. As this data becomes available, federal and private funding sources are responding by initiating new disability-prevention efforts. Some of these efforts deal with prevention through such methods as personal care, communication or mobility. Others address disability prevention by gender or diagnostic categories, as is the case with the new federally-funded arthritis initiative discussed in objective 4-8.

Iowa needs a way to track research, identify new funding, and respond to requests for proposals in a timely manner. Locating funding will be critical to expanding state health promotion and prevention to all disability groups.

4-7.1 Action Step
Recommend a mechanism during 2004 to identify and respond to collaborative prevention-of-disability and health promotion for persons with disabilities funding opportunities. (An Iowa Department of Public Health and Prevention of Disabilities Policy Council action step.)

4-7.2 Action Step
Obtain resources to implement the recommended collaborative prevention-of-disability and health promotion activities of this and other Healthy Iowans 2010 chapters during 2004 and beyond. (An Iowa Department of Public Health and Prevention of Disabilities Policy Council action step.)

4-7.3 Action Step
In the current mid-course revision of Healthy Iowans 2010, all chapters will consider and/or include appropriate disability-related goals, activities, and/or data collection. (An Iowa Department of Public Health and Disability Chapter Task Force action step.)
4-8 Goal Statement

Maintain and expand the Iowa Arthritis Program with activities that include surveillance, public awareness, healthcare provider and consumer education and interventions to decrease disability and improve quality of life by 2010.

Rationale

It is estimated that 585,000 adult Iowans (27.8%) have been diagnosed with arthritis by a doctor. An additional 447,000 adult Iowans (21.3%) have chronic joint symptoms but do not have doctor-diagnosed arthritis (2002 BRFSS). Arthritis is the second leading cause of disability in non-institutionalized adults in Iowa. It is also a leading cause of work-related disability, and the leading cause of disability for adults over age 65 in Iowa (2002 BRFSS).

The Iowa Arthritis Program was established in 1999 and the Iowa Arthritis Task Force was convened in 2000. The Iowa Arthritis Action Plan was issued in 2001. In addition to surveillance and healthcare provider and consumer information and resources, the program and plan promote awareness of arthritis and the expansion of existing evidence-based self-management programs. Strategies such as weight control, physical activity and self-management education can help Iowans with doctor-diagnosed arthritis and chronic joint symptoms manage the disease. These management strategies need statewide implementation. Maintaining and expanding the Iowa Arthritis Program within the Iowa Department of Public Health will bring together the resources of various public, private and voluntary stakeholders to reduce the impact of arthritis and improve the quality of life of Iowans affected by arthritis.

4-8.1 Action Step

Secure funding annually to maintain and expand the Iowa Arthritis Program by July 1 each year. (An Iowa Department of Public Health action step.)

4-8.2 Action Step

Update the Iowa Arthritis Action Plan by December 2005. (An Iowa Department of Public Health and Arthritis Task Force action step.)

4-8.3 Action Step

Convene the Iowa Arthritis Task Force a minimum of two times annually to provide guidance to the Iowa Arthritis Program and assist in arthritis interventions in the Iowa Arthritis Action Plan by December 31 each year. (An Iowa Department of Public Health action step.)

4-9 Goal Statement

Plan and conduct at four Arthritis Self-Help Course leader training workshops annually.

Rationale

Evidence-based self-management education, such as the Arthritis Self-Help course, has proven to reduce arthritis-related pain and healthcare costs. Nationally, these programs are estimated to reach a small percentage of people with arthritis. The Arthritis Self-Help Course is available in communities across the state but expansion is limited by the lack of leaders to deliver the course. Availability of self-management courses in rural counties is particularly important because they lack existing healthcare providers. The needs of an increasingly aging population also contribute to the challenge. The Arthritis Self-Help Course should be available in all areas of the state.

4-9.1 Action Step

Identify locations statewide for Arthritis Self-Help Course leader training workshops and promote to targeted groups and individuals in February and August each year. (An Iowa Department of Public Health, Arthritis Foundation Iowa Chapter and Iowa Arthritis Task Force action step.)

4-9.2 Action Step

Plan and conduct two spring and two fall Arthritis Self-Help Course leader training workshops in May and October each year. (An Iowa Department of Public Health and Arthritis Foundation Iowa Chapter action step.)

4-9.3 Action Step

Provide technical assistance, training resources and materials to Arthritis Self-Help Course leaders throughout the year. (An Iowa Department of Public Health and Arthritis Foundation Iowa Chapter action step.)

4-9.4 Action Step

Assess the effectiveness of Arthritis Self-Help Course leader training workshops in July and December each year. (An Iowa Department of Public Health and Arthritis Foundation Iowa Chapter action step.)

4-9.5 Action Step

Collect and evaluate participant and Behavioral Risk Factor Surveillance System (BRFSS) survey data by December 31 each year. (An Iowa Department of Public Health action step.)
4-10 Goal Statement

Plan and conduct at least three arthritis presentations annually for healthcare providers.

Rationale

In recent years, many advances in the management of arthritis have occurred. Iowa healthcare providers need access to information and resources in the treatment and management of arthritis, including health communications materials and assistive devices.

4-10.1 Action Step

Identify audiences and events for the presentation of arthritis information and materials by April 30 each year. (An Iowa Department of Public Health and Iowa Arthritis Task Force action step.)

4-10.2 Action Step

Plan and conduct presentations by November 15 each year. (An Iowa Department of Public Health action step.)

4-10.3 Action Step

Collect evaluations and evaluate the effectiveness of presentations by December 31 each year. (An Iowa Department of Public Health action step.)

4-11 Goal Statement

Collect and analyze data every odd year through 2009 and report on the impact of arthritis in Iowa every even year through 2010.

Rationale

Surveillance is important for assessing the impact of arthritis in Iowa, related risk behaviors, describing how arthritis affects various subpopulations and for monitoring trends over time. It is also important for guiding and evaluating Iowa Arthritis Program efforts. Arthritis and related data is available through the BRFSS and other sources such as outpatient/ambulatory. Findings on the impact of arthritis from surveillance should be clearly and routinely communicated to the healthcare community, arthritis stakeholders and the public through state of arthritis reports.

4-11.1 Action Step

By November 30 in even years, ensure that the arthritis optional module is a part of the odd year Iowa BRFSS survey. (An Iowa Department of Public Health action step.)

4-11.2 Action Step

By December 31 in odd years, collect BRFSS arthritis and related data. (An Iowa Department of Public Health action step.)

4-11.3 Action Step

By June 30 in even years, analyze data from the BRFSS and identify and analyze data from sources other than the BRFSS. (An Iowa Department of Public Health action step.)

4-11.4 Action Step

By September 30 in even years, complete and disseminate a state of arthritis report with odd year BRFSS data and data from other sources. (An Iowa Department of Public Health action step.)

4-12 Goal Statement

Establish and maintain an Office of Disability and Health within the Iowa Department of Public Health through 2010 to boost awareness of the need for health promotion and prevention for people with disabilities; facilitate the development of core data to identify issues and disparities for people with disabilities; gather and disseminate information about effective health promotion and prevention to people with disabilities, health planners and healthcare providers; and assist state and local groups in establishing health promotion and prevention programs for people with disabilities.

Rationale

Although people with disabilities make up nearly one-fifth of the state’s population, there has been no concerted effort to assure they are included in the state's health promotion and prevention efforts. In general, there has been limited awareness of the health needs of the disabled, and many providers have lacked the information needed to implement effective health promotion and prevention for this group.

Now, critical data about disability and health are being gathered at the national and state levels and research is beginning to identify effective health promotion and prevention that can be offered in inclusive, community settings. This situation highlights the need to identify an entity to focus the state’s disability and health efforts. It could create public awareness of the issues, facilitate the gathering and dissemination of new information, and promote the development of inclusive, community-based prevention. Creating an Office for Disability and Health within the Iowa Department of Public Health is an important step in eliminating disparities for people with disabilities.
4-12.1 Action Step
Present a formal request for the creation of an Office of Disability and Health to the public-health director and appropriate councils within the Iowa Department of Public Health during 2000. (A Prevention of Disabilities Policy Council action step.)

4-12.2 Action Step
Develop and implement a plan to secure funding to support the Office of Disability and Health and its activities over the coming decade. (An Iowa Department of Public Health and Prevention of Disabilities Policy Council action step.)

4-12 Goal Statement
Develop by 2010 and initiate other mechanisms to provide up-to-date information to providers and pre-service health-education programs.

Rationale
The curricula of many health care educational programs do not specifically deal with the needs of persons with disabilities. Even if basic introductory information is provided, information without experience is easily forgotten. Few providers have frequent contact with persons with a disability.

Frequent opportunities for further education, plus the ability to obtain information on the disabilities of a given patient, will improve care to persons with disabilities. Also, diagnoses and treatment change frequently with new research. Finally, some aspects of disability are so rare that appropriate information is difficult to find.

4-12.1 Action Step
By 2006, convene an ad hoc committee to develop and implement strategies for incorporating competencies in working with people who have disabilities into licensure requirements of pre-service and continuing education programs accredited by the Iowa Department of Public Health. (An Iowa Department of Public Health action step.)

4-12.2 Action Step
On going through 2010, provide pre-service education on a wide variety of disability-related topics to graduate students and post-doctoral fellows through the Iowa Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program. (A Center for Disabilities and Development action step.)

4-12.3 Action Step
Ongoing through 2010, identify funding sources for provision of information on the health care needs of individuals with disabilities through the Center for Disabilities and Development’s Disability Resource Library and a website to be updated monthly. (An Iowa Department of Public Health and Center for Disabilities and Development action step.)

4-12.4 Action Step
Ongoing through 2010, identify funding sources for provision of information on the health care needs of individuals with disabilities through the Center for Disabilities and Development’s Disability Resource Library and a website to be updated monthly. (An Iowa Department of Public Health and Center for Disabilities and Development action step.)

4-12.5 Action Step
Ongoing through 2010, identify funding sources and expand development of continuing education programs using the Iowa Communications Network (ICN) or related technologies on advances in primary and secondary prevention, diagnosis, and treatment of medical problems associated with disability, diversity awareness, and adaptations required to provide appropriate primary, secondary, and tertiary care to people with disabilities. (An Iowa Department of Public Health and Center for Disabilities and Development action step.)

4-13 Goal Statement
Perform accessibility checks on new facilities leased by state agencies within 20 working days of receiving the request.

Rationale
All Iowans, including Iowans with disabilities, should be able to access state agencies to obtain information and services, including transportation, employment, social services, personal support services, and other services necessary to be economically self-sufficient, live independently and enjoy good health. Executive Order #46 and the Governor’s Directive dated Aug. 23, 1990 requires state agencies to comply with the Americans with Disabilities Act (ADA) guidelines.

Transition plans for each state agency to accomplish this were to be completed by July 1992. However, there has been no structured follow up on agency progress. While the Division of Persons with Disabilities in the Iowa Department of Human Rights makes recommendations, there is no assurance they are being followed. Currently, only the Iowa departments of human services, inspections and appeals, corrections, general services, and the Division of Vocational Rehabilitation Services, the ICN (Iowa Communications Network), the
Department of Public Health and state-court administrators use this service. In addition, the Division of Persons with Disabilities has heard of many instances where employees of state agencies have not treated Iowans with disabilities with respect or provided them service in an equitable manner. With appropriate attitude and accommodation training, services will improve.

4-13.1 Action Step
Send accessibility survey to agencies requesting it within five working days. (A Department of Human Rights action step.)

4-13.2 Action Step
Process survey within five working days of receiving it. (A Department of Human Rights action step.)

4-13.3 Action Step
Mail results within 10 working days. (A Department of Human Rights action step.)

4-15 Goal Statement
Train employees on the Americans with Disabilities Act (ADA), and provide information to city and county governments about making their services physically accessible to residents with disabilities.

Rationale
All Iowans, including those with disabilities, should have equal access to goods and services by cities and counties to maintain healthy lifestyles and be participating members of their communities. Each city and county are to have designated ADA coordinators, but they are usually assigned this as an additional duty and have no training on ADA or similar state laws.

Many people with disabilities cannot live where they choose because of current laws and practices. Many people with disabilities are denied loans to buy housing because of a lack of a credit history. Only a handful of builders use universal design concepts in their single-family housing. Some people with disabilities can’t find accessible and/or affordable housing in their communities. Apartment managers often are reluctant or unwilling to make ADA accommodations; and many times, tenants are afraid to "make waves" or simply don’t know their rights.

These barriers have a dramatic impact on the health and well being of Iowans with disabilities and their families, who are often primary caregivers. Establishing systems and policies that enhance choices in living and community participation can reduce the social isolation that leads to depression.

4-15.1 Action Step
Provide training for cities and counties on making facilities and programs accessible by January 2003. (A Department of Human Rights action step.)

4-15.2 Action Step
Provide cities and counties with information on an ongoing basis to become resources for private service providers who have questions or need information on serving Iowans with disabilities. (A Department of Human Rights action step.)

4-15.3 Action Step
Provide ADA training upon request. (A Division of Persons with Disabilities action step.)

4-16 Goal Statement
Create access to additional housing by 2010 for Iowans with disabilities.

Rationale
Personally-owned or controlled housing and personalized support have become part of the nation’s agenda as people have challenged the standard way of providing services for persons with developmental and other disabilities. Throughout the nation, advocates and innovative service providers have made significant shifts from institutions and group homes to the creation of community supports, including housing, that allow people to live in homes of their choosing. This trend is part of a broader shift away from traditional, agency-controlled services toward a focus on resources that foster personal control and community inclusion. In 2002, Governor Vilsack challenged the state to create 1,000 new accessible housing units. In 2003, the Lt. Governor hosted a Housing Summit that resulted in comprehensive housing plan.

4-16.1 Action Step
Assess needs and barriers of housing options for people with disabilities. (A Developmental Disabilities Council action step.)

4-16.2 Action Step
Identify by 2004 partners to determine available housing resources and options; provide information about those resources to Iowans with disabilities; assess the capacity of resources to meet existing need; and recommend strategies to handle any gaps. (A Developmental Disabilities Council action step.)

4-16.3 Action Step
Identify and engage partners by 2005 to implement the recommendations on available housing and any
discovered gaps; to be completed. (A Developmental Disabilities Council action step.)

4-16.4 Action Step
Increase the number of tradesman that are knowledgeable about accessible housing, home modifications and Universal Design by 2010. (An Iowa Program for Assistive Technology, Iowa Contractor Network/FMR and Olmstead Real Choices Task Force action step.)

4-17 Goal Statement
Improve Iowa’s Medicaid Buy-in program for employed persons with disabilities by removing the systems “bias to poverty”.

Rationale
Iowans with disabilities continue to live longer and move to sustainable employment and economic self-sufficiency. Much remains to be done before employment parity is reached for people with disabilities. By removing the “bias to Poverty” in Iowa’s Medicaid program it will remedy the lack of significant incentives for program enrollees to work in a meaningful way; save/accumulate assets and become self-sufficient.

4-17.1 Action Step
By September 30, 2004 restructure the premium scale through amending the current sliding fee scale to encourage people to earn more. (An Iowa Department of Human Services action step.)

4-17.2 Action Step
By March 2005, amend Iowa’s Medicaid policies and procedures to require that everyone enrolled in MEPD pays a premium to participate in the program to better manage the substantial woodwork effect that enrollees in “symbolic employment” present to the system and as a means to “triage” those who really do want to become substantially employed. (An Iowa Department of Human Services action step.)

4-17.3 Action Step
By January 2005, link premiums more substantially to the “unearned” cash benefits applying a higher premium to the unearned portion of MEPD beneficiaries income and a premium equation that applies lower premium rates on earnings. (An Iowa Department of Human Services action step.)

4-18 Goal Statement
Increase the earning power of Iowans with disabilities to promote building assets, accumulation of savings, and “wealth creation”.

Rationale
Incentives are needed to induce Iowans with disabilities to enter and remain in the workforce. Accumulating assets will provide a powerful incentive to do this.

4-18.1 Action Step
By January 2005, allow program policies to promote the creation of wealth and accumulation of assets through incentives for people to earn more and raising resources/assets so people can earn more. (A Department of Human Services, Center for Disabilities and Development Employment Policy Group, and Workforce Development action step.)

4-18.2 Action Step
By January 2005, enhance the allowable resource provisions of MEPD by allowing higher wage earners to have higher allowable asset/resource limits to provide incentives to earn more. (An Iowa Department of Human Services, Center for Disabilities and Development’s Employee Policy Group action step.)

4-18.3 Action Step
By September 30, 2004, track the performance of the approved accounts (medical savings, Retirement Savings and Assistive Technology) to assess effects. (A Department of Human Services action step.)

4-19 Goal Statement
Improve the interface with private health insurers and other systems.

Rationale
An argument must be developed and disseminated that the MEPD program is cost effective. Private health insurers must be engaged to be a part of this process.

4-19.1 Action Step
By January 2005, identify “private sector insurance champions to assist the Iowa Department of Human Services to structure a business model design of the MEPD program and promote it. (An Iowa Department of Human Services, and Center for Disabilities and Development action step.)

4-19.2 Action Step
Utilize actuarial data to develop cost projections for analyzing system outcomes by January 2006. (An Iowa
4-19.3 Action Step

By January 31, 2004, encourage the Office of the Governor to direct the Division of Vocational Rehabilitation to provide services to individuals whose employment status is in jeopardy until their employment is no longer compromised, affording the State of Iowa the opportunity to match for federal dollars to pay for employment-related support services at a richer federal return than Medicaid currently permits. (A Center for Disabilities and Development Employment Policy Group action step.)

4-20 Goal Statement

Create a viable “infrastructure” of employment and workplace services and supports that Iowans with disabilities want.

Rationale

Empowering Iowans with disabilities to remain gainfully employed may require a number of workplace services and supports. Investing in these services and supports will eventually pay dividends as Iowans with disabilities remain on the job and become self-supporting, tax paying citizens.

4-20.1 Action Step

Amend Iowa’s six HCBS waiver services to incorporate a self-direction option by March 31, 2004. (An Iowa Department of Human Services action step.)

4-20.2 Action Step

By September 30, 2005, through utilization of blended funding and “cashing out” strategies, implement an enhanced infrastructure by executing a 1115 demonstration waiver targeted towards youth ages 14-25; assisting them to achieve improved transition results. (An Iowa Department of Human Services, Center for Disabilities and Development’s Employment Policy Group, Iowa Workforce Development and Iowa Department of Education action step.)

4-20.3 Action Step

By March 31, 2006, apply the successes and “lessons learned” from the enhanced 1115 demonstration infrastructure to a variety of populations, assuring fidelity to the self-direction model throughout Iowa’s service delivery system. (An Iowa Department of Human Services action step.)

4-21 Goal Statement

Create an expanded array of assistive strategies by 2005 for Iowans with disabilities to enable them to contribute in the workplace.

Rationale

Despite the promises of the New Freedom Initiative and its related federal and state programs, many barriers remain. Persons with disabilities, transition youth, their service providers and employers need information, training and supports to fully include all persons in the workforce.

4-21.1 Action Step

Make available statewide employment-related Personal Assistance Services (PAS) in post-school environments by 2006. (An Iowa Department of Human Services and Iowa Creative Employment Options action step.)

4-21.2 Action Step

Increase access to assistive technology and rehabilitation engineering services that can improve the quality of life for people with disabilities and enhance their ability to participate in the workplace. (An Iowa Program for Assistive Technology/Iowa COMPASS, Division of Vocational Rehabilitation, and Center for Disabilities and Development action step.)

4-21.3 Action Step
4-21.4 Action Step
Advocate for expanded tax credits prior to 2008 to provide incentives for the employment of people with disabilities. (An Olmstead Real Choices Task Force and Iowa Employment Policy Group/Center for Disabilities and Development action step.)

4-22 Goal Statement
Expand the role of the State Level Transportation Coordination Council to facilitate coordination among publicly-funded programs providing passenger transportation services.

Rationale
Agencies that fund transportation need to work together to encourage the enterprises they fund to coordinate their transportation efforts so that the funds can be spent more effectively and the benefits of public spending can reach all Iowans, including persons with disabilities. A State Level Transportation Advisory Council was established in 1993 to serve this function, but has not met since 1996.

While it was active, the council met quarterly to discuss transportation coordination issues, deal with any identified institutional or regulatory barriers to coordination and assist the Iowa Department of Transportation (IDOT) in reviewing compliance with the coordination mandates in Chapter 324A of the Code of Iowa.

Membership included the Iowa Department of Transportation and the Iowa departments of human services, elder affairs and education, plus the Iowa State Association of Counties. But the rules establishing the council provide that additional public or private-sector members can participate. Recent funding initiatives on welfare-to-work make Workforce Development a potential major source of funds for transportation services and an addition to council membership. Interest has also been expressed in adding the Iowa Department of Human Rights’ Division of Persons with Disabilities to the council.

4-22.1 Action Step
Establish regular meeting schedule (at least quarterly) for the State Level Transportation Coordination Council by fall 2004. (An Iowa Department of Transportation/Coordination Council action step.)

4-22.2 Action Step
Review council membership and attendance policies by December 2004. (A Coordination Council action step.)

4-23 Goal Statement
Expand availability of public transit services to persons with disabilities and all others throughout the state of Iowa.

Rationale
Increasing the hours of transit service is critical to increasing access to society by persons relying on public transit, including a large percentage of persons with disabilities. Under current political conditions, the welfare reform and/or welfare-to-work programs are the best prospect for funding expansion of transit service hours. (Eleven transit systems applied successfully for the first round of funding under the Federal Transit Administration’s (FTA) Job Access/Reverse Commute (JARC) program in Fiscal Year 1999, using Temporary Aid to Needy Families (TANF) funds as a partial match.)

Every effort should be made to see that the services provided during the additional hours are available to all citizens -- not just those coming off welfare. This is consistent with Iowa’s mandate for coordination of publicly funded passenger-transportation services and the concept of creating long-term solutions to the transportation needs of former welfare recipients.

4-23.1 Action Step
Meet with each state agency administering funding under federal programs that can be used to support transportation programs, by December 2005, to discuss need for expanded transportation opportunities and to explore the mechanics of using program funds to support coordinated public transit services. (An Iowa Department of Transportation/Coordination Council action step.)

4-23.2 Action Step
Establish mechanism to anticipate applications under selected federal programs and to bring program applicants and transit systems together to develop transportation components which will result in increased availability of transit services. (An Iowa Department of Transportation/Coordination Council action step.)

4-24 Goal Statement
Establish a central repository for information on availability of public transit services throughout the state of Iowa.

Rationale

Lack of transportation has been identified in a number of studies as a critically important issue for the disability community. An ongoing system that tracks the availability of accessible transportation for Iowans with disabilities will identify gaps in service delivery. As problems are identified, proposals can be developed to meet those needs.

4-24.1 Action Step
Survey Iowa transit systems and human services agencies to document the transportation services that are available in each of Iowa incorporated cites by December 2004. (An Iowa Department of Transportation/Coordination Council action step.)

4-24.2 Action Step
Publish transit availability data via the Internet by June 2005. (An Iowa Department of Transportation/Coordination Council action step.)

4-24.3 Action Step
Establish procedure for periodic review and updating of transit availability data by December 2005. (An Iowa Department of Transportation/Coordination Council action step.)

4-25 Goal Statement

Provide consumer training about requirements of the Americans with Disabilities Act (ADA) for public transit by December 2008.

Rationale

The Americans with Disabilities Act (ADA) guarantees consumers of public transportation several rights. The disability community should have a working understanding what those rights are under the law. This is necessary to ensure compliance with this provision of the law.

4-25.1 Action Step
Develop an educational program in collaboration with transportation consumers by December 2005. (A State Level Transportation Coordination Council action step.)

4-25.2 Action Step
Present the disability education program in each of Iowa's metropolitan areas by December 2007. (A State Level Transportation Coordination Council action step.)

4-25.3 Action Step
Develop a customized version for rural audiences and present to at least six rural audiences by December 2008. (A State Level Transportation Coordination Council action step.)

4-26 Goal Statement

Refocus the service system to include innovative models for the delivery of cost effective, community-based services in rural and urban areas that meet the medical, psychological, behavioral, employment, and housing needs of all persons with a disability by 2008.

Rationale

Iowa must ensure the availability of services in the community in which a person lives. The new focus is on developing innovative individual and family-centered services that offer a range of options, from day care to out-of-home placement, through accessible programs and facilities. Funding should be directed toward innovative, cost-effective services designed by persons with disabilities to meet the needs of persons with disabilities to maximize independence and participation in the community.

4-26.1 Action Step
By 2006, as required by House File 2537 (signed into law April 19, 2004 and effective July 1, 2004) plan, collect and analyze data on system costs and projected costs; identify revenue sources and cost projections in support of system redesign proposals; and support legislation seeking enactment of system redesign proposals with the identified revenue sources and cost projects. (An MH/MR/DD/BI Commission and Iowa Department of Human Services action step.)

4-26.2 Action Step
By 2008, implement Service Vouchers and Counseling for individuals eligible for Medicaid HCBS waivers, providing these individuals the opportunity to choose and direct their own services. This will incorporate services labeled as non-traditional, such as Personal Assistance Services. (An Iowa Department of Human Services in consultation with the Olmstead Real Choices Consumer Task Force action step.)

4-27 Goal Statement

Eliminate the county of legal settlement as a criterion for receiving services by 2010.
**Rationale**

The first step for many Iowans with disabilities to live in the community of their choice is for them to be able to access services any place in Iowa (not linked to their county of legal settlement). Iowans without disabilities choose where they want to live based on employment and educational opportunities, family and friends, cultural and recreational opportunities, and a host of other factors. Many disabled Iowans do not have those options because of the way services are funded. Iowa’s out-dated system of county-based "legal settlement" must be eliminated for all Iowans to have equal access to housing and the option to live independently.

**4-27.1 Action Step**

Ongoing, implement the legal settlement dispute resolution process required by House File 2537, signed into law April 19, 2004 and effective July 1, 2004. The process settles legal settlement disputes for a person receiving services under Code chapter 222 (state resource centers); Code chapter 230 (state mental health institutes); and Code chapter 249A (medical assistance [Medicaid] program.) (An Iowa Department of Human Services action step.)

**4-27.2 Action Step**

By 2005, complete planning called for in House File 2537 so that legislation changing legal settlement to legal residency can be drafted for consideration during the 2006 legislative session. Planning should:

a. Establish statewide standard of proof of residency
b. Plan a data system for identifying residency of eligible individuals
c. Plan how individuals in county by court order of criminal sentence will become county residents (presumably upon leaving court supervision)
d. Plan contested residency dispute resolution
e. Address other implementation issues

(An MH/MR/DD/BI Commission action step.)

**4-27.3 Action Step**

By 2010, contingent upon appropriate legislative action, replace legal settlement with legal residency. (An Iowa Department of Human Services action step.)

**4-28 Goal Statement**

Assure that persons with disabilities understand the health and other benefits of assistive technology (AT), how to select and obtain it, and have access to information about the health-related funding sources for AT.

**Rationale**

Assistive technology enables many people with disabilities to live independently, be successful in school and work, and fully included in their communities. AT can prevent secondary disabilities and can be used to make health-promotion and injury-prevention programs accessible. People with disabilities need current and ongoing information about the benefits of AT, the kinds of AT available, and how to obtain it.

**4-28.1 Action Step**

Provide ongoing information and referral services to all Iowans about health-related and other assistive technology via Iowa COMPASS through 2010. (An Iowa Program for Assistive Technology/Iowa COMPASS action step.)

**4-28.2 Action Step**

Provide AT awareness activities in collaboration with other disability-related organizations through 2004 and beyond as funding allows. (An Iowa Program for Assistive Technology action step.)

**4-28.3 Action Step**

Provide technical assistance on assistive technology to disability-related consumer entities and advocacy organizations to increase their capacity to provide AT consumers through 2004 and beyond as funding allows. (An Iowa Program for Assistive Technology action step.)

**4-28.4 Action Step**

Collaborate with community and state programs to provide awareness and training on the benefits of AT to people from minority populations, in rural areas, and other under-represented populations through 2004 and beyond as funding allows. (An Iowa Program for Assistive Technology action step.)

**4-29 Goal Statement**

Assure that healthcare providers recognize the benefits of assistive technology, provide information about AT to their clients, make appropriate referrals for AT, provide direct AT services, and facilitate their client's access to third-party funding.

**Rationale**

Assistive technology enables many people with disabilities to live independently, be successful in school and work, and fully included in their communities. It can prevent secondary disabilities and be used to make health-promotion and injury-prevention programs
accessible to maximize their independence. Healthcare providers need more information and training about all aspects of AT.

4-29.1 Action Step
Provide ongoing information and referral services through Iowa COMPASS to healthcare providers about medically appropriate and health-related AT through 2010. (An Iowa Program for Assistive Technology/Iowa COMPASS action step.)

4-29.2 Action Step
Provide ongoing information about AT to the Iowa’s University Center of Excellence on Disabilities training programs for students in medicine, nursing, psychology, social work, physical therapy, audiology, occupational therapy, dentistry, health administration, nutrition, recreation therapy and speech-language therapy through 2004 and beyond as funding allows. (An Iowa Program for Assistive Technology action step.)

4-29.3 Action Step
Distribute to physicians the American Medical Association publication, Guidelines for the Use of Assistive Technology: Evaluation, Referral and Prescription, as well as the Iowa Program for Assistive Technology’s companion video, Improving Access to AT: Physician Training through 2003. (An Iowa Program for Assistive Technology action step.)

4-29.4 Action Step
Collaborate with other entities, including Easter Seal’s Iowa’s Rural Solutions program to do awareness and training activities on AT with rural service providers and other under-represented groups through 2004 and beyond as funding allows. (An Iowa Program for Assistive Technology and Rural Solutions action step.)

4-29.5 Action Step
Provide technical assistance on AT to the Department of Elder Affairs and to area agencies on aging’s health and community education service providers through 2004 and beyond as funding allows. (An Iowa Program for Assistive Technology and Area Agencies on Aging action step.)

4-29.6 Action Step
Increase collaboration on dissemination of information on health-related AT to service providers from public health programs, health-related grant projects, and university programs. (An Iowa Program for Assistive Technology action step).

4-30 Goal Statement
Increase access to assistive technology through policy changes and increased funding options.

Rationale
Publicly funded programs in health, housing, employment, aging, and education must develop policies that better combine resources and move the state toward non-categorical coverage of AT and appropriate home and vehicle modifications throughout life. For individuals to live as independently as possible, home and vehicle modifications are necessary. Many aids to independent living, or low-tech AT, are not covered under traditional health policies. All health insurance programs should provide coverage for a broad range of AT rather than use exclusive lists. People need home and vehicle modifications based on individual needs rather than programmatic caps. People in care facilities should also have access to AT.

4-30.1 Action Step
Review policies and practices and initiate policy change on the provision of adapted wheelchairs and other AT to residents of care facilities during 2005. (An Iowa Program for Assistive Technology in collaboration with the University of Iowa's College of Law Clinical Program action step.)

4-30.2 Action Step
Provide technical assistance to state agencies and local communities on how to expand coverage of assistive technology, home and vehicle modifications for individuals with disabilities through expansion of the Medicaid, Medicaid waiver programs, Community Development Block Grant and other sources of funding by 2005 and beyond as funding allows. (An Olmstead Real Choices Task Force, Iowa Program for Assistive Technology, and University of Iowa's College of Law Clinical Program action step.)

4-30.3 Action Step
Increase the number of people with disabilities obtaining services through their county managed-care plans who know and exercise their rights by 2008. (An Olmstead Real Choices/DHS action step.)

4-31 Goal Statement
Establish local disability peer support groups within communities to provide a mechanism for mutual support, and to advocate and mobilize for change.

Rationale
Historically, society has kept persons with disabilities “with their own kind.” No one wants a return to segregation and isolation associated with that philosophy. However, peer support is universally
defined by people with disabilities as critical to their well-being. People draw strength from their common experiences by sharing information and resources, and validating experiences.

Peer support comes in a variety of forms: friendships, one-on-one peer counseling (as done through CIL’s), or local peer support groups. It can be interaction among people with similar disabilities, although “cross-disability” interactions are often preferred. Peer support may include mutual support, information sharing, training opportunities, peer counseling, technical assistance, social and/or recreational opportunities, advocacy and systems change.

The focus of this goal recognizes that there are many barriers to the development of these support groups including costs/availability of transportation and PAS (including interpreters), and limited community organizing and leadership experience on the part of local leaders with disabilities, inadequate administrative capacity and resources, and the lack of funding for long-term success.

4-31.1 Action Step
Through a coalition of advocacy and human service groups, identify and leverage resources needed to develop a network of local cross-disability and single-disability peer support and self-advocacy groups (to include traditionally underserved areas) to provide mutual support and peer counseling, information and resource sharing, social opportunities, and/or advocacy on the local, state, and national levels by 2008. (A Center for Disabilities & Development and DD Council action step.)

4-31.2 Action Step
Develop and maintain a list of local peer support groups and their contacts, and make that information available to people with disabilities as resources permit by 2006 and beyond. (An Iowa COMPASS action step.)

4-31.3 Action Step
Provide self-advocacy, self-determination, health & Wellness, and other training directly to Iowans with disabilities and use it as a springboard for on-going peer support as resources allow on an ongoing basis. (A Center for Disabilities & Development and DD Council action step.)

4-31.4 Action Step
Connect local peer support groups and individuals with disabilities together through a state association as resources allow by 2008. (See Goal 4-32.) (A DD Council action step.)

4-31.5 Action Step
Identify on-going funding resources for local peer support groups by 2008. (A DD Council action step.)

4-32 Goal Statement
Establish a unified, cross-disability presence within the state of Iowa to articulate the demand for change.

Rationale
Clearly, there must be a statewide organization connecting Iowans with disabilities, and unifying the Disability Community with a clear voice. This entity must include opportunities for leadership and policy training, and for influencing public policy about disability and health issues.

Such an entity must be managed and directed by Iowans with disabilities, but must also reach out to family groups, providers, professionals, vendors, and the business community. Care must be given to find ways to collaborate with non-traditional groups (e.g., the elder community) without compromising the voice of Iowans with disabilities.

4-32.1 Action Step
Fund a dedicated staff to promote information sharing among peer support groups and individuals with disabilities and coordinate activities related to this goal by 2006. (A DD Council action step.)

4-32.2 Action Step
Conduct an annual, statewide conference to promote networking among people with disabilities, and provide for the advancement of issues of importance to those attending as resources permit by 2009. (A DD Council action step.)

4-32.3 Action Step
Continue the IDA LISTSERV (Iowa Disability Advocates) and InfoNet, or similar mechanisms, to connect advocates with and without disabilities from across the state together for information and resource sharing ongoing. (A Conner Center and DD Council action step.)
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Central Iowa Center for Independent Living
Person with a Disability

Mary Ann Young
Iowa Department of Elder Affairs