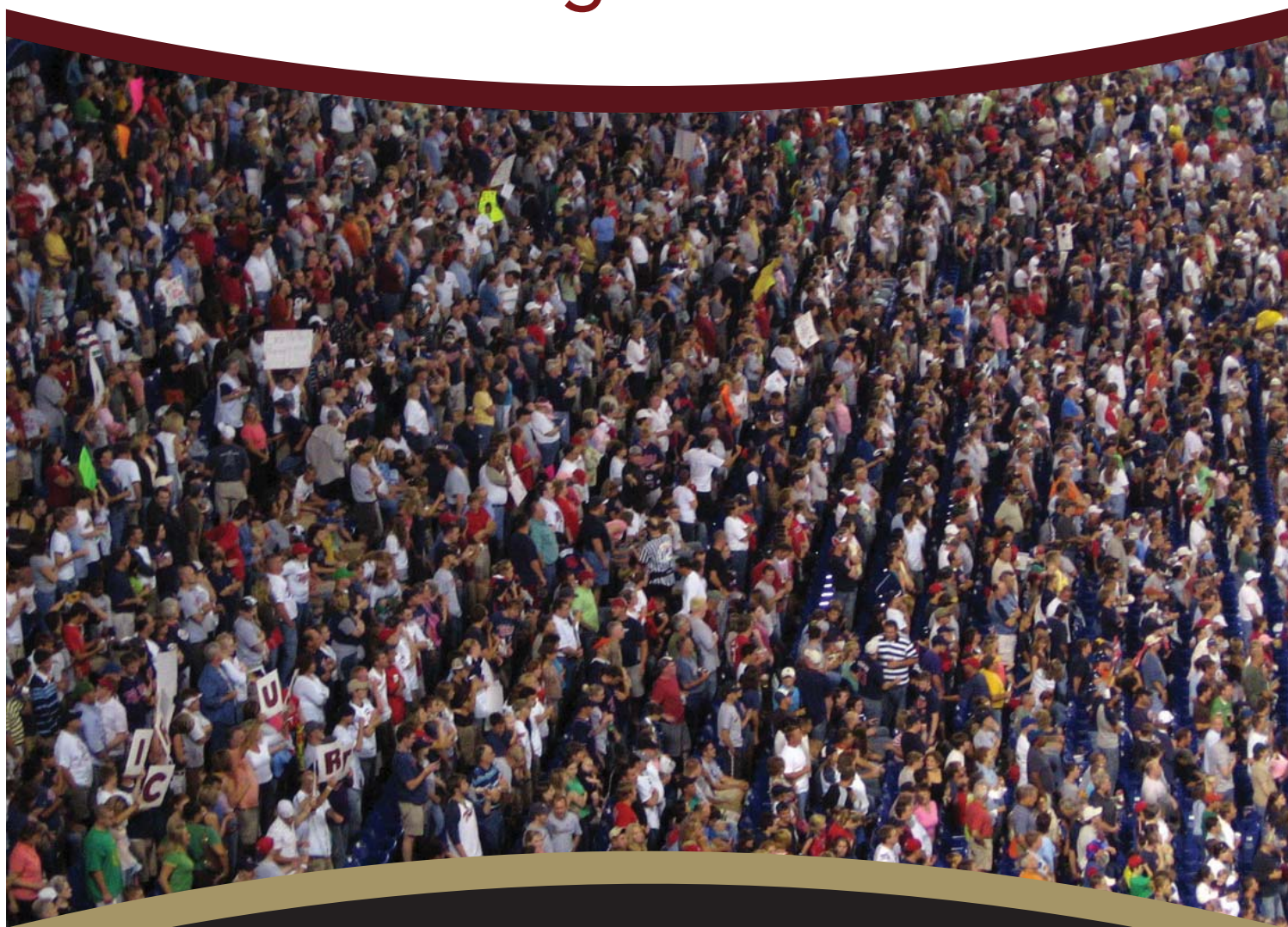


Promoting Better Health for Minnesotans With Disabilities:

Ending Exclusion



August 2007



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Ending Exclusion

**A State Plan
Developed by the
Minnesota Disability Health Project**

August 2007



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PREFACE: HOW TO USE THIS PLAN

Why have a plan?

- It keeps us focused and helps us prioritize.
- It is based on information from people who are affected by disability health issues.
- It defines problems and the most effective ways to solve them.
- It suggests actions for individuals, organizations, and agencies.
- It helps us evaluate what has been done and what work is left to do.

What is the Minnesota Disability Health Program?

The Minnesota Disability Health Program (MDHP) was funded under a two-year grant from the Centers for Disease Control and Prevention to develop a plan to promote the health of children and adults with disabilities (functional limitations) and to prevent secondary conditions that are related to their disabilities.

The Advisory Work Group to the MDHP includes representatives of state agencies, disability advocacy groups, and a university research program. Members are listed in Appendix B.

Developed collaboratively, this plan is intended to become a tool for future policies and interventions in Minnesota. Support will be sought to implement the recommendations of this plan, and infrastructure changes will be discussed and implemented.

How was the plan developed?

The Advisory Work Group, led by an Executive Committee, met in 2005 and 2006 to provide guidance about the secondary health issues faced by individuals with disabilities, based on their varied experiences. The full Advisory Work Group met six times and the Executive Committee, 10 times in intervening months. Six subgroups met a total of 19 times during the summer and fall of 2006, developing problem statements and recommendations for the topic areas reflected in this document. Staff (1.5 full-time equivalents) from the Minnesota Department of Health Injury and Violence Prevention Unit provided knowledge and expertise in epidemiology, health education, disability issues, data analysis, and administrative support.

Advisory Work Group members provided resources from their own organizations, such as needs assessments, publications, information on funding opportunities, and connections with other individuals who provided input. Members of the Advisory Work Group will be sharing the completed plan with others within their organizations and in their networks, all of whom will have a role in implementing the plan.

How is the plan organized?

This plan begins with a statement of vision for the health of Minnesotans with disabilities. Chapter 1 is a framework for the plan: definitions, needs assessment, ecological model for action, and secondary conditions of particular concern in Minnesota. Chapters 2 through 5 focus on four priority issues: Access, Mental Health, Abuse Prevention, and Employment. Each of these chapters defines the problem, summarizes data and trends, and recommends strategies. Chapter 6 recommends infrastructure changes needed to accomplish the recommendations of the plan.

How do we make the plan come alive?

- Do not keep this plan on the shelf.
- Implement those activities in which you have an interest, role, or responsibility.
- Communicate with others; together, we can make a difference.
- Educate others about ways to promote the health of people with disabilities and prevent secondary conditions.
- Start with what is now possible.
- Assess progress periodically.
- Modify work plans based on evaluation results.
- Share the news of your accomplishments.
- Celebrate your successes!
- Repeat the cycle.

A companion document, *Turning Strategies Into Action*, lists the levels where action can occur and the specific groups or individuals who can take action.

VISION STATEMENT

Health Care for Persons with Disabilities

This statement was drafted by the Vision Statement Subgroup of the Minnesota Disability Health Project: John Tschida, Chair; Gene Martinez, Sarah Thorson; Mitchell Davis; Ronna Linroth; and Ceci Shapland.

All Minnesotans with disabilities, regardless of their age, type of disability, or place of residence, will have access to a coordinated system of services that is cost-effective. It must meet individual needs, support good health, prevent secondary conditions, and ensure the opportunity for a satisfying and meaningful life.

This system of services will:

- Ensure that preventive care is offered to children and adults with disabilities and is available to everyone, including screening and care for chronic diseases, mental health, and vision and hearing
- Develop health-related benchmarks of wellness that meet individual needs across the continuum of care
- Coordinate the medical and social service needs of those with complex health conditions
- Provide information that is accessible and consumer friendly
- Reduce disparities and incorporate cultural values and concerns
- Ensure the safety and security needs of individuals, including prevention of abuse
- Align financial incentives to reward positive outcomes over time, including full participation in work and community life
- Assure universal participation in health care by children and adults with disabilities
- Ensure that community health and service providers are knowledgeable of issues relating to disability
- Empower the voice of the consumer and promote choice

CHAPTER 1: Defining Disability Health in Minnesota

What do we mean by disability?

Disability, or functional limitation, does not just happen to “someone else.” It may occur at any time and from any cause. Thus aspects of this plan will apply to everyone at some time in his/her life.

The World Health Organization (WHO) has recommended a functional rather than medical definition for disabilities, called the International Classification of Functioning, Disability and Health (ICF). This definition describes how people live with their health condition: body functions and structures, activities and participation. Health is a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity.

Since an individual’s functioning and disability occur in a context, ICF also includes a list of environmental factors that go beyond the individual condition.

Following is an excerpt from an article that describes ICF:¹

ICF is named as it is because of its stress on health and functioning, rather than on disability. Previously, disability began where health ended; once you were disabled, you were in a separate category. We want to get away from this kind of thinking. We want to make ICF a tool for measuring functioning in society, no matter what the reason for one’s impairments. So it becomes a much more versatile tool with a much broader area of use than a traditional classification of health and disability. This is a radical shift. From emphasizing people’s disabilities, we now focus on their level of health.

Minnesota has been using a functional definition of disability since the early 1980s. Some of the definitions of disability that have been used in Minnesota are found in **Appendix C**.

What is health promotion?

As defined by the Minnesota Department of Health (MDH) Health Promotion and Chronic Disease Division, health promotion is “work to reduce the burden of suffering and death from chronic diseases and injuries . . . , by providing leadership in the prevention of chronic diseases and injuries, conducting public health surveillance, and developing, implementing, evaluating and supporting public health interventions.” ²

¹ World Health Organization, International Classification of Functioning, Disability and Health (ICF). <http://www.who.int/classifications/icf/en/>

² Minnesota Department of Health, Health Promotion and Chronic Disease Division. <http://www.health.state.mn.us/divs/hpcd/>

What are secondary conditions?

Efforts to promote health and to prevent secondary conditions are intertwined. CDC has defined secondary conditions broadly, as medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences.³ The Institute of Medicine limits the definition more specifically to physical or mental health problems.⁴ Whatever definition is used, the absence of secondary conditions does not necessarily mean well-being for a person with a disability or special health need, nor does well-being by itself ensure that secondary conditions will not develop.

As indicated in this chapter, there are many potential secondary conditions. After discussion, the Advisory Work Group decided to use the broader CDC definition and to focus on a few priorities, those issues that assessments done by Minnesota disability organizations (**Appendix D**) have found to be the most pressing in Minnesota.

How was this plan developed?

Several of the organizations represented on the Advisory Work Group shared their assessments of persons with disabilities, family members, and professionals dealing with health-related issues in Minnesota. The assessments are summarized in **Appendix D**.

This chapter distills the Advisory Work Group's discussions of issues common to all of their organizations. Group members and others joined one or more subgroups -- Access, Employment, Mental Health, Abuse Prevention, Infrastructure, and Vision for the Future -- to identify problems, develop goals, and recommend strategies. Members of the subgroups are listed in each chapter.

Why are secondary conditions important?

The CDC Disability and Health Program provides grants to states to build statewide capacity in health promotion and the prevention of secondary conditions and supports demonstration programs. According to data on the program's Web site:⁵

There are 54 million people with disabilities in our country.

About 40 percent of them, or 22.4 million persons, experience at least one secondary condition each year.

An estimated 60 percent of secondary conditions could be prevented each year if all persons with disabilities participated in programs of health promotion. That translates to a savings of \$40 billion/year in Medicare, Medicaid and private health insurance costs.

3 Healthy People 2010 Objectives for People with Disabilities, Summary. <http://www.cdc.gov/ncbddd/dh/hp2010.htm>

4 Margaret Turk, cited in Workshop on Disability in America: A New Look - Summary and Background Papers (2006), http://fermat.nap.edu/openbook.php?record_id=11579&page=185

5 Disability and Health, Centers for Disease Control and Prevention, <http://www.cdc.gov/ncbddd/dh/default.htm>

Health promotion programs and programs to prevent secondary conditions have been proven to be effective in teaching people with disabilities to become more responsible for their health care and better health consumers and advocates.

What do we know about disability in Minnesota?

To prevent secondary conditions, we must collect epidemiological data about disabilities and their determinants, risk factors, and consequences. Many data sources exist, although they do not all measure the same things or have the same purpose.

What secondary health conditions are of greatest concern to Minnesotans with disabilities?

Members of the Advisory Work Group and others identified many issues from their organizations' experiences and from their own experiences as persons with disabilities or family members. They noted that some conditions may be considered a primary disability rather than a secondary condition. They recommended that a secondary condition defined in this plan should be easily defined and measurable, so that progress toward prevention can be evaluated. Various levels of the ecological model shown in this chapter can have impact on a single secondary condition ... or on multiple secondary conditions ... so all levels should be considered when developing interventions. Interventions should be appropriate to all cultures and all socio-economic levels, adaptable for various age groups, and achievable in rural as well as metropolitan areas.

Through discussion and sharing of experiences and resources, the Advisory Work Group identified these secondary conditions as Minnesota concerns:

Mental health issues

- Depression
- Anxiety (can also be positive)
- Low self-esteem
- Chemical dependency
- Serious and persistent mental illness, which also may be a primary condition

Psychological/social issues

- Isolation
- Lack of romantic relationships
- Difficulty making friends/reduced social skills
- Lack of social networks
- Alienation from family
- Problems getting out/getting around
- Cultural barriers to acceptance or understanding of disability

Physical/neurological complications

- Obesity
- Arthritis
- Hypertension
- Pressure sores
- Extreme fatigue
- Bowel/bladder problems

- Falls or other injuries
- Respiratory infections
- Sleep disorders
- Asthma
- Skin problems
- Dental, vision, or hearing problems

Chronic pain

- Can result from a number of disabilities
- May lead to chemical dependency or other issues

Secondary conditions beyond the focus of this plan are cited in many articles and in *Healthy People 2010, Chapter 6: Disability and Secondary Conditions*.⁶ The Advisory Work Group viewed health issues and conditions along a continuum and developed Table 1. Many secondary conditions are implied in the column titled “Barriers/Negative Factors.” Wellness is comprised of positive attributes, as well as the absence of secondary conditions. Progress can be made and measured at any point along the continuum. The barriers can make it difficult to prevent or resolve secondary conditions, particularly if they last over an extended period or time, or if more than one barrier affects the same individual.

Table 1. The Wellness Continuum

<<< Lack of Wellness	Wellness (physical, mental, spiritual) >>>
Barriers/Negative Factors		Goals/Positive Factors
Discrimination/social isolation	↔	Inclusion/acceptance/family or intimate relationships
Lack of access to health care	↔	Improved access
Unemployment/underemployment	↔	Employment
Abuse	↔	Empowerment and respect
Lack of, or deficient, health care (see physical/neurological and chronic pain list)	↔	Quality preventive health care, treatment, and follow-up care
Cutbacks/service reductions	↔	Access to care coordination
Poverty (as predictor of other barriers)	↔	Adequate means/supports/social services
Attitudes/lack of understanding	↔	Education about disabilities
Mental illness: depression, anxiety, low self-esteem, chemical dependency	↔	Improved mental health in areas listed
Lack of emergency planning	↔	Plans in place
Lack of transportation	↔	Transportation more available

⁶ <http://www.healthypeople.gov/Document/HTML/Volume1/06Disability.htm>

The concept of “access” underlies many of these issues. As noted in Chapter 2, access can be defined as physical access, program access/social inclusion, or financial access. To be accessible, services need to be affordable, available, and appropriate, and individuals need to be empowered to make choices.

Disparities in health clearly affect people with disabilities. When people with disabilities are part of, or relate to, a race or ethnicity that is not in the majority, the disparities are compounded. It is essential for health care providers to be culturally competent, so that services are appropriate to people’s backgrounds, beliefs, and needs.

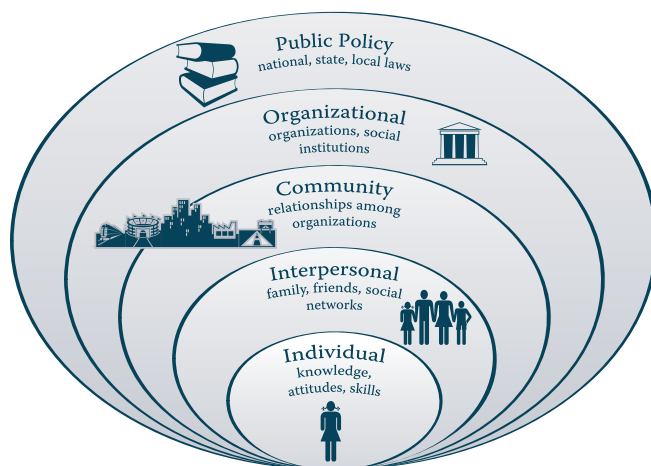
Health care costs are a concern that underlies all the barriers or issues described above. Many of the prevention strategies recommended in this plan will have initial costs. It is expected that, over time, costs will be reduced as people experience better health and are empowered to prevent chronic disease. Dignity and respect are essential to wellness, and as one Minnesota advocate said, “They don’t cost a dime.”

Who should be involved in preventing secondary conditions?

Because many external factors can be involved in an individual’s health, an ecological model can help put the issue in context. Interventions proposed in this plan can occur at several levels of the model, as indicated in *Turning Strategies Into Action*.

Figure 1 is adapted from a model⁷ that is used by public health practitioners to enhance understanding of the factors that interact when preventing health-related conditions. In this adaptation, we define the levels in ways that prevent secondary conditions and promote the health of people with disabilities or functional limitations.

Figure 1. Intersecting Ecological Levels



Each level of this model depends on, and relates to, the other levels. The individual is at the center because he or she is ultimately responsible for lifestyle choices related to health. But levels beyond the individual impact those choices and influence the individual’s knowledge, skills, attitudes, and behaviors. The converse also is true: an individual’s actions affect other levels of the model.

⁷ *Minnesota Heart Disease and Stroke Prevention Plan 2004–2010*. St. Paul, Minnesota: Minnesota Department of Health, 2004. <http://www.health.state.mn.us/divs/hpcd/chp/cvhplan/pdf/cvhplan.pdf>

Example:

A state agency makes a change in eligibility for vocational services (Public Policy), so a local organization (Organizational) contacts people who receive services (Community and Individual). The individual (Individual) may need to work with his/her family (Interpersonal) to make financial adjustments and consider changes in employment (Community), and may meet with a rehabilitation counselor (Organizational). The individual's experience and input may show that there are needs for further change in other parts of the system (Community, Organizational, Public Policy).

How can we measure change?

The Minnesota Disability Health Plan has reviewed various data sources on disability to determine how best to measure changes in people's health and in secondary conditions, and thus to evaluate the effectiveness of interventions. A summary of Minnesota census data is found in Disability Health Data Brief: Demographics 2000-2004 (**Appendix E**).

This plan is related to national disability health objectives as outlined in *Healthy People 2010*,⁸ a 10-year plan to encourage and guide federal, state, local, private, and community health promotion and wellness activities and policies to improve the health of Americans. The U.S. Department of Health and Human Services reformulates this plan every 10 years, with other public health agencies and partners. People with disabilities are included throughout *Healthy People 2010* with a special focus in Chapter 6 (**Appendix F**).

The Minnesota Disability Health Plan also includes goals to be achieved by 2010. System change can be slow, but goals should be revisited periodically as we work toward improving the health of people with disabilities.

8 Healthy People 2010, www.health.gov/healthypeople.

CHAPTER 2: Access To Health Care

Contributors to this chapter:

Chair: John Schatzlein, Minnesota Spinal Cord Resources Network. Members: Dr. Brian Abery, Institute on Community Integration, University of Minnesota; Melissa Cummings, Opportunity Partners; Betty Hanna, Neighborhood Health Network; Margot Imdieke-Cross, Minnesota State Council on Disability; Mark Kinde, Minnesota Department of Health; Adrienne Mason, disAbility speaker/advocate; Mike Sandmann, HealthEast Minnesota; Julie Wegscheid, Metropolitan Center for Independent Living.

Statements of the Problem and Recommended Strategies are based on discussions by the Access Subgroup of their personal experiences and their knowledge of issues faced by other Minnesotans with disabilities. Citations are provided for proven or promising interventions.

“Access” is most often understood as physical accessibility of buildings and services. This plan defines access more broadly, as inclusion of everyone in programs that promote health. Inclusiveness includes physical access, attitudes, education, insurance coverage, and more. When people with disabilities have access to programs that promote health and prevent secondary conditions, the quality of their lives improves. When they are screened and treated for the same conditions and receive the same preventive care as everyone else, care is better and more cost-effective.

Access to health care can save everyone money in the long run by preventing costly secondary conditions or making them less severe. Having welcoming, accessible health care also makes patients feel more positive about their health care providers. This chapter suggests some strategies to improve access so that these positive outcomes will occur.

Goals

- Policy planning and the design of physical and social environments, systems, and programs will contribute to greater accessibility and inclusion of all people.
- Wellness and preventive health care will be maximized, while secondary complications will be reduced.
- People with disabilities will have more choice and control and will develop interdependent partnerships with providers/systems.

Trends

- As the population ages, more people are developing functional limitations and will need specialized health care. People with disabilities are aging in the community (living on their own, with families, in group residences) rather than in institutions. Therefore, community services, equipment and staffing need to be more available and accessible.
- Continuing advances in neonatal intensive care, emergency medicine and lifesaving procedures mean that more people are surviving and living with limitations.

- Veterans with disabilities, from both recent and past conflicts, have conditions that result in increasing needs for service, including prosthetics, other assistive technology, mental health care, traumatic brain injury care, and home health or residential services.
- Many health-related services for people with disabilities have experienced funding reductions.
- Accessibility regulations of the Americans with Disability Act (ADA) are not being consistently enforced.

A. Physical Access

Physical access is essential. Even the best and most appropriate services are of no use if people cannot get to them or use them. In regard to physical access, universal design is defined as an approach to the design of products, services and environments to be usable by as many people as possible regardless of age, ability or situation.⁹

Statement of the problem

- ADA requirements have not been adjusted to consider the growing number of older Americans with mobility limitations.
- Accessibility issues in health care facilities prevent many people with disabilities from obtaining appropriate preventive care. Problems include:
 - Inadequate size of waiting spaces for persons using wheelchairs and walkers.
 - Inaccessible exam rooms (including dental cubicles), with examination tables or chairs that cannot be adjusted for height.
 - Inadequate hours of operation for people who depend on unreliable transportation.
 - Lack of “door-through-door” transportation services to provide assistance to an individual to find treatment locations within a building.
 - Inadequate number of trained staff members who can lift or transfer clients.
 - Inadequate numbers of support staff or volunteers to assist people during appointments.
 - Inadequate number of fully-accessible restrooms available on every floor.
- Transportation and parking problems have a major impact on access to health care.
 - Buses, taxis, and other forms of transportation often are not accessible and available. Some taxi companies charge a special fee for carrying wheelchairs, or charge more for units equipped with lifts.
 - Adequate disability parking is a problem for many people with mobility impairments. Properly-striped van-accessible parking spaces are difficult to find and are sometimes misused by people who have disability parking permits but do not need the wider access aisle.
 - Enforcement is lacking for improper use of parking spaces identified for use with State of Minnesota Disability Permit.
- People with disabilities and elderly people are not always considered in emergency and evacuation planning.

Recommended Strategies

Public Policy

- Provide incentives for businesses and health care facilities to remove barriers and make accessibility improvements.
- Require all health care facilities to complete an ADA health care accessibility audit.

⁹ http://en.wikipedia.org/wiki/Universal_design

A good assessment tool is North Carolina's *Removing Barriers to Health Care: A Guide for Health Professionals*.¹⁰

- Develop public awareness messages to help people understand correct usage of disability parking spaces, particularly those reserved for lift- and ramp-equipped vans.¹¹
- Consider changes in ratio of disability parking in the design of parking lots.
- Integrate emergency preparedness needs of people with disabilities into emergency planning and see that people have evacuation plans appropriate to their needs.
- Determine best ways for people with disabilities to identify themselves to first responders.
- Train emergency responders about the aspects of specific disabilities that may become issues in emergencies.
- Ensure that Web sites and other communications materials meet state and federal guidelines for accessibility. The Minnesota State Council on Disability has a comprehensive list of accessibility resources on its website.¹²
- Review eligibility standards set by the Minnesota Non-Emergency Transportation program, so that all persons who need it are provided with door-through-door transportation assistance.
- Investigate the legality of higher fees charged by taxi companies when they provide accessibility.
- Communicate with health care providers about ADA accessibility requirements.

Minnesota Department of Health

- Study reimbursement issues for health care providers in accepting Medical Assistance patients, and make recommendations for change.
- Lead efforts to involve people with disabilities in emergency preparedness programs.

Community/Organizational/Educational

- Educate community planners that accessibility (universal design) benefits everyone, particularly as people age. Technology improvements come slowly if they are seen to benefit only a few people.
- Provide incentives to health care providers to do more than the minimum in making examination services and parking accessible.
- Involve architects, people with disabilities, and experts in disability access issues in building design, improvements, and accessibility reviews, including lifting systems. Ensure rural access to clinics and specialists, through transportation and location of services. Promote assistive technology for farmers with disabilities, through the United Way, Goodwill/Easter Seals Agribility, and other programs.

Family/Individual

- Encourage use of technology that enables people to have access to their own medical information, and interpret results when possible.

¹⁰ Removing Barriers to Health Care: A Guide for Health Professionals, North Carolina Office on Disability and Health, 2005, <http://www.fpg.unc.edu/~ncodh/rbar/>

¹¹ Ibid., drawings on p. 6 and 11.

¹² Minnesota State Council on Disability <http://www.state.mn.us/portal/mn/jsp/home.do?agency=MSCOD>

B. Social Inclusion/Program Access

Social inclusion enables people to have access to services by making them feel welcome, accepted, and understood. It is made possible by the attitudes of health care providers and others, by appropriate expectations, and by empowerment of people with disabilities to speak and make decisions on their own behalf.

Statement of the Problem

Negative attitudes may be due to lack of understanding of disabilities. Culturally, Minnesota has become diverse, and many new languages are being spoken (more than 80 in Minneapolis schools). Patients have limited access to translators and sign language interpreters. Even when language translation is provided, cultural differences can keep people from getting appropriate health care. Some issues and barriers include these:

- An individual may not be able or willing to relate to procedures or medication that are not familiar to his/her culture.
- Health care providers may not see the need for timely preventive examinations for patients with disabilities or may make incorrect assumptions about the person's ability to understand instructions. The client may be unable to comply with follow-up care because of lack of transportation, financial limitations, or need for personal assistance.
- Health care providers may focus on disabilities rather than strengths, and may not look for alternative methods to educate or treat patients with disabilities, such as illustrations or picture cards.
- Appropriate levels of communication may not be available for persons who are deaf or hard of hearing, blind or with limited vision, or those who have cognitive disabilities.
- "Medical necessity" for people with disabilities may include services beyond those needed by others, in order to receive the same health outcomes. The State of Michigan has model criteria for people with developmental disabilities who receive Medicaid services.¹³ The criteria are designed to help the individual achieve goals of community inclusion and participation.
- Despite regulations against discrimination, some health care providers routinely refuse to place people with disabilities on lists of organ transplant recipients.

¹³ State of Michigan Medicaid information,
http://www.michigan.gov/mdch/0,1607,7-132-2945_5100-43782--,00.html

Recommended Strategies

Public Policy

- Implement programs that enable individuals with disabilities to obtain care that is appropriate and is comparable to the care offered to the general population. The Hudson Health Plan¹⁴ exemplifies creativity in providing a range of services to people who receive Social Security Income and has been recognized by advocacy groups for cultural sensitivity toward disabled populations.
- Identify and implement ways to provide health care coordinators to people with disabilities, through models such as community health care workers (community clinic model), health care coordinators (Axis model), and health disparities collaboratives. A care coordinator should be considered a reasonable accommodation.
- Advocate with the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) to require individual hospitals to develop and enforce policies to ensure that persons with disabilities do not experience discrimination in receiving organ transplants.¹⁵ JCAHO's recommendations are in a paper called *Health Care at the Crossroads: Strategies for Narrowing the Organ Donation Gap and Protecting Patients*.¹⁶ Additionally, The Journal of Pediatric Transplantation carried an article on the accessibility of transplants to children with mental retardation and the outcomes of surgery.¹⁷
- Provide ADA training for all health care personnel in hospitals that includes information on transplantation policies.
- Expand health care providers' knowledge and attitudes about disabilities through pre-service and in-service training, to improve interactions with and sensitivity toward people with various disabilities.

Minnesota Department of Health

- Compile or connect with a repository of disability awareness materials and resources, making them available to health care providers.
- Provide information on ways to achieve long-term health and wellness to parents of children with disabilities as well as to adults with disabilities.
- Develop ways to identify experienced health care providers, including specialists, who can and will serve people with disabilities.

Community/Organizational/Educational

- Identify ways to increase community access and participation (including and beyond health care facilities) by people with disabilities. Fund therapeutic recreation and creative arts staff (music, art, dance) in facilities and programs. Greater involvement can prevent secondary conditions such as depression, poor

14 Hudson Health Care, http://www.chcs.org/info-url3969/info-url_show.htm?doc_id=317315

15 Joint Commission on the Accreditation of Health Organizations, quoted in *Lives Worth Saving: Organ Transplantation and People with Disabilities*, an essay by Bruce Kappel, June 2004, Minnesota Governor's Council on Developmental Disabilities.

16 http://www.jointcommission.org/NR/rdonlyres/E4E7DD3F-3FDF-4ACC-B69E-AEF3A1743AB0/0/organ_donation_white_paper.pdf

17 <http://www.blackwell-synergy.com/doi/abs/10.1111/j.1399-3046.2006.00545.x>

nutrition, and lowered self-esteem.

- Encourage routine screening for people with disabilities by primary care providers, including mammograms, colonoscopies, blood pressure, cholesterol, and diabetes.
- Ensure that children with disabilities receive routine vision and hearing screening.
- Screen for family history of chronic disease among children and adults with disabilities, so that prevention can occur.
- Encourage clear signage in multiple languages (for example, instructions for using services, prescription labels) and provide translators when needed.
- Conduct media campaigns that encourage people to see that everyone will experience functional limitation or a disability in their lifetime and that those with disabilities are not "someone else."
- Develop relationships with diverse cultural groups, as culture has an impact that goes far beyond language. Be sensitive to cultural norms in spirituality, concept of time, preferences for alternative medicine, and role of family vs. "outsiders." Develop partnerships with medicine men/shamans/other healers specific to cultures.
- Provide information to immigrants and refugees to help them understand and navigate the health care system.
- Adjust clinic administration practices to be more "customer friendly" to people with disabilities. Make sure that patients understand follow-up home-care instructions, such as when appointments should be made and when medications should be taken.
- When sign interpreters are not available, learn about and use other services to enhance communication with deaf and hard of hearing persons: assistive listening devices, real-time transcription, telemedicine technology, video remote interpreting, interpreting online, pictograms, written notes, or captioned videotapes.
- Improve communication between providers and patients so that individuals can understand reports on their condition and how to manage or improve their own health. When providing lab results, for example, care providers need to indicate whether the results are within the normal range, and what the patient should do to maintain or improve health.

Family/Individual

- Seek training in self-advocacy skills to monitor one's own health care.
- Seek training on youth transition in health care, moving from pediatric care to adult services.

C. Financial Access

Financial access is simply equity and fairness. Affordable services allow people to maintain and improve their quality of life and become less dependent on others. Earlier intervention can prevent further problems or secondary conditions, e.g., dental services, wound care, psychiatric care. When services are affordable, people can reach life goals, and may become less reliant on public benefits.

Statement of the problem

- Insurance coverage and financial support plans are often complex, inflexible, and counter-productive to reducing health care costs. Some of them encourage dependence and discourage independence.
- Few specialists accept Medical Assistance (MA) and limited insurance plans, making their services inaccessible to many people with disabilities. Preventive care providers, such as dentists, also set limits on the number of MA patients, so many people with disabilities do not receive regular checkups.
- Insurance coverage for medical supplies and equipment is often inflexible and does not allow for changing needs of individuals.
- Medicare and many private insurance plans do not cover hearing aids and other assistive devices.
- Medicare Part D provides limited drug coverage and a limited array of drugs. Benefits currently are so complex that many people with disabilities have difficulty accessing a plan that is best for them. Individuals who are dually eligible for Medicare and Medicaid have lost their Medicaid coverage for prescription drugs, which had critical cost containment protections. Finally, some lower-income individuals must pay 100% of Part D costs after a certain amount of benefits have been paid and before a ceiling is reached; this is referred to as a “donut-hole” issue.
- Transportation is a particular challenge for people with lower income, limiting access to employment and community participation.

Recommendations

Public Policy

- Monitor proposals and work with advocates to promote universal participation in health care coverage.
- Seek equity in insurance coverage and benefits – including supplies and prescriptions -- by working with managed care and private insurance leadership.
- Simplify plan information, and increase outreach and education resources for consumers to address the confusion.
- Work with advocates to promote reinstatement of cost containment protections in Medicare Part D for individuals who are “dual eligibles,” receiving both Medicare and Medical Assistance.
- Ensure equitable access to financial benefits or supports. Different cultural beliefs may require flexibility about the types of services a person can receive, such as alternative forms of medicine or healing.

- Seek equity in coverage for durable medical equipment such as hearing aids and prostheses, and other assistive technology.
- Seek more equitable funding for specialized transportation services.
- Review services that are paid for by Medical Assistance and share information with disability advocacy organizations.
- Create or increase incentives, such as tax credits, for health care providers to serve individuals who receive Medical Assistance or other public benefits.

Minnesota Department of Health

- Examine how health care providers set limits on the number of people they serve who are on Medical Assistance, and seek ways to increase the limits.
- Obtain data on the rates of health insurance coverage for people with disabilities and on the categories of disabling conditions/functions of people who are not insured.

Community/Organizational/Educational

- Develop relationships with organizations that represent lower-income people, as socio-economic level has a major effect on people in obtaining health care.
- Increase disability and cultural awareness and respect for customers on the part of insurance company personnel, including claims representatives and customer service representatives.
- Increase state funding to improve availability of transportation modalities, times of service, and reliability.

Family/Individual

- Seek information about options to form trusts and other financial arrangements to provide for children with disabilities in the future.
- Become informed about financial issues and self-advocacy skills.
- Become informed about current insurance coverage and advocate for change if appropriate.

Web sites of organizations represented on Access Subgroup

HealthEast Minnesota

<http://www.healtheast.org/>

Institute on Community Integration, University of Minnesota

<http://www.ici.umn.edu/>

Metropolitan Center for Independent Living

<http://www.mcil-mn.org/modules.php?name=ADAProgram>

Minnesota Disability Health Project, Minnesota Department of Health

<http://www.health.state.mn.us/injury/topic/topic.cfm?gcTopic=15>

Minnesota State Council on Disability

<http://www.state.mn.us/portal/mn/jsp/home.do?agency=MSCOD>

Neighborhood Health Care Network

<http://www.nhcn.org/directory.php?type=general>

Opportunity Partners

<http://www.opportunities.org/>

Chapter 3: Mental Health

Contributors to this chapter:

Chair: Roberta Opheim, Minnesota Ombudsman for Mental Health and Developmental Disabilities. Members: Sue Hanson, National Alliance on Mental Illness, Minnesota chapter; Dianne Naus, Minnesota Disability Law Center; Walter Warranka, Lifetrack Resources.

Statements of the Problem and Recommended Strategies are based on discussions by the Mental Health Subgroup of their personal experiences and their knowledge of issues faced by other Minnesotans with disabilities. Citations are provided for proven or promising interventions.

Statement of the Problem

One can look at the complex relationship between mental health and disability in at least two ways:

- Mental illness can be a disability itself and can lead to other disabilities. Psychotropic medications can have side effects -- psychosis, coordination or mobility problems, and vision problems -- that can lead to further disability. In addition, isolation because of mental health issues can make one vulnerable to chronic illnesses such as diabetes, heart disease, and multiple sclerosis.
- Also, mental health issues, particularly depression, can be secondary conditions arising from a variety of disabilities. Sometimes, this is situational, as when a person with a physical disability becomes depressed because of limited social opportunities. Other times, the secondary condition may have a genetic/biological component that is brought out due to the stress of the primary disability.

Whether mental illness is a primary or secondary condition, similar problems or issues surround it.

Uninformed treatment

- Mental health problems often are unrecognized. A person may receive the wrong diagnosis, or the person making the diagnosis may not realize that a behavior problem is related to mental illness. In both cases, the individual receives the wrong treatment or medication, or no treatment at all.
- People with mental illness may not realize that they have a problem or may not be able to seek help. If the individual does not seek help, the system may not respond to others speaking on his or her behalf.
- Professionals may not respect the knowledge of the family, who often may provide the best insight about what works for the individual.
- Professionals may not understand that depression may have a biological cause, that it may have existed before the disability (even in childhood), or that the disability may be made worse by depression.
- Professionals who deal with physical or mental health may not be knowledgeable about mental health services available; this may result in inappropriate referrals.

- Mental health professionals may not be informed about community services, such as job placement. Employers may resist hiring a person with mental illness.
- The recommended treatment may simply be the most available and convenient; the person is expected to fit into the program, rather than making the program fit the individual. A person's failure in a particular program may be blamed on him or her, rather than on the effectiveness of the program itself.
- Programs often are based on a person's weaknesses or deficits rather than strengths.
- When there is a co-occurring disorder along with mental illness, integrated treatments may not be available or may not be known to those making referrals.

Lack of awareness and stigma

Media often mis-portray mental illness or apply the label inaccurately.

- The general public has a negative attitude and fears people with mental illness.
- Individuals with mental illness are so aware of stigma that they may not acknowledge their mental illness and seek treatment or support. They may also isolate themselves.
- People who are homeless and have mental illness are less likely than others to be referred to appropriate services.
- People may assume that those with mental illness can overcome it, or that they are totally responsible for their behavior. Some unacceptable behaviors may be symptoms of a mental illness and can be modified or mitigated, if the person receives appropriate treatment.
- Adults with mental illness may be spoken to as children, or treated as "cases," diminishing their self-esteem.
- Children with mental illness may be ostracized or bullied by others, which can make their illness worse or result in other disorders such as Post Traumatic Stress Disorder.

Problems within the service system

- The system often is not flexible enough to meet unique individual needs.
- Services may not reflect cultural competency.
- Government money may be spent inappropriately because of lack of knowledge of appropriate services.
- Some mental health services need to be re-evaluated, as they were developed, funded and entrenched in old theory and outdated research.
- Mental illness is a hidden disability, so needs and accommodations are not always obvious.
- Funding cutbacks often reduce staffing or increase caseloads; this can result in less timely services and the need for more expensive services later.
- Minimal coverage of mental health services in private insurance is resulting in increased demand on the public system.
- Transition from prevention to treatment to recovery is not a smooth process. The medical model emphasizes treatment and does not look at mental illness as a long-term chronic condition that will have "cyclical reoccurrences."
- Prevention is not emphasized, so services often are not provided until the individual has failed and are reserved for those who have failed the most often.

- Procedures and deadlines for obtaining mental health services are not flexible, and people's conditions may make it difficult for them to meet deadlines.
- Courts and law enforcement may not understand that some criminal behavior can be related to untreated mental illness. In addition, people with disabilities are more likely than others to be victims of crimes but are less likely to be believed or be perceived as a credible witness.
- The threat of civil commitment (loss of individual freedom without having committed a crime) sometimes leads to persons refusing to seek help when they need it.
- When services are accessible only online or require travel; many persons with mental illness cannot use them because of lack of transportation or access to computers.

Trends

- Professionals seem to be less knowledgeable about the system of services.
- Services have become more complex and therefore less accessible to many people with mental illness.
- People with mental illness seem to feel increasingly hopeless and frustrated.
- Stigma toward those who have mental illness is a continuing issue.

In research, when doing a psychological experiment with rats, if the experiment does not work we do not say the rat is crazy. The researcher re-examines assumptions and tries a new course. But when we try a treatment plan on a psychiatric client and it does not work, we blame the client.

Quote from a former research scientist who had a traumatic brain injury, after reading her chart during a stay in a hospital psychiatric ward.

Goals

- Better coordination/integration of physical and mental health services, along with more seamless movement among services.
- Better education of the public, including the media, and professionals in mental health and other community services.
- Greater understanding of and sensitivity toward people with mental illness on the part of law enforcement (larger number of police departments that have had training about mental illness).
- More public understanding that people with mental illness should be allowed/encouraged to take risks and participate in decision-making.
- Stronger system of support, including families, empathetic listeners with similar disability, support groups, friends, employers, and neighbors.

Minnesota Deaf and Hard of Hearing Services provides this example of the inter-relationship between mental health and hearing disabilities:

Many people who experience hearing loss later in life become so frustrated with their difficulties in communicating that they withdraw from social situations and isolate themselves. This often leads to depression. Therapists may not treat the problem appropriately if they are unaware of the correlation between hearing loss and depression.

Recommended Strategies

Public Policy

- Increase the accountability of agencies that oversee health care (Minnesota Department of Health for managed care and Minnesota Commerce Department for fee-for-service care) to assure that mental health services are available within the distances required by Minnesota law.
- Coordinate services from birth through adulthood, and from identification and crisis management through stabilization and ongoing services in the community.
- Increase the number and quality of Assertive Community Treatment (ACT)¹⁸ teams, comprised of various professionals who interact with the person with mental illness in a comprehensive, cross-disciplinary, long-term approach.
- Develop mental health courts throughout Minnesota (successful pilots exist in Hennepin County¹⁹ and Ramsey County²⁰). Ensure that judges, county attorneys, and public defenders are aware of mental health issues that may affect defendants. Similar courts might be created for people with other disabilities, such as traumatic brain injury, who encounter the legal system.
- Develop a link between research and practice by encouraging evidence-based practice.
- Plan a conference to present ways to improve system-wide coordination and communication about mental health issues. The Minnesota State Mental Health Advisory Council²¹ would be a primary partner. This planning group might continue its work by coordinating and implementing other strategies in this document.
- Ensure that mental health services are equitably distributed throughout the state. This might mean reallocation or additional allotment to underserved areas.

Minnesota Department of Health

- Working with the Department of Human Services, develop incentives to fully integrate mental health care into the health care system so that services can be obtained when needed throughout the life span.
- Continue to provide early intervention and detection so that problems are detected and treated before they become severe. Expand Early and Periodic Screening, Detection, and Treatment²² to increase the number of children who are screened for mental health needs and referred to appropriate services.

18 Assertive Community Treatment Teams

http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs_id_019807.pdf

19 Mental Health Court (Hennepin County), http://consensusproject.org/programs/one?program_id=414

20 Mental Health Court (Ramsey County), <http://www.mncourts.gov/district/2/?page=1576>

21 Minnesota Mental Health Action Group, <http://www.citizensleague.net/what/projects/mmhag/>

22 Minnesota Department of Health, Early and Periodic Screening, Diagnosis and Treatment
<http://www.health.state.mn.us/divs/fh/mch/candtc.html>

Community/Organizational/Educational

- **Improve professional standards for those who work with people with mental illness.**
 - a. Improve in-service training of all health professionals, including those in mental health, about the range of services available, so they can make appropriate referrals.
 - b. Improve licensure requirements for social workers/case managers, to increase their knowledge base and to provide resources when problems occur.
 - c. Assure that social workers and related professionals have reasonable caseloads, as required by the State of Minnesota Rules 9520.0903, Subp.2 (B).²³
 - d. Develop statewide standards, core competencies, or outcomes for mental health providers who receive funds from the state. Seek training on cultural competency, person-centered planning, and recovery-focus. Work with the Minnesota Department of Human Services to incorporate those standards into funding streams.

- **Provide training and education**
 - a. Review and improve, where appropriate, materials for medical professionals on dual diagnoses (mental illness and other disabilities, no matter which is considered the primary diagnosis).

•Promote mental health screening at primary care clinics, particularly for people with all disabilities, and referral to appropriate services.
 - b. Work with colleges and universities that train medical personnel, to develop curriculum that includes sensitivity to mental health issues.
 - c. Educate journalists about mental illness, both through curricula in schools of journalism and through outreach to news media.
 - d. Provide accurate resources to organizations that offer information and referral services to consumers and parents.
 - e. Enhance patient and family education on mental illness provided at the time of release, to let people know how to manage medications, what to expect as they re-enter the community, and what support resources are available.
 - f. Integrate mental illness materials into police training and in-service programs, through the Police Officers Standards and Training (POST) board. Encourage use of a U.S. Department of Justice video²⁴ on police response to people with mental illness.

²³ Minnesota annual survey of mental health caseloads http://www.dhs.state.mn.us/main/groups/publications/documents/pub/DHS_id_003927.pdf

²⁴ Minnesota Peace Officers Standards and Training, website and training video
<http://www.dps.state.mn.us/newpost/license.asp>
<http://www.ada.gov/videogallery.htm#Anchor-Dial-47492>

Individual/Family

- Identify community organizers who can strengthen local support systems for persons with mental illness and their families. Resources might include the University of Minnesota Institute on Community Integration²⁵ or the Humphrey Institute of Public Affairs.²⁶
- Create, strengthen, and support self-advocacy resources for people with mental illness, to make people aware that they can and should speak up for themselves. Provide coaches, peers, and written material.

Resources

Mental Health Disability Advocacy and Information

http://www.bazon.org/links/nat_advocates.htm

Mental Health: A Report of the Surgeon General

<http://www.surgeongeneral.gov/library/mentalhealth/chapter1/sec1.html>

National Alliance on Mental Illness

<http://www.nami.org/>

Substance Abuse and Mental Health Services Administration

Mental Health Information Center

<http://mentalhealth.samhsa.gov/links/default2.asp>

Web sites of organizations represented on Mental Health Subgroup.

LifeTrack Resources

<http://www.lifetrackresources.org/>

Minnesota Disability Law Center

<http://www.mndlc.org/>

Minnesota Ombudsman for Mental Health and Developmental Disabilities

<http://www.ombudmhm.state.mn.us/default.htm>

Minnesota chapter, National Alliance on Mental Illness

<http://www.namimn.org/>

²⁵ Institute on Community Integration, University of Minnesota

<http://www.ici.umn.edu/>

²⁶ Hubert H. Humphrey Institute of Public Affairs

<http://www.hhh.umn.edu/>

A Success Story

Even without this personal experience, workers can make a difference by empathizing, putting themselves in the place of the person who come to them.

A social worker for a nonprofit agency in Minnesota was working with a single mother with severe attention deficit disorder who had four young children. The mother was experiencing stress because she had to move but did not know where to move. Her challenges were organizational skills and staying focused on necessary tasks. Many social workers would have given her some telephone numbers to call, or left her to find them herself. But this worker went the extra mile ... making some initial calls for her, making sure she got to an appointment, offering her own pickup truck to get furniture from a free store, etc. When asked, the social worker said she remembered what it was like to be a single mother and what kind of help she really needed.

Chapter 4: Abuse Prevention

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Statements of the Problem and Recommended Strategies are based on discussions by the Abuse Prevention Subgroup of their personal experiences and their knowledge of issues faced by other Minnesotans with disabilities. Citations are provided for proven or promising interventions.

Statement of the Problem

According to Dick Sobsey of the University of Alberta, prevention of abuse includes: "All activities that are undertaken to reduce the risk of potential abuse and the harm it inflicts...no prevention effort...can ensure absolute safety for any individual. Thus, prevention implies risk management rather than invulnerability to risk."²⁷

Sobsey developed this ecological model of abuse to show the impact of multiple levels.

²⁷ Sobsey, D. *Violence and Abuse in the Lives of People with Disabilities*, 1994, Baltimore: Paul H. Brookes Publishing Co., p. xviii. Cited by permission of author and publisher.

An Integrated Ecological Model of Abuse

Table 1. Individual, environmental, and cultural aspects of the integrated ecological model of abuse²⁸

Potential Victim	Potential Abuser	Culture	Environment
Impaired physical defenses	Need for control	Emphasizes control	Devalues victims
Impaired communicative functioning	Authoritarian	Attracts abusers Isolated from society	Objectifies victims
Lacks critical information	Low self-esteem	Provides awarded models of aggression	Teaches compliance
Learned helplessness	Displaced aggression	Covers up allegations	Emphasizes vulnerabilities
Learned compliance	Exposed to abusive models	Transient caregivers	Disinhibits aggression
Undeveloped sense of personal space	Little attachment to victim	Dehumanizes potential victims	Denies problems
Dependency	Devaluing attitudes	Eliminates nonabusers	Discourages attachment
	Impulsive behavior	Clusters risks	Discourages solutions
		Many caregivers	
		Discourages attachment	

Minnesota Children With Special Health Needs suggests that when parents become abusers, it may be due to frustration and lack of understanding of child development. When frustrated, parents may be more inclined to use aversive discipline. Almost three times as many parents who reported being frequently frustrated also spanked frequently, compared with parents who reported infrequent frustration.²⁹ The risk for child abuse increases when there is a lack of parenting skills, unrealistic expectations about a child's capabilities, uncertainty on how to manage difficult behavior, and lack of understanding of child development.³⁰

What is the history of abuse?

People with disabilities have been abused for centuries. During the 19th and 20th Centuries, institutions sanctioned practices such as sterilization, restraint, lobotomies, overmedication, cells, isolation, and other aversive treatments. The peak of abuse against people with disabilities was Third Reich Germany, when an estimated 100,000 of people with physical and mental disabilities were killed prior to widespread genocide.³¹

In more recent times, the knowledge about abuse is mostly anecdotal, because data and reporting are imprecise. Abuse of people with disabilities is underreported. This may be because of fear of retribution, both to the individual who is abused and to the person who reports it. The culture is silence, and the problem is often invisible.

28 Ibid., p. 163.

29 Regalado, M et al. "Parents' Discipline of Young Children: Results From the National Survey of Early Childhood Health". *Pediatrics*, Jun 2004; 113: 1952 - 1958.

30 Bethea, L. Primary Prevention of Child Abuse. *American Family Physician*. March 15, 1999. www.aafp.org.

31 <http://www.mncdd.org/parallels/four/4e/4.html>

Many people with disabilities are not considered to be reliable reporters. Media exposures provide an occasional reminder to the general public that a problem exists. We make some attempt to track abuse but have not done much to prevent it.

How extensive is abuse?

Emotional and verbal abuse are underreported and have a strong impact on people with disabilities: physical wounds heal, but emotional wounds do not. All types of abuse can lead to depression and to lowered self-esteem.

Why does it happen?

According to Sobsey, the abuse of people with disabilities is an issue of values, including:

- Values held about people with disabilities
- Attitudes toward abuse and violence
- Belief by parents that they “own” their children with disabilities
- Economic and gender imbalances
- Lack of knowledge about sexuality of people with disabilities

It is difficult to balance protecting individuals with providing freedom and dignity. At highest risk for abuse are children, females, older adults, those who are the most dependent, those who are the most impoverished, those who are most isolated, those with greatest communication difficulties, and those with the lowest educational levels.

Who is most vulnerable?

A few findings from studies about abuse and people with disabilities:

- Persons with disabilities are four to ten times more likely than others to become victims of violence, abuse, or neglect.³²
- Children with disabilities are more than twice as likely as other children to be physically or sexually abused³³
- Similar proportions of women with and without disabilities report having experienced physical violence, sexual violence, or emotional abuse.³⁴ Women with disabilities, however, report greater numbers of perpetrators and longer time periods of individual episodes than women without disabilities.³⁵

Who commits acts of victimization?

- More men than women³⁶ are reported to commit acts of physical violence, sexual violence, emotional abuse, or neglect against persons with disabilities.
- Family members have been reported to commit crimes of victimization while

32 Petersilia JR. Crime victims with developmental disabilities: a review essay. *Criminal Justice & Behavior* 2001;28(6):655–94.

33 Ibid., and Sobsey D, Mansell S. An international perspective on patterns of sexual assault and abuse of people with disabilities. *International Journal of Adolescent Medicine & Health* 1994;7(2):153–78.

34 Ibid.

35 Young ME, Nosek MA, Howland C, Chanpong G, Rintala DH. Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine & Rehabilitation* 1997;78(12 Suppl 5):S34–8.

36 Brown H, Turk V. Sexual abuse in adulthood: ongoing risks for people with learning disabilities. *Child Abuse Review* 1994;3(1):26–35, and Marley JA, Buila S. Crimes against people with mental illness: types, perpetrators, and influencing factors. *Social Work* 2001;46(2):115–24.

caring for a relative with disabilities.³⁷ • Personal home care attendants³⁸ or health care workers at institutions³⁹ have been reported to perpetrate emotional abuse and sexual violence against persons with disabilities.

- In institutional settings, persons with disabilities may commit acts of physical violence or sexual violence against other persons with disabilities⁴⁰
- Some caregivers and even family members take advantage of people with disabilities through control of their finances.
- In school programs, the rate of substantiated abuse against children with disabilities is higher than their overall representation in the schools (Maltreatment Annual Report, Minnesota Department of Education). The Maltreatment of Minors Act in Minnesota establishes a system of reporting abuse by school personnel.

What factors make a person with disabilities susceptible to victimization?

Societal Factors

- Some people believe incorrectly that “having a disability protects a person from victimization”; the risks to a person with disabilities are thought to be less than the risks to a person who has none.⁴¹
- Unemployment or underemployment of persons with disabilities restricts their income and limits their choices for caregivers, leading to an increased risk of physical and sexual violence, emotional abuse, or neglect.⁴²
- Lack of money often causes persons with disabilities to live in areas where crime rates are high and the potential for physical and sexual violence is greater than in wealthier neighborhoods.⁴³

Community Factors

- Community resources for victims of physical and sexual violence, emotional abuse, or neglect are usually designed to assist people without disabilities.⁴⁴ In Minnesota, most domestic violence and sexual violence shelters are not accessible for people

37 Milberger S, Israel N, LeRoy B, Martin A. Violence against women with physical disabilities. *Violence and Victims* 2003;18(5):581–91, and Stromsness MM. Sexually abused women with mental retardation: hidden victims, absent resources. *Women & Therapy* 1993;14(3–4):139–52.

38 Oktay JS, Tompkins CJ. Personal assistance providers’ mistreatment of disabled adults. *Health & Social Work* 2004;29(3):177–88, and Saxton M, Curry MA, Powers LE, Maley S, Eckels K, Gross J. “Bring my scooter so I can leave you”: a study of disabled women handling abuse by personal assistance providers. *Violence Against Women* 2001;7(4):393–417.

39 Brown H, Turk V. Sexual abuse in adulthood: ongoing risks for people with learning disabilities. *Child Abuse Review* 1994;3(1):26–35, and Sequeira H, Halstead S. “Is it meant to hurt, is it?”: management of violence in women with developmental disabilities. *Violence Against Women* 2001;7(4):462–76.

40 Sobsey D, Doe T. Patterns of sexual abuse and assault. *Sexuality & Disability* 1991;9(3):243–59.

41 Young ME, Nosek MA, Howland C, Chanpong G, Rintala DH. Prevalence of abuse of women with physical disabilities. *Archives of Physical Medicine & Rehabilitation* 1997;78(12 Suppl 5):S34–8.

42 Stromsness MM. Sexually abused women with mental retardation: hidden victims, absent resources. *Women & Therapy* 1993;14(3–4):139–52.

43 Curry MAA, Hassouneh-Phillips D, Johnston-Silverberg A. Abuse of women with disabilities: an ecological model and review. *Violence Against Women* 2001;7(1):60–79.

44 Swedlund NP, Nosek MA. An exploratory study on the work of independent living centers to address abuse of women with disabilities. *Journal of Rehabilitation* 2000;66(4):57–64. Chang JC, Martin SL, Moracco KE, Dulli L, Scandlin D, Loucks-Sorrel MB, et al. Helping women with disabilities and domestic violence: strategies, limitations, and challenges of domestic violence programs and services. *Journal of Women’s Health* 2003;12(7):699–708. Cramer EP, Gilson SF, DePoy E. Women with disabilities and experiences of abuse. *Journal of Human Behavior in the Social Environment* 2003;7(3–4):183–199.

with physical disabilities.

- Organizations that provide such resources do not routinely collaborate with organizations that assist persons with disabilities.⁴⁵
- Frequently, health care⁴⁶ and law enforcement⁴⁷ professionals are uninformed about victimization of persons with disabilities. Thus, they may not have the specialized knowledge or skills to identify and assist these individuals when victimized.

In the field of disabilities, euphemisms are used to decriminalize offenses, as shown in this table⁴⁸ from Sobsey's book. Use of these euphemisms has diminished the significance of abuse of people with disabilities as a criminal issue.

Table 1. Glossary of euphemisms used to decriminalize offenses committed against people with disabilities

<i>Generic term</i>	<i>Term applied to people with disabilities</i>
Assault	Psychological abuse, threat
Battery	Abuse, punishment procedure, aversive treatment, physical prompting, assistance, guidance
Crime	Infraction
Criminal offense	Administrative infraction, discrimination
Homicide	Euthanasia, neglect, medical discrimination
Kidnapping	Detention
Murder	Euthanasia, neglect, assisted suicide, allowing to die
Poisoning	Chemical restraint
Police (investigating unit)	Personnel relations (investigating unit)
Rape	Abuse, professional misconduct
Sexual assault	Abuse, professional misconduct
Slavery	Exploitation of labor
Torture	Treatment
Unlawful imprisonment	Detention, restraint, seclusion

The less-severe terminology may be intended to make criminal prosecution more successful by reducing the burden of proof -- and thus to reduce the risk of abusers being hired to perform services for people with disabilities. Through the Department of Human Services, Minnesota has an Abuse Registry that is used by agencies that are hiring staff.

45 Curry, op. cit., Swedlund, op. cit., Chang, op. cit.

46 Swedlund, op. cit., Chang, op. cit., Cramer, op. cit.

47 Department of Justice (DOJ) (US), Office of Justice Programs, Office for Victims of Crime. Working with victims of crime and disabilities. Washington (DC): Government Printing Office; 1998. OVC Bulletin No.:1. p. 1-15.

48 Sobsey, Op cit., p. xix.

Trends

- People with disabilities are living longer. As the population ages, more people develop disabilities and become vulnerable to abuse (including financial abuse) and neglect.
- More people are living in the community; but data has not shown an increase in abuse as was predicted. This may be a result of “sunshine working as the best disinfectant.” Community members can observe and be reporters.
- Trend data about levels of abuse and deaths from abuse are unknown at this time.

Vision for Change

All children and adults with disabilities from all ethnic and racial groups should live free from abuse, neglect, exploitation, injuries, and preventable deaths.

Goals

- Prevention efforts will be coordinated, focused, and sustained, and agencies will be committed to a culture of abuse prevention.
- All Minnesota communities will be more informed about abuse and neglect issues.
- Individuals with disabilities will understand what abuse is, will become stronger self-advocates, and will report any abuse.
- Families will be strengthened to reduce the risk of abuse.
- Agencies will share data to provide comprehensive knowledge about the extent of abuse, neglect, and maltreatment.
- Investigations will be timely and responsive, and the criminal justice system will prosecute crimes.
- Health care professionals will be knowledgeable about recognizing and reporting abuse, and treating/referring patients appropriately.

Recommended Strategies

Public Policy

1. Develop a statewide emphasis on abuse prevention

- Create a leadership group to plan for prevention of abuse of people with disabilities: to develop vision and ethical standards, to integrate disability concerns within other violence and abuse prevention campaigns, to sponsor conferences as appropriate, and to review existing prevention curricula for effectiveness. This group should include state agencies and nonprofit organizations that provide advocacy for persons with disabilities.
- Utilize this group to implement recommendations in this chapter.
- Encourage all agencies (including Independent Living Centers) that have direct contact with children and adults with disabilities to renew their commitment to preventing abuse.

2. Coordinate statewide data systems, measurement, and analysis

- Enhance communication and linkage among abuse reporting systems that currently exist in the following agencies: State Attorney General's office; Minnesota Department of Health Office of Health Facility Complaints and licensing/certification of long term care facilities; Minnesota Department of Education, Maltreatment of Minors Act office; Minnesota Department of Human Services Licensing division, Vulnerable Adults and Child Protection staff, Surveillance & Integrity Review Systems; Minnesota Ombudsman for Mental Health and Developmental Disabilities; Minnesota Disability Law Center; Minnesota Department of Public Safety.
- Through the leadership group cited above, coordinate data systems. They should be integrated, easy to understand, available, and transparent to the consumer; should track trends, levels, and comparisons; should identify problems and hot spots; should be useful in developing interventions; and should employ state of the art technology (web based reporting).
- Ensure that data systems use uniform definitions, standards, and protocols and make comparisons with the general populations. The systems should allow someone to track a complaint and learn what happens at each step.
- Work with data systems to ensure that abuse report forms indicate disability status to enable greater precision in analysis.
- Produce annual reports on statewide levels and trends of abuse, neglect, exploitation, injuries, and deaths. Community level report cards should also be generated and distributed.
- Urge child mortality committees to consider and act on disability issues.

3. Act on criminal justice system issues

- Seek legislation to assure that those who abuse, neglect, and maltreat people with disabilities receive the same consequences as those who commit similar crimes against people without disabilities.
- Review sentencing guidelines and make changes where appropriate.
- Seek federal legislation to create a national database of abusers to supersede state-by-state databases.
- See that abusers permanently lose professional license or certification and receive stronger sentences.
- Provide training for law enforcement, first responders, emergency room staff, and court personnel about the characteristics and needs of persons with disabilities whom they encounter.
- Provide training to enable first responders to recognize signs and symptoms of abuse.

Minnesota Department of Health

Convene a leadership group with the following responsibilities:

- Explore ways to implement recommendations in this plan.
- Compile and analyze data.
- Increase communication and coordination among systems and agencies.
- Integrate concerns of people with disabilities into existing MDH programs,

including compliance monitoring and home visiting.

- Partner with local public health agencies to increase awareness of abuse prevention and of abuse issues that may arise in their communities.

Community/Organizational/Educational

Provide information, education and training that is statewide, system-wide, and sustainable. Following are topics that should be included for various groups:

• Organizations that provide services

1. Values: A deep understanding of the theory of normalization, integration, inclusion, and self-determination.
2. Policies and Procedures: Clear reporting; ways to manage challenging behaviors without physical intervention, restraints, chemical restraint, punishment, and aversive procedures.
3. Staff: Improved working conditions, job descriptions, community integration and inclusion activities, recognition of exemplary employees.
4. Design and Organization: Fundamental belief in preventing abuse, setting standards, confronting issues, making human services humane, setting realistic expectations, and working directly with employees (unions). Victim service programs should have accessible facilities and be aware of the needs of victims who have disabilities.
5. Screening: Health care providers should ask all persons, including those with disabilities, if they have experienced abuse.

• Staff and caregivers

The following should be observed in hiring and training of staff in programs that serve people with disabilities:

1. Careful selection of employees
2. Strict screening processes for employees
3. Background checks
4. Reference checks
5. Extensive interviews
6. Codes of expected conduct
7. Orientation and training on self-determination, inclusion, and abuse prevention
8. Working conditions that do not support or cause abuse
9. Clearly understood policies and procedures for reporting and investigating abuse, including the Abuse Registry at the Minnesota Department of Human Services.⁴⁹
10. Support and treatment for those who have been abused.

⁴⁹ Abuse Registry, Minnesota Department of Human Services. http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_005710

- **Health care providers**

1. Provide pre-service training to health care providers to recognize signs and symptoms of abuse in their patients. Make curricula available through colleges of medicine, nursing, and other health care professions.

Individuals/Families

Families who are caregivers

- Provide family support, respite, parent-to-parent groups, and information and best practices on parenting. Training should include:
 1. Improving parenting skills
 2. Overcoming isolation
 3. Facilitating bonding, including father/child
 4. Supporting parental relationships
 5. Reducing substance abuse
 6. Supporting parents who have disabilities themselves
 7. Managing stress and anger
 8. Being aware of signs and symptoms of abuse
 9. Ensuring that individuals and families are in control of resources
 10. Providing assistance for those on waiting lists for waived services or other benefits
 11. Developing the capacity of crisis nurseries to serve children with medical technology needs

Individuals with disabilities (self-advocacy)

- Provide self-advocacy in all parts of Minnesota through organizations such as Centers for Independent Living, People First, and support groups. Set a goal that every individual with a disability has at least one key relationship and a circle of friends, family or unpaid staff.
- Put less emphasis on encouraging compliance, so that individuals will speak up. Every Minnesotan with a disability should be able to request an individual interview to discuss quality issues.
- Create mechanisms for anonymous reporting of abuse, such as hot lines. People should be promptly surveyed to determine satisfaction with services that handle complaints or concerns.
- Provide means of communication for individuals who have limited verbal skills and thus are especially vulnerable
- See that no single agency has 24-hour control over a person's life.
- Give individuals the means to choose provider, staff, and where to live and work.
- Permit every student with a disability and all school personnel to participate in abuse prevention curricula. Self-advocacy training and education should include the following areas:
 1. Personal safety skills
 2. Individual rights
 3. Assertiveness and self esteem; understanding that abuse is not acceptable

4. Self-advocacy skills
5. Communications skills
6. Social skills
7. Sex education
8. Self defense
9. Dealing with bullying
10. Transition and futures planning

Resources

American Academy of Pediatrics, Maltreatment of children with disabilities

<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;108/2/508>

Council on Crime and Justice Researching Sexual Violence Project (RSVP) has published Participatory Approaches to Research: Understanding Sexual Violence in the Deaf Community

<http://www.crimeandjustice.org/Pages/Publications/Reports/RSVP.PAR.Final.pdf>

Center for Research on Women with Disabilities (CROWD), Baylor University

<http://www.bcm.edu/crowd/?PMID=0>

International Center on Abuse and Disabilities, Alberta, Canada

<http://www.ualberta.ca/~jpdasddc/abuse/ICAD/ICAD-faq.html>

Newspaper exposes (file maintained by Minnesota Governor's Council on Developmental Disabilities)

Minnesota Attorney General's Office, Medicaid fraud

<http://www.ag.state.mn.us/Default.asp>

Minnesota Center on Violence and Abuse (MnCAVA), University of Minnesota

– Web page from MnCAVA's library on violence and disability <http://www.mincava.umn.edu/library/disability/>

Minnesota Department of Education, School maltreatment incidents.

Minnesota Department of Health, Office of Health Care Facilities (Nursing Home Inspectors)

<http://www.health.state.mn.us/divs/fpc/fpc.html>

Minnesota Department of Human Services, Disability Policy Division: Licensing data.

Minnesota Network on Abuse in Later Life www.mnall.org

Minnesota State University, Mankato. *Shadow Victims*, a training curriculum for law enforcement about disabilities. Not available online.

National Clearinghouse on Family Violence, Public Health Agency of Canada

http://www.phac-aspc.gc.ca/nfv-cnivf/familyviolence/pdfs/2005femdisabl_e.pdf

Ombudsman for Mental Health and Developmental Disabilities, Abuse reports.

<http://www.ombudmhm.state.mn.us/advisory/default.htm>

Victims of Crime with Disabilities Resource Guide.

<http://wind.uwyo.edu/resourceguide/>

Comprehensive collection of information and resources on ending crimes against people with disabilities. The web site includes an extensive resources database, a bibliography of books and articles, current news and updates, a searchable calendar of events, information on funding opportunities, and online discussions.

World Institute on Disability

<http://www.wid.org/>

Web sites of organizations represented on the Abuse Prevention Subgroup

Minnesota Children with Special Health Needs

<http://www.health.state.mn.us/divs/fh/mcshn/mcshn.html>

Minnesota Department of Human Services, Disability Policy

http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=Disabilities

Minnesota Disability Law Center

<http://www.mndlc.org/>

Minnesota Governor's Council on Developmental Disabilities

<http://www.mncdd.org/>

Minnesota Indian Affairs Council

<http://www.mniac.org/>

Minnesota Ombudsman for Mental Health and Developmental Disabilities

<http://www.ombudmhm.state.mn.us/advisory/default.htm>

Chapter 5: Employment

Contributors to this chapter:

Chair: Gail Lundeen, Minnesota Department of Employment and Economic Development.

Members: Nadia Facey, Minnesota State Council on Disability; John Schatzlein, Minnesota Spinal Cord Injury Resources Network; Walter Waranka; Lifetrack Resources; Colleen Wieck, Minnesota Governor's Council on Developmental Disabilities.

Statements of the Problem and Recommended Strategies are based on discussions by the Employment Subgroup of their personal experiences and their knowledge of issues faced by other Minnesotans with disabilities. Citations are provided for proven or promising interventions.

Statement of the Problem

Employment and good health are closely linked. Employment, through health insurance, is for many the door to health care. In addition, employment in our culture is connected to a person's identity and provides socialization, friendships, and natural support.

Without health insurance, we have limited access to preventive or primary care. Without such care, both physical and mental health can deteriorate. Additionally, unemployment fosters poverty, which can result in poorer nutrition, lower levels of education, substandard housing, lack of transportation, dependency on public programs and, ultimately, further declining health. All of these circumstances lead to a lower employment rate for people with disabilities, and therefore, lack of available health insurance.

Here are a few statistics that underscore the problem for people with disabilities:

1. Nationally, Minnesota has the tenth highest workforce participation rate for people with disabilities, and the ranking has slipped in recent years. Cornell University's *2005 Disability Status Report : Minnesota*⁵⁰ indicates that 45 percent of Minnesotans with disabilities are employed, compared with 84 percent of working age people without disabilities, a 39 percentage-point discrepancy. This discrepancy is increasing.
2. The 45 percent employment rate for people with disabilities does not paint a complete picture. Only 26 percent of working-age people with disabilities work full time, compared to a full-time employment rate of 59 percent for Minnesotans without disabilities.³⁰
3. The 2004 National Organization on Disability/Harris Poll⁵¹ indicates that 63 percent of people with disabilities who do not have jobs would like to be working.
4. In 2005, the poverty rate of working-age Minnesotans with disabilities was 21 percent, compared to 6 percent for working-age people without disabilities, according to the Cornell report.³⁰

50 2005 Disability Status Reports: Minnesota. Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC), Cornell University. www.DisabilityStatistics.org

51 2004 National Organization on Disability/Harris Poll, reported in The Source, WorkSource Corporate Communications, http://www.enebuilder.net/worksource/e_article000478771.cfm?x=b11,0,w

Here are a few of the barriers to employment:

- **Complexity of the public support system.** The system of government supports is complex, difficult to navigate, and requires people to be in poverty to qualify. Financial benefits are sharply reduced as people earn income, so the system discourages employment.
- **Fears and misunderstandings.** Employers may fear that the worker with a disability will cost more and not be able to do the job. Employees may fear that they will lose public benefits and health care, as their income increases.
- **Low expectations.** Historically, schools, parents, and employers have had low expectations for young people with disabilities as potential employees. If young people are not aware of positions in which they can succeed, or have not had good school-to-work transition services, they become underemployed.
- **Lack of transportation.** Transportation is a major barrier to employment. The quality and availability of specialized paratransit services vary widely around the state. Currently, seven Minnesota counties offer no public transportation. Only eight counties have developed localized transportation options for people with disabilities.
- **Hidden disabilities issues.** People with mental illnesses or traumatic brain injuries have particular issues related to employment because of the cyclical nature of their disabilities. They may need to come back to work slowly and perhaps not at their previous level. They may need to depend on public health care programs because private programs often do not provide adequate coverage. People with other hidden disabilities also face issues in seeking and maintaining employment.
- **Inadequate career counseling.** Job counseling in schools and employment agencies does not always offer genuine consumer choice in a holistic approach -- looking at ways an individual can make a contribution that is meaningful to him or her. The options presented may be limited to rather stereotypical positions that often are filled by people with disabilities.
- **Inadequate assistive technology (AT).** AT is any item, piece of equipment, or product system, that can increase, maintain, or improve functional capabilities of individuals with disabilities. People with disabilities who are unemployed are less likely to have access to AT. Many employers believe that funding is a barrier for supplying AT, though data from the Job Accommodations Network shows that actual costs are minimal.⁵² Lack of AT can have a direct impact on employee independence, productivity, ability to perform tasks, and ability to effectively communicate in the workplace.

⁵² Job Accommodations Network, www.jan.wvu.edu

Trends

- Worker shortages and the aging workforce (including workers with disabilities) will create opportunities to employ additional people with disabilities.
- Skill levels of young people with disabilities are increasing, creating a more qualified workforce. The U. S. Department of Education found that between 1987 and 2003 the school completion rate of youth with disabilities increased by 17 percentage points. Youth with disabilities doubled their participation in post-secondary education in the same period of time.⁵³
- Because more graduating students with disabilities have been included in regular classes for much of their school career, they and their parents have higher expectations about career potential.
- However, the amount of career and technical education provided in Minnesota's schools has decreased. Minnesota's student-to-counselor ratio has risen to 806:1, according to the American School Counselors Association.⁵⁴
- Poverty is increasing for people with disabilities. National data show that in 1989, 27 percent of working-age adults with disabilities lived in households with incomes below the poverty line. In 2000, despite the nation's healthy economic expansion, working-age adults with disabilities actually had a higher poverty rate – 28.5 percent. In contrast, the poverty rate for working-age adults without disabilities fell over the same period, from 9.0 percent to 8.1 percent.⁵⁵
- Funding for vocational rehabilitation services has not kept up with the increasing demand, so counseling and placement services are less available. The demand is fueled by the 21,000 Minnesotans who joined SSDI rolls between 2000 and 2004.⁵⁶

• In Minnesota, the poverty rate of working age people with disabilities increased from 18 percent in 2003 to 21 percent in 2005, according to *2005 Disability Status Reports: Minnesota*, Cornell University.¹

Goals

- Society will understand that all people with disabilities can work, and that needed supports or accommodations should be supplied. This belief will be held by people with disabilities, their families and friends, educators, staff who support them, and employers.
- The gap between employment rates of people with and without disabilities will be reduced.
- All people will have adequate health insurance that is not tied to employment.
- People with disabilities will choose their own career paths based on their strengths, capacities, and interests. (Pathways To Employment)

53 Office of Special Education Programs, U.S. Department of Education: National Longitudinal Transition Study, June 2000.

54 As quoted in *2006 Policy Advisory*, Governor's Workforce Development Council, <http://www.gwdc.org>

55 Stapleton, D.C., Burkhauser, R.V., and Houtenville, A.J., *Has the Employment Rate of People with Disabilities Declined? Policy Brief*, December 2004, Cornell University <http://digitalcommons.ilr.cornell.edu/edicollect/92/>

56 Communication with Social Security Administration, January 2005.

- People with disabilities will be able to be competitively employed, in the same environments as everyone else, with full accessibility
- Employers will offer the same opportunities for training, coaching, and advancement to employees with and without disabilities.
- Eligibility requirements for government benefits will be changed to focus on a person's ability to do the functions of the job and life's tasks, not on their employment incapacity.

Recommended Strategies

Public Policy

- Promote appointment of a statewide employment ombudsman to help people with disabilities resolve employment problems, both public and private. This office might be part of state government but independent of agencies that provide employment services.
 - Fund Minnesota's Vocational Rehabilitation program at a level to serve all people who desire vocational counseling and support. Improve assistance for people to obtain employment, as well as the longer-term support programs.
 - Promote greater use of Medical Assistance for Employment of People with Disabilities (MAEPD). Make recommendations for increasing its effectiveness as a health insurance option for people with disabilities who are working.
 - Promote and expand use of other work incentive programs such as Ticket To Work, Work Incentives Connection (Benefits Planning and Outcomes), Plan to Achieve Self-Sufficiency, and Impairment-Related Work Experience. Ensure that participation in these programs does not create financial disincentives.
 - Base eligibility requirements for government benefits on a person's ability to perform life tasks; currently, a person must first prove he/she *cannot* work to receive services.
- Work through the Minnesota Department of Employee Relations to assure that all state agencies become models for employment of people with disabilities, including hiring numbers of employees with disabilities that are appropriate to the size of the agencies.
- Prioritize resources from waivers and other programs to assure that employees with disabilities, including those who experience disability after employment, receive needed employment support and accommodations. Ensure that people with hidden disabilities, such as traumatic brain injury and depression, are accommodated.
 - Study transportation as an issue of access to employment. Adopt transportation recommendations in the Access chapter of this plan.
 - Call for an enhanced and flexible funding stream for various options including job coaching, day training and habilitation, and supported employment services, so that people with disabilities will have support that is appropriate to their needs.
 - Ensure that the employment requirements of the Americans with Disabilities Act are enforced, as well as the Olmstead Act, which sets standards for providing services in the most integrated community setting.

Minnesota Department of Health

- Assure that the MDH is a model employer for hiring and supporting people with disabilities.
- Convene a Minnesota Disability Data Conference. To advance collaboration, the conference should seek to develop common definitions and data sets.
- Publish an annual fact sheet or report on Minnesotans with disabilities: health status, health insurance coverage, access to health care, full- and part-time employment, poverty rates, and high school completion. The information should address the impact of these factors on people with disabilities who are from various cultural and ethnic groups.
- Work with managed care leadership (MDH) and with private insurance leadership (Minnesota Department of Commerce), to seek equity in insurance coverage.
- Explore the value of “minute clinics” as an option to provide care for people with no health insurance or inadequate coverage and thus reduce reliance on emergency rooms.
- Work with health plans to ensure that health care providers are reimbursed for counseling families of children with disabilities about their children’s potential to fully participate in the community, including meaningful work.

Community/Organizational/Educational

- To further the vision of a society in which all people with disabilities can work, enhance education about the employment of people with disabilities:
 - extensive public education campaign on disability employment, similar to anti-smoking campaigns,
 - pre-service training for educators on the employment potential of young people with disabilities,
 - business school curriculum on the employment potential of people with disabilities.
- Collaborate among agencies to increase children’s and young people’s preparation for entering job market and post-secondary education. This can be done by ensuring that transition supports are available to all students who need them (adapted from Cornell²⁹), by encouraging school districts to begin transition program in earlier grade levels (even preschool), and by forming partnerships with businesses to create internships, mentorships, work-based learning, and apprenticeships (Governor’s Workforce Development Commission⁵⁷).
- Form partnerships with businesses and employers to learn from them what barriers exist to employment of people with disabilities. Address employers’ concerns that hiring people with disabilities may have an effect on their health insurance policies. Educate them about the potential of employees with disabilities.
- Support the work of community networks such as the Business Leadership Network, local Chambers of Commerce, the Business Partnership, and the Itasca Group to increase involvement in hiring people with disabilities. This might include training events, mentorship and internship programs, and cooperation with Mayors’ Committees on Disability (adapted from Pathways To Employment recommendations).

57 2006 Policy Advisory, Governor’s Workforce Development Council, <http://www.gwdc.org>

- Measure the effect of health insurance on the health of people with disabilities. Identify strategies to prevent health insurers from refusing to insure people with disabilities.
- Prioritize resources to insure that all Minnesotans with disabilities, including those who experience disability after employment, receive needed accommodations.

Individual/Family

- Inform parents of opportunities and resources that will be available for their children as they prepare for and enter the workforce.
 - Encourage families to advocate with their employers for appropriate health care coverage.
 - Inform individuals and families about the effects of employment on benefit coverage.
 - Encourage families of varied cultural and ethnic groups to recognize that their relatives with disabilities can work and are entitled to benefits.
- Encourage consumer choice in planning, so people select employment or volunteer activities based on their interests and abilities.

Primary Resources Used in Developing This Chapter

1. *Dismantling the Poverty Trap: Disability Policy for the 21st Century*. Policy Brief. Stapleton, C.C., Livermore, G.A., O'Day, B., Imparato, A.J., Cornell University, 2005.
2. *Integrating Individuals with Disabilities into the Workforce, Final Report and Recommendation*, Community Connections Subcommittee, Governor's Workforce Development Council, May 17, 2006.
3. *2006 GWDC Policy Advisory*, Report from Governor's Workforce Development Council, 2005-06 Committees.
4. *Overview of Strategic Plan to Increase Competitive Employment of People with Disabilities, 2006-2010*, Pathways To Employment: Minnesota's Comprehensive Employment System/Medicaid Infrastructure Grant: February 2006.

Other References

- Manisses Communication Group, Inc. (2003). "NGA report urges states to develop supported employment programs." *Mental Health Weekly* 13:33, 1-3. Found at: <http://www.worksupport.com/resources/viewContent.cfm/375>
- Rising Poverty in the Midst of Plenty: The Case of Working-age People with Disabilities*. Burkhauser, R, Houtenville, A, Rovba, L., Cornell University, unpublished paper, September 2006.
- National Longitudinal Transition Study 2: Changes Over Time in the Early PostSchool Outcomes of Youth with Disabilities*. Office of Special Education Programs, U.S. Department of Education, June 2005. http://www.nlts2.org/reports/2005_06/nlts2_report_2005_06_complete.pdf

Chapter 6: Infrastructure: The Foundation for Action

Contributors to this chapter:

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What is infrastructure?

Infrastructure is the basis or foundation that enables programs and activities to develop. In this plan, we are recommending system or structural changes to ensure a stronger focus on disability and health issues. Some of these changes should occur within the Minnesota Department of Health, and others involve other state agencies, local organizations and agencies, disability organizations and services, people with disabilities and their families, and the general public.

Infrastructure can include organizational policies, the number and qualifications of staff needed to work on the issues, the funding sources, and the broader support by systems that support change. Programs that work in disability health should be visible to elected or appointed officials and to the communities that are affected. Disability health issues must be included in plans of all affected agencies and organizations.

As described by the Maternal and Child Health Bureau (MCH), Health Resources and Services Administration,⁵⁸ infrastructure can include:

- Needs assessment
- Evaluation
- Planning
- Policy development
- Coordination
- Quality assurance
- Standards development
- Monitoring
- Training
- Applied research
- Information systems
- System of care

Systems of care, according to this MCH statement, should be family centered, community based, and culturally competent. As a disability health program is developed, it is important to build in evaluation, quality assurance, and quality improvement.

⁵⁸ Maternal and Child Health Bureau, Health Research and Services Administration <http://mchb.hrsa.gov/>

What is happening now?

All the organizations that are part of the Minnesota Disability Health Program are concerned about health issues affecting people with disabilities. For some, health concerns are part of their charge. The planning grant has brought together partners who have expressed common needs and are now in direct communication on these issues. Implementation of this plan will assure that their work will bear fruit.

What organizations and agencies need to be involved?

Changes recommended in this chapter will yield a stronger focus on disability health issues across several state agencies and statewide organizations as they collaborate on addressing these issues. Health promotion and the prevention of secondary conditions affect people with all disabilities, including those represented directly by Advisory Work Group members and indirectly by the coalitions in which they participate. Through the regional and local partners of these many agencies and grassroots organizations, people throughout the state will benefit from this collaboration. As work progresses, physicians, other health professionals, county case managers, and others are likely to be involved.

What are the best ways to ensure that services and systems meet people's needs?

Many of the organizations that are part of the Advisory Work Group conduct periodic health care needs assessments of persons with disabilities, asking their input on health-related issues. Additionally, a number of national surveys such as the Behavioral Risk Factor Surveillance Survey and the American Community Survey report on Minnesotans with disabilities. The Minnesota Student Survey is an excellent resource. As data are collected and analyzed, needs and gaps become evident, and other interventions will be recommended. A statewide disability data conference is being planned, and reports and data briefs on disability in Minnesota will be developed.

How might disability health work be coordinated?

The implementation grant application to CDC seeks staff positions across agencies and organizations to carry out the recommendations in this plan and to expand future efforts in health promotion and prevention of secondary conditions. Regardless of funding, an advisory committee representing Minnesotans with a range of disabilities will continue to provide advice to the effort and to encourage continuing work throughout the disability community.

The following are suggested roles and responsibilities of the disability health program:

1. Develop policy initiatives, in cooperation with a cross-agency advisory committee.
2. Evaluate the initiatives as they are implemented.
3. Coordinate and deliver training on issues identified as priorities in this plan, such as abuse, mental health, employment, and access.
4. Coordinate data collection and reporting across the disability community. For policy change to occur, people who disseminate data and those who use it need to be in close communication. Key decision makers, advocates, news media, and others need to be informed and aware of disability data.

What system or structural changes might need to be made to ensure continuity?

Within the Minnesota Department of Health (MDH), disability health programs need to be coordinated. Because disability health issues affect many units and divisions, the precise organizational location of the core programs within MDH has not yet been determined. Current relationships with chronic health programs within MDH need to be expanded, and other parts of the MDH need to relate more strongly to the philosophy of consumer choice and consumer-directed services, as referenced throughout this plan. In addition to the core coordinating staff, a position focusing on transition of children and youth with disabilities to adult health services might be located within the MDH Minnesota Children with Special Health Needs. Transition planning has been a focus of several Minnesota programs concerned with education and employment, but to date there has been little training on transition to the adult health care system. The importance of this intervention is pointed out in the CDC document *Disability and Health in 2005: Promoting the Health and Well-Being of People with Disabilities*.⁵⁹

Other programs of MDH also are stakeholders in disability health: within the Center for Health Promotion, interest has been expressed by programs that focus on diabetes, arthritis and aging, heart disease and stroke, obesity, nutrition, physical activity, and chemical health. The Genomics program, housed in a different division, has reviewed this plan and made major contributions to it. The MDH also has a Health Economics Program and a Managed Care Program that would be instrumental in the implementation work.

Beyond MDH, several other Minnesota state agencies and the University of Minnesota have major disability responsibilities that relate to this plan. To increase communication and collaboration, it is suggested that staff efforts should focus on disability health within these agencies.

- The Minnesota State Council on Disability (MSCOD) can provide the disability perspective and knowledge. It partners with the Consortium on Citizens with Disabilities, a grassroots coalition that can lobby for disability issues such as health care reform. A Committee on Health Care is interested in working on recommendations in this plan. MSCOD has a focus on building ADA resources and promoting ADA enforcement. Through its town hall meetings, MSCOD provides regular informational forums with local and regional consumers and agency staff to learn about needs and issues in the disability community. Support from the Disability Health Program would intensify and improve the Council's work on health issues affecting people with disabilities. MSCOD currently has a staff member with some focus on health policy issues.
- The Minnesota Department of Human Services (DHS) can provide data from Medicaid claims that relate to the services being provided to people with disabilities. An effort has begun to analyze this data with short-term funding and needs to be continued.
- Pathways to Employment is Minnesota's Medicaid infrastructure initiative for competitive employment. It is funded through a grant to the Minnesota

⁵⁹ *Disability and Health in 2005: Promoting the Health and Well-Being of People with Disabilities*, Centers for Disease Control and Prevention

http://0-www.cdc.gov.mill1.sjlibrary.org/ncbddd/factsheets/Disability_Health_AtAGlance.pdf

Department of Human Services from the Centers for Medicaid and Medicare Services; partners are the MSCOD, DHS, and the Minnesota Department of Employment and Economic Development. Its mission is to increase competitive employment of people with disabilities by bringing together people with disabilities, employers, businesses, government and providers. Pathways should be closely involved with the MDH disability health initiative; such a tie-in would help accomplish the objectives in the Employment chapter of this plan.

- The University of Minnesota's Institute on Community Integration can take a role in health issues for people with all disabilities, through its expertise in training professionals, conducting research, and evaluating programs. The Institute has already provided consultation to the planning process. Further activities might be carried out through contracts.

Other organizations and agencies also have important roles in implementing this plan:

- Since medical education is a priority recommendation throughout the plan, university-level programs that educate physicians, nurses, and other health care personnel will have an integral role in both pre-service and in-service education on disability issues.
- Licensure agencies will be involved in developing requirements for continuing education of health professionals.
- This plan requires close work with, and actions by, health maintenance organizations, health care facilities, and insurance companies. Through connections with MDH and other participating organizations, the health care and public health community will discuss and implement specific recommendations in the plan.
- Local public health agencies, which have ongoing working relationships with health care providers in their communities, can convene and coordinate local activities.

What policy changes might be needed?

Each section of this plan – access, mental health, abuse prevention, and employment – contains recommendations for policy change. Many of these changes can be made at the administrative level, often with little or no cost. It is expected that the project's Advisory Committee will advise disability health staff on ways to achieve recommended changes and provide advocacy assistance when appropriate. Some of the recommendations involve legislative changes. In those cases, the program will work through the strong existing disability advocacy community, which is organized in many coalitions for advocacy and other common purposes. Examples include PACER Center, a coalition of 18 disability organizations for special education advocacy, and the Minnesota Consortium for Citizens with Disabilities, a coalition of more than 100 organizations that focus on legislation and policy issues.

What funding sources are needed?

Initial implementation activities are expected to be funded by the Centers for Disease Control and Prevention (CDC).

Depending on the resources available, some of these efforts may be funded by federal or state grants, some by contracts or interagency agreements, some by foundations or businesses, and others by realignment of priorities.

We recognize that many of the strategies in this plan are long-range and will require significant funding beyond the implementation grant. It is already clear that the organizations and agencies involved in developing the plan are committed to making its goals a reality, working individually and together, through a variety of means. Stable funding will be sought from the Minnesota Legislature, from additional federal resources, and from foundations, health plans, businesses, and business networks.

What is a reasonable timeline for accomplishing these recommendations?

Implementation funds from CDC are expected to support action for the next five years. Many of the plan's recommendations, however, go beyond the scope of the implementation grant and will be discussed and implemented over a longer period of time. These needs, identified by the disability community through the Advisory Work Group, are broad-based and deal with root causes of problems.

Some of the recommendations point toward making long-term systemic changes: examples include improving access to health care services, coordinating and analyzing disability data, preventing abuse, changing licensing requirements, and resolving employment and transportation issues. Ending exclusion is a vision that needs systematic attention.

The implementation of this plan embodies a different way of thinking for Minnesota. We recognize that there will be costs, but the cost of doing nothing is not acceptable. As the plan is implemented, people with disabilities will experience better health and many secondary conditions will be reduced or prevented. Through a stable, carefully planned infrastructure, we can achieve these goals.

Appendix A

Fact Sheet, Minnesota

Disability Health Project

Minnesota Disability Health Project

What is it?

The Minnesota Disability Health Project is a collaborative effort to promote the health of people with disabilities and to prevent secondary conditions:

Who funds it?

The Minnesota Department of Health's Injury and Violence Prevention Unit in April 2005 received a planning grant from the Centers for Disease Control and Prevention (CDC), Division on Birth Defects and Developmental Disabilities. The group listed below is developing a plan and recommending activities.

Who participates?

An Advisory Work Group represents agencies and organizations that work with people with disabilities. Current members are:

- The Arc of Minnesota
- Brain Injury Association of Minnesota
- Council on Black Minnesotans
- Courage Center
- Gillette Lifetime Specialty Healthcare
- Healthy and Ready To Work
- Lifetrack Resources
- Mental Health/Developmental Disabilities Ombudsman Office
- Minnesota Department of Employment and Economic Development
- Minnesota Department of Health
 - Executive Office
 - Injury and Violence Prevention Unit
 - Minnesota Children with Special Health Needs
 - Office of Minority and Multicultural Health
- Minnesota Department of Human Services, Disability Services
- Minnesota Disability Law Center
- Minnesota Governor's Council on Developmental Disabilities
- Minnesota Indian Affairs Council
- Minnesota Spinal Cord Injury Resources Network
- Minnesota State Council on Disability
- National Association for the Mentally Ill, Minnesota Chapter
- PACER Center
- Southwest Minnesota Center for Independent Living
- University of Minnesota Institute on Community Integration

In addition to developing a long-range plan, the project also will analyze Minnesota data on prevalence of disabilities. The American Association on Health and Disability, www.aahd.us and the CDC provide technical assistance.

Want to be involved, or get further information?

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Appendix B

Advisory Work Group Roster

Roster

Minnesota Disability Health Project, Advisory Work Group

As of May 2007 * **Bold:** Executive Committee

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Appendix C

Definitions of Disability

Definitions of Disability

How does one define disability? The answers are complex. The following citation summarizes recent research on the conceptual framework of disability.

Research on Definitions of Disability from The National Institute on Disability and Rehabilitation Research (NIDRR)¹

In recent years a number of efforts to develop conceptual frameworks to organize information about disability have been initiated.

Prevailing definitions, based in statute and supporting program authorities, clearly do not reflect new paradigm concepts of disability. Nearly all definitions identify an individual as disabled based on a physical or mental impairment that limits the person's ability to perform an important activity. Note that the complementary possibility--that the individual is limited by a barrier in society or the environment--is never considered. . . .

It is useful to regard an individual with a disability as a person who requires an accommodation or intervention rather than as a person with a condition or impairment. This new approach derives from the interaction between personal variables and environmental conditions. Because accommodations can address person-centered factors as well as socio-environmental factors, a "need for accommodation" is a more adaptable concept for the new paradigm. The various definitions of disability that have formed the basis for both program eligibility and survey data collection Among these efforts are:

(1) The International Classification of Impairments, Disabilities, and Handicaps, which was developed in 1980 by the World Health Organization The ICIDH is a manual issued by the WHO in 1980 as a tool for the classification of the consequences of disease, injury, and disorder, and for analysis of health-related issues. The ICIDH was designed to provide a framework to organize information about the consequences of disease. An ongoing revision process is considering social, behavioral, and environmental factors to refine the concept of "handicap." "Classifications of diseases fail to capture the variety of experiences of people who live with health conditions, and the ICIDH was designed to fill that gap," says the WHO.

The 2001 revision, called the **International Classification of Functioning, Disability and Health**, or ICF, goes further, classifying functioning at both the level of body/body part, whole person, and whole person in social context. (More on the ICF from the World Health Organization's website at <http://www.who.int/icidh/>; a good introduction is available at <http://www.who.int/icidh/brochure/content.htm>.)

(2) The "Nagi model": The Institute of Medicine in 1997 stated that disability is a function of the interaction of individuals with the social and physical environments. The revised "Nagi model" (From "Disability Concepts Revisited: Implications for Prevention," by S.Z. Nagi, which was presented by the Institute of Medicine in its 1991 Disability in America report (Disability in America: Toward A National Agenda for Prevention by

¹ Research on Definitions of Disability from NIDRR, <http://www.accessiblesociety.org/topics/demographics-identity/nidrr-lrp-defs.htm>

A.M. Pope and A.R. Tarlov (Eds.), 1991, Washington, DC: National Academy Press) describes the environment as including the natural environment, the built environment, culture, the economic system, the political system, and psychological factors. The new model includes a state of “no disabling condition.”

The state of disability is not included in this model because disability is not viewed as inherent in the person, but rather as a function of the interaction of the individual and the environment

(3) The schematic adopted by the National Center for Medical Rehabilitation Research (NCMRR) in its Research Plan (1993, p. 33) added the concept of societal limitation.

None of these, though, has explanatory power for research purposes.

Such frameworks gradually are becoming part of definitions used in various programs. But achieving uniformity is a huge task. Federal Statutory Definitions of Disability² lists 66 different disability definitions used by various federal agencies, covering civil rights, education, employment, housing, Internal Revenue code, Social Security, social services, veterans and Armed Forces, and “miscellaneous.” Here are two that have general usage.

Americans With Disabilities Act of 1990³

The term “disability” means, with respect to an individual:

- a physical or mental impairment that substantially limits one or more of the major life activities of such individual,
- a record of such an impairment, or
- being regarded as having such an impairment.

For a fuller description, see website cited below.

Rehabilitation Act of 1973⁴

This Act contains the following definition of an individual with a disability, used for employment purposes:

Except as otherwise provided in subparagraph (B), the term “individual with a disability” means any individual who

- (i) has a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment; and
- (ii) can benefit in terms of an employment outcome from vocational rehabilitation services provided pursuant to subchapter I, III, or VI of this chapter.

To help employers understand what constitutes a disability and what their responsibilities might be, Cornell University prepared a paper called *Definition of Disability Under the ADA: A Practical Overview and Update*.⁵ It defines “life activity,” “substantial limits,” “mitigating measures,” and other employment concepts within ADA.

² Federal Definitions of Disability, <http://www.icdr.us/documents/definitions.htm>

³ Americans with Disabilities Act, <http://www.usdoj.gov/crt/ada/adahom1.htm>

⁴ Rehabilitation Act of 1973, <http://www.eeoc.gov/policy/rehab.html>

⁵ *Definition of Disability Under the ADA: A Practical Overview and Update, September 2000* <http://digitalcommons.ilr.cornell.edu/edicollect/30/>

Appendix D
Selected Assessments of Minnesotans on
Disability Health Issues

Selected Assessments of Minnesotans on Disability Health Issues

MN Governor's Council on Developmental Disabilities	
Group assessed	Findings/Implications
<p>1. Providers of services to people with developmental disabilities (part of research report for 5-year plan) - 2005</p>	<p>Top priorities for improvements in next 5 years in services for people with disabilities:</p> <ol style="list-style-type: none"> (1) employment-related activities, (2) health-related activities, (3) self-advocacy activities <p>Within Health (2), the providers felt there are committed health care providers and that good care is available in Minnesota, though it's not always accessible. Areas for improvement most often mentioned:</p> <ul style="list-style-type: none"> More physicians should accept patients who have Medical Assistance coverage. Better, simpler insurance coverage is needed. Transportation is difficult and costly. Physicians need training about developmental disabilities. More prevention is needed. Providers need to communicate better among themselves. Too many benefits have been cut. <p>Also mentioned:</p> <ul style="list-style-type: none"> Low-cost insurance is needed. Persons are needed to accompany clients to appointments and help with paperwork. More waived (non-institutional) services are needed. <p>Themes: (1) need to improve awareness of issues affecting people with developmental disabilities, (2) funding cuts are impacting programs, (3) need better coordination of services and communication among providers</p>
<p>2. Individuals with developmental disabilities (5-yr. plan needs assessment): issues people will face in coming years - 2005</p>	<p>Most critical issues (in order):</p> <ul style="list-style-type: none"> Financial Access to services (recreation transportation, etc.) Access to health care <ul style="list-style-type: none"> quality, appropriate health care affordable health care medications therapies Employment
Town Meetings: Citizens Forum on Health Care Costs	
<p>General population, attendees at 12 regional 2003 Town Hall meetings conducted by Sen. Durenberger's Citizens Forum on Health Care Costs - 2003</p>	<p>Make prevention a stronger priority (insurance companies should support it). Prevention education should focus on:</p> <ul style="list-style-type: none"> • patient literacy • diet, exercise, smoking • dental care <p>Cover evidence-based alternative medicine. Improve coordination of services.</p> <p>Universal coverage is needed:</p> <ul style="list-style-type: none"> • a basic tier of services should be public, others should be private. • There should be a pool for public employees, or all employees, but insurance shouldn't be based on employment. <p>Rural access: use new technology to get care to patients. Consumer-directed health care saves money. Parents of children with disabilities have experienced unfair increases in parent fees. Maintain/improve the Disability Health Option; provides more appropriate treatment, coverage. Expand mental health services.</p>

MN Children with Special Health Needs (MCSHN)	
Group assessed	Findings/Implications
Minnesota students: 6 th , 9 th , 12 th grades through Minnesota Student Survey, 2004. MCSHN analyzed responses by students who self-identified as having "mental or physical condition of other health problem that has lasted at least 12 months."	<p>Compared with their healthy peers, students with disabilities/health problems reported feeling significantly more stress or pressure, felt more discouraged or hopeless, were more likely to have tried to kill themselves, were more likely to have been physically assaulted, and had greater risk for non-familial sexual abuse, and experienced more violence at school.</p> <p>MCSHN addressed mental health issues in its analysis and called for more screening for depression among this population, as well as development of strategies to reduce stress and depression.</p>
	MCSHN found that Minnesota students with special health care needs are much more likely than others to be dissatisfied with their personal lives, are less likely to feel safe at home or at school, and more frequently feel isolated. These and other disparities because of disability or health need should be addressed, much as racial and ethnic health disparities are being studied and acted upon.
	School violence/bullying -- including being hit, threatened, or insulted; having property stolen -- is a major issue for children with health needs or disabilities, leading to absences, further violence, lower self-esteem, declining grades, and lifelong problems. Many MN schools have instituted training programs, but much work remains.

National Health Information Survey –Disability	
Population survey of people who reported a person with disability in the household. (University of Minnesota Analysis, 2004)	<p>People covered by public health plans were less likely to report excellent or very good health than those in HMOs or fee for service plans. They had less access to "out of plan" coverage, less dental coverage, more doctor and hospital visits, and had more unmet health care needs.</p> <p>They are in poorer health, have poorer service outcomes, and are less satisfied with quality of service.</p> <p>People with intellectual or developmental disabilities are much more likely to be covered by public health care plans than are others (general population).</p> <p>They experience ...</p> <ul style="list-style-type: none"> .. lack of preventive care and screenings .. lack of follow-up for diseases .. unmet medical needs .. unmet mental health needs .. unmet dental health needs .. unmet prescription medication needs .. unmet equipment needs

Appendix E

Disability Health Data Brief: Demographics



Disability Health Data Brief

Demographics

2000-2004

Overview

As currently defined by the World Health Organization, disability relates to functional limitations rather than medical conditions. The US Census Bureau, however, has traditionally collected self-reported medical conditions and those results are noted in this analysis – which excludes responses by those institutionalized. Therefore, please use these data with caution, as there are concerns due to survey methodology that these data may not accurately reflect those with disability.

Disability-type definitions

Go-outside-home: Difficulty going outside the home alone to shop or visit a doctor's office (ages 16 and older) *.

Employment: Difficulty working at a job or business (ages 16 to 64) *.

Physical: Conditions that substantially limit basic physical activities (e.g., walking, climbing stairs, reaching, lifting, or carrying).

Mental: Difficulty learning, remembering or concentrating *.

Self-care: Difficulty dressing, bathing, or getting around inside the home *.

Sensory: Conditions that include blindness, deafness, or a severe vision or hearing impairment.

Yearly rate of disability

The U.S. Census Bureau's decennial Census and its yearly American Community Survey collect disability-related data from a sample of Americans. The data are then estimated to the total civilian and non-institutionalized population. Mental, physical sensory and self-care disabilities are recorded for ages 5 and older.

The age-adjusted rate of Minnesotans with disabilities declined between 2000 and 2003 but increased in 2004, the most current year of data. Age-adjusted rates are formulated using a weight based on age groupings of the U.S. population – weighting in this manner allow for comparison between states. Between 2000 and 2004, Minnesota's rate declined 15 percent, compared to a national decline of 18 percent. Despite the greater national decline, the national age-adjusted rate was still higher than Minnesota's in 2004, 16,086 compared to 13,036 per 100,000.

* Due to a self-defined physical, mental, or emotional condition lasting 6 months or more.

Highlights

- Rates of Minnesotans with disabilities increased in 2004 after decreasing from 2000 to 2003.
- Minnesotans with a disability, ages 21 and older, are most likely to have a physical limitation; while mental limitations are the dominant disability for those ages 5 to 20 – this may be due to educational assessments of school age children.
- Employment is declining for Minnesotans with disabilities.
- Between ages 5 and 15, the rate of boys with a disability is nearly twice that of girls; however, in adulthood rates are more even among males and females.

Minnesotans with disabilities, 2000-2004

Rate per 100,000



Source: U.S. Census Bureau

Prepared by: Minnesota Department of Health

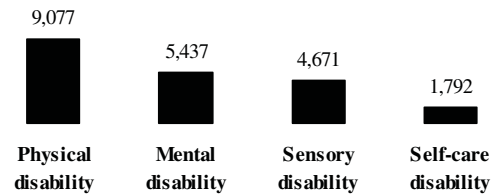
Type of disability

Minnesotans of all ages are most likely to be living with a physical than any other type of disability. This is especially true for adults 21 and older, for whom physical disability accounted for nearly half of disabilities. In the younger years, mental disability dominates, affecting three-fourths of those aged 5 to 20 with disabilities. The high mental disability rate may be attributed to school assessments related to emotional, behavioral and learning disorders, especially among young males.

Note: Go-outside-the-home and employment disabilities were not included in the above analysis due to variation in data collection methodology between 2002 and 2003.

Minnesotans with disabilities, type of disability, 2000-2004

Age-adjusted rate per 100,000



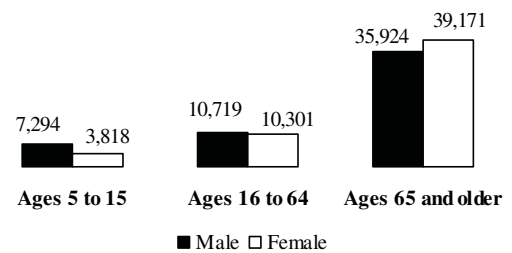
Source: U.S. Census Bureau
Prepared by: Minnesota Department of Health

Males and females by age group

Males and females have a similar age-adjusted rate of disability – 13,555 and 13,111 per 100,000, respectively. Young males, ages 5 to 15, are nearly twice as likely to have a disability than young females. Between ages 16 and 64, rates are very similar, but by ages 65 and older, the female rate is higher, 39,171 compared to the male rate of 35,924 per 100,000.

Minnesotans with disabilities, males and females by age group, 2000-2004

Rate per 100,000



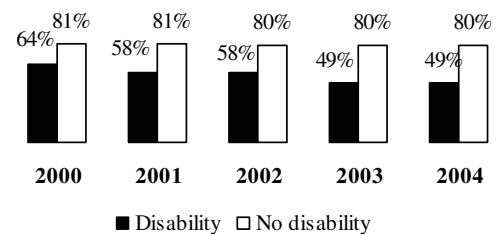
Source: U.S. Census Bureau
Prepared by: Minnesota Department of Health

Employment

The Census collects data on the employment of Americans between the ages of 16 and 64. Employment and poverty are closely related. At both the national and state level, employment among people with disabilities has been declining since the economic boom of the 1990s. Employment of Minnesotans with a disability declined 15 percentage points from 2000 to 2004.

Employed Minnesotans (ages 16-64) by disability status, 2000-2004

Percent



Source: U.S. Census Bureau
Prepared by: Minnesota Department of Health

If you require this document in another format, such as large print, Braille or cassette tape, call 651.201.5454.

Disability Health Data Brief: Demographics was prepared by: Debra Hagel, Evelyn Anderson and Mark Kinde.

Appendix F

Healthy People 2010: Disabilities and Secondary Conditions

Healthy People is a national 10-year plan intended to encourage and guide federal, state, local, private, and community health promotion and wellness activities and policies to improve the health of Americans. The U.S. Department of Health and Human Services reformulates this plan every 10 years, in coordination with other public health agencies and partners. The plan for 2010 is available at www.health.gov/healthypeople. Two major HP2010 goals are to increase quality and years of healthy life, and eliminate disparities. People with disabilities are included throughout HP2010 as well as in Chapter 6 which contains 13 objectives:

- 6-1 Include in the core of HP2010 surveillance tools a standard set of questions that identify people with disabilities.
- 6-2 Reduce the proportion of youth with disabilities who are reportedly sad, unhappy, or depressed.
- 6-3 Reduce the proportion of adults with disabilities who report feelings, such as sadness, unhappiness, or depression, that prevent them from being active.
- 6-4 Increase the proportion of adults with disabilities who participate in social activities.
- 6-5 Increase the proportion of adults with disabilities who report having sufficient emotional support.
- 6-6 Increase the proportion of adults with disabilities who report satisfaction with life.
- 6-7 Reduce the number of people with disabilities living in congregate care facilities, to achieve a permanent living arrangement that permits lifestyle choices e.g. caregiver.
- 6-8 Eliminate employment rate disparities between working-aged (18 to 62 years) adults with and without disabilities.
- 6-9 Increase the proportion of children and youth 6 to 21 years old with disabilities who spend at least 80% of their time in regular education programs.
- 6-10 Increase the proportion of people with disabilities who report having access to health, wellness, and treatment programs and facilities.
- 6-11 Reduce the proportion of people with disabilities who report not having the assistive devices and technology they need.
- 6-12 Reduce the proportion of people with disabilities who report encountering environmental barriers to participating in home, school, work, or community activities.
- 6-13 Increase the number of states and tribes that have public health surveillance and health promotion programs for people with disabilities and their caregivers.

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