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Illinois Department of Public Health

Illinois Disability and Health Action Plan 2012-2017

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To learn more about the Illinois Disability and Health Program, or to receive the report in accessible formats, contact the Illinois Department of Public Health, Disability and Health Program, at 217-557-2939, TTY 800-547-0466.

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Acronym List

CDC	U.S. Centers for Disease Control and Prevention
CDSMP	Chronic Disease Self-Management Program
CILs	Centers for Independent Living
Department	Illinois Department of Public Health
ICBRFS	Illinois County Behavioral Risk Factor Survey
ILBRFSS	Illinois Behavioral Risk Factor Surveillance System
INCIL	Illinois Network of Centers for Independent Living
NCPAD	National Center on Physical Activity and Disability
SHIP	State Health Improvement Plan
SIU	Southern Illinois University
UIC	University of Illinois at Chicago
VLOGS	Video Logs

Executive Summary

One in every five Illinois adults (19.7 percent) has a disability according to the 2010 Illinois Behavioral Risk Factor Surveillance System (ILBRFSS). The number of Illinois adults with disabilities rose from 1.77 million in 2001 to 1.91 million in 2010. Although having a disability should not be equated with poor health, the health status of people with disabilities in Illinois clearly is lagging behind those without disabilities. Chronic disease rates such as asthma, diabetes, arthritis and heart disease, for example, are higher among Illinois adults with disabilities than those without disabilities.

Risk factors associated with chronic disease also are more common among Illinois adults with disability than those without disability. Illinoisans with disability exercise less often, are more likely to be obese, and are more likely to have high cholesterol and high blood pressure than those without disability.

Yet, health services are often not developed with the needs of people with disabilities in mind. People with disabilities often encounter inaccessible medical offices and equipment, transportation barriers, communication barriers, and attitudinal barriers. Consequently, people with disabilities in Illinois face an increased risk of developing additional health conditions. Health promotion programs must be developed and refined to be more inclusive for people with disabilities to ensure that they have equal access to these services. Reducing barriers and expanding access to health services and health promotion programs are critical steps in supporting the independence of people with disabilities.

Established in 2001, the Illinois Disability and Health Program is a partnership between the Illinois Department of Public Health, Office of Health Promotion, and the University of Illinois at Chicago, Department of Disability and Human Development. Since 2005, the Illinois Disability and Health Program Partnership, consisting of nearly 100 individuals representing people with disabilities and state and local organizations working in the field of disability advocacy, health promotion, public health, rehabilitation, assistive technology, recreation and other relevant fields, have come together to provide their expertise to the program. The program's mission is to develop, sustain and support activities to improve the health and quality of life and reduce the risk of chronic conditions among people with disabilities in the state. The program, with the assistance of many dedicated program partners and stakeholders, has accomplished much in the areas of health promotion, professional development and service accessibility, and surveillance of health disparities between people with and without disabilities.

This revised action plan, which guides health promotion activities targeting people with disabilities throughout the state for the next five years, is an outcome of a well-built partnership among the Illinois Disability and Health Program, its many dedicated program partners, and other stakeholders. Implementing specific interventions and activities with limited resources is challenging and no one person or group can do the needed work alone. The goals and objectives outlined here will only be achieved through the accomplishment of many partner agency's activities along with the work of the Illinois Disability and Health Program. By working together we can continue to make progress in improving the health and quality of life of people with disabilities in Illinois.

Part 1

Introduction and Background

History of the Illinois Disability and Health Project

The Office of Health Promotion, Division of Chronic Disease Prevention and Control within the Illinois Department of Public Health (Department), and the University of Illinois at Chicago (UIC), Department of Disability and Human Development, began collaborating to address secondary and chronic conditions among people with disabilities in November 2001. Partnering with the Department, UIC was funded by the U.S. Centers for Disease Control and Prevention (CDC) from April 2002 to March 2005. In March 2005, a two-year resubmission to expand efforts in Illinois was recommended for approval but not funded. The Department and UIC, however, continued to provide limited activities to strengthen the capacity for the project and to develop the infrastructure in preparation for a strong grant application in 2007.

The success of the CDC funded project during the first cycle of funding provided a solid foundation from which to expand activities. Project activities from April 2005 to March 2007 included:

1) creating and maintaining the Illinois Disability and Health Partnership (partnership), an advisory group consisting of key stakeholders in the field of public health and disability in the state;
2) developing the first population-based *Illinois Disability and Health Data Report* to more effectively profile the magnitude of disability and health disparity between people with and without disability in the state;
3) conducting focus group interviews to explore personal perspectives of Illinois' residents with disabilities regarding their access to health promotion information, barriers and facilitators affecting utilization of preventive health services, and their ability to achieve and maintain a healthy lifestyle;
4) developing the first *Illinois Disability and Health Action Plan 2007-2010* citing priorities, objectives and strategies for prevention and management of chronic conditions among Illinois' citizens with disabilities; and
5) building stronger collaborations with chronic disease prevention programs within the Department to include people with disability in the on-going state efforts.

In March 2007, the Department, with continued strong collaboration and support from UIC, applied and was funded for a five-year grant entitled "State Implementation Projects for Preventing Secondary Conditions and Promoting the Health of People with Disabilities." During the past five years, the project has continued to build capacity by maintaining the Illinois Disability and Health Partnership and by developing and maintaining three work groups to focus on specific activities in the areas of surveillance, professional education, and health promotion. A logic model was developed to guide program efforts (See Appendix A). A web page was developed and posted on the Department's website http://www.idph.state.il.us/idhp. Chronic Disease Program Integration Work Plans were developed outlining mutual goals and strategies for chronic disease programs to integrate services and activities with the Disability and Health Program to increase accessibility.

Accomplishments within the three workgroup focus areas include the following.

1) Health Promotion

- Seven health promotion fact sheets were developed targeting people with disabilities. Topics included arthritis, nutrition, diabetes, fall prevention, high blood pressure, preparing for a doctor's visit, and "What is chronic disease?" Three of the fact sheets (arthritis, nutrition, diabetes) were translated into Spanish. (Fact sheets can be downloaded at http://www.idph.state.il.us/idhp/publications.htm.)
- A *Health Promotion for People With Disabilities Guide* was developed and disseminated to more than 80 partners and 121 local health department health educators, 33 parish nurses, 30 Illinois Society for Public Health Education members, and 25 university staff who work in health education.
- A blood pressure training video was developed targeting people with disabilities and caregivers in collaboration with the Department's Cardiovascular Health Program.
- The Illinois Disability and Health Program collaborated with the University of Illinois at Chicago, College of Medicine, to offer eight classes titled "Health Promotion for People With Intellectual and Developmental Disabilities," as an elective for UIC medical students and residents. Collaborating with Seguin Services, a community-based agency providing services to people with intellectual and developmental disabilities, 19 third year medical students and six family medicine residents developed health promotion presentations/activities reaching 100 people with developmental disabilities.
- Collaborating with two local Centers for Independent Living (CILs), an Area Agency on Aging, Southern Illinois University (SIU), the state chapter of the Arthritis Foundation, and the National Center on Physical Activity and Disability (NCPAD), evidence-based and proven practice interventions were made available to people with disabilities. Interventions included the Chronic Disease Self-Management Program (CDSMP), the Arthritis Foundation Exercise Program and the NCPAD's "14-Weeks to a Healthier You" online physical activity/exercise and nutrition program. In addition to implementing the programs, four CDSMP leaders with disabilities were trained, and 93 staff of community-based developmental disability service agencies were trained to lead the "14 Weeks to a Healthier You" in-person intervention for people with intellectual/developmental disabilities.
- The Department's Chronic Disease program staff provided health promotion presentations on healthy lifestyles for disease prevention to 78 individuals with disabilities.
- The CDC's Right to Know breast cancer screening awareness campaign targeting women with disabilities was implemented in two areas, Chicago and west-central Illinois, in collaboration with the Rehabilitation Institute of Chicago and the Western Illinois Area Health Education Center.

- People with disabilities were included in the Department's H1N1 influenza prevention and control activities through the distribution of 28,000 "Cover Your Cough" and other promotional flyers and H1N1 influenza educational materials, 20,000 bottles of hand sanitizer and the offering of 35 flu shot clinics targeting people with disabilities. This project was accomplished through a collaboration between the Illinois Disability and Health Program, the Department's Division of Disaster Preparedness and Readiness, the Illinois Network of Centers for Independent Living (INCIL), 12 Centers for Independent Living, UIC, and 120 community-based organizations.

2) Professional Education/Service Accessibility

- Disability awareness curriculum was adopted by University of Illinois at Chicago, College of Medicine; Northwestern University, Feinberg School of Medicine; and Southern Illinois University, School of Medicine. Between 2009 and 2012, more than1,500 medical and physician assistant students have been reached.
- Disability awareness trainings were held for diabetes educators and exercise instructors in collaboration with Illinois Department of Human Service Diabetes Program, the Arthritis Foundation, two local CILs and NCPAD.
- The Disability and Health Program staff exhibited or presented at professional conferences including the Illinois Women's Health Conference, the Department of Human Services Critical Issues Conference, and the Statewide Oral Health Conference.
- Accessibility materials, including a booklet on improving accessibility to health care, American's with Disabilities Act checklists, contact information for CILs, and information on using people first language, were sent to all 95 Local Health Departments in Illinois, and two disability awareness trainings were held at local health departments.
- A webinar about creating accessible electronic information was developed targeting local health department staff reaching more than 100 people through a collaboration with the University of Illinois at Chicago's Great Lakes ADA Center. The webinar continues to be available on the Department's website.
- A fact sheet targeting health professionals about the use of Video Relay Services was developed and disseminated.
- Data on 7,000 dentists' and oral hygienists' training experience in treating patients with disabilities were collected through a dental workforce census survey. Based on this data, the program partnered with the Western Illinois Area Health Education Center, the Department's Division of Oral Health and the IFLOSS Coalition, a statewide coalition of oral health professionals, to develop a professional education opportunity to better equip dentists and dental hygienists to treat patients with disabilities.

3) Surveillance and Data

- Five annual data reports were developed to monitor health disparities between people with and without disabilities and progress toward *Healthy People 2010* objectives using data from the Illinois BRFSS, an annual state-level population-based health survey, through a collaboration with Illinois Department of Public Health, Center for Health Statistics.

- A Data Distribution Plan was developed outlining methods to disseminate program data.
- Four data fact sheets (i.e., disability prevalence, obesity, smoking and exercise), capturing health disparities between people with and without disability at the sub-state level, were developed using the Illinois County-based Behavioral Risk Factor Survey (ICBRFS) data through a collaboration with the Department's Center for Health Statistics.

In an effort to sustain program achievements and create more programs that are inclusive of people with disabilities, the Illinois Disability and Health Program devoted a portion of time during the final year of this grant cycle, to develop this revised action plan to guide health promotion activities targeting people with disabilities throughout the state.

Illinois Disability and Health Partnership

To ensure a community-based, multi-level approach to address improving health and reducing the risks for chronic conditions among people with disabilities, the Illinois Disability and Health Partnership was formed in 2005 to guide project activities of the Illinois Disability and Health Program in promoting the health of people with disability in the state.

Partners include nearly 100 individuals including people with disabilities and representatives from state and local organizations working in the field of disability advocacy, health promotion, public health, rehabilitation, assistive technology, recreation and other relevant fields with similar goals of reducing chronic conditions and promoting the health and wellness of people with disabilities. Partners have been meeting at least twice a year to assist in conducting project activities. Each partner brings their own expertise to the project in supporting people with disabilities and promoting their health. Partners also provide input on professional development and health promotion strategies. Their knowledge and resources enable the Illinois Disability and Health Program to widen its perspective and to prioritize its activities.

Defining Disability

In the context of the present action plan, the Illinois Disability and Health Program defines disability as:

> *"a limitation of a person's functional ability in daily life activities, which is the result of interactions between the person and his/her physical, social and psychological environment."*

The definition being used in the present action plan is based on the social model of disability that has been widely adapted in the Americans with Disabilities Act (1990), *Healthy People 2010* (2000), the Surgeon General's *Call to Action to Improve the Health and Wellness of Persons with Disabilities* (2005), and the World Health Organization (2001). The social model defines disability as a social construct rather than as an illness. It perceives that disability is only a difference from an average, and that the dichotomy between disability and non-disability is arbitrary. Further, the model emphasizes that the limitation in daily life can be alleviated by altering the environment, which interacts with the person. By adapting the social model of disability, the Disability and Health Program underscores that reducing physical, social and psychological barriers and increasing opportunities and access are critical agenda items for improving the health of people with disabilities in Illinois.

Plan Development Process

In consultation with the U.S. Centers for Disease Control (CDC) and other CDC-funded Disability and Health states, the Illinois Disability and Health Program staff developed a three step procedure for updating the existing *Illinois Disability and Health Action Plan: 2007-2010*. The procedure was approved by partners and work group members in April and May 2011. The first step involved development of a key informant interview script by the Illinois Disability and Health Program staff to identify existing state capacity, vision, and long-term goals to improve the health of people with disability in the state. The script was piloted in June and July 2011 and fully implemented in August 2011. Nearly 50 individuals, representing 38 agencies and organizations throughout the state, served as key informants through telephone interviews to ensure that the *Illinois Disability and Health Action Plan* is a comprehensive, statewide effort with input from people with disabilities, all partners and many other stakeholders. (See Appendix B – List of Agencies Participating in State Plan Development. A copy of the interview is provided as Appendix C – Key Informant Interview Survey).

In the second step, program staff compiled the information gathered from the interviews and drafted a plan for review by each of the three existing work groups in September 2011. Work group recommendations were incorporated into the plan draft, which was shared and discussed extensively during the full Partnership meeting in October 2011. In the third step, based on partnership recommendations, a final draft was then completed and sent to all partners and stakeholders for final comments. Partners were asked to choose and commit to activities listed in the plan, thus creating buy-in and sustainability of the efforts and assuring a statewide, integrated method for accomplishing the goals they helped create.

Mission

The mission of the Illinois Disability and Health Program Partnership is to develop, sustain and support activities to improve the health and quality of life and reduce the risk of chronic disease among people with disabilities.

Vision

The Illinois Disability and Health Partnership, consistent with objectives identified in the U.S. Surgeon General's *Call to Action to Improve the Health and Wellness of Persons with Disabilities 2005* and the *Healthy People 2020* disability and health objectives, has the commitment, capacity and resources to create data collection mechanisms, implement health promotion and professional interventions, and enhance accessibility to achieve the following:

Health Promotion

- **Improve physical accessibility** to increase access to recreation, transportation, employment, housing, health care facilities and supports to allow people with disabilities greater independence to live in the community.
- **Promote or offer health promotion activities** to people with disabilities.
- **Develop and distribute health promotion information** that is accessible, easy to understand, and available in a variety of formats and languages.
- **Educate people with disabilities, family members and caregivers** about state health programs and services, especially among those with language or cultural barriers, and about how to advocate for themselves.
- **Improve accessibility and promote inclusion** of people with disabilities in existing health promotion programs.

Professional Education

- **Educate providers** on barriers and challenges faced by people with disabilities in accessing community-based health services.
- **Educate public health and community-based organization workers** about the independent living philosophy, what disability is and what resources are available to promote health service access in the community.
- **Improve Medicaid Managed Care and other support programs** through a patient centered approach.
- **Collaborate** with organizations and programs in the fields of aging, disability and public health to reach service providers effectively to enhance the educational efforts.
- **Provide disability awareness trainings** to professionals in a wide variety of fields who provide services to people with disabilities.

Surveillance and Data

- **Enhance collection and utilization of health data** on people with disabilities to capture the changing health profile of people with disabilities, identify their health risks and encourage implementation of services to address them.

Part 2

Chronic Condition Disparities Among People With Disabilities

Data to Support Need

One in every five Illinois adults (19.7 percent) has a disability. The number of Illinois adults with disabilities rose from 1.77 million in 2001 to 1.91 million in 2010. This suggests that people with disabilities will continue to make up a large part of the population of Illinois. Although having a disability does not always lead to poor health, there are important differences between the health of people with and without disabilities.

Chronic disease rates are higher among Illinois adults with disabilities than those without disabilities.

- Three times as many adults with disability have doctor-diagnosed **arthritis**.
- The **asthma** rate among Illinoisans with disability is almost double that of those without disability.
- **Diabetes** rates are more than twice as high among Illinoisans with disability.
- **Cancer** rates are more than double among adults with disability.
- **Cardiovascular disease**, which includes a variety of heart and blood vessel diseases, occurs much more often among Illinoisans with disability. The heart attack rate for adults with disability is nearly four times higher for adults with disability, and the rate of stroke is more than five times higher.

Risk Factors associated with chronic disease also are higher among adults with disability.

- Illinoisans with disability **exercise less often** than Illinoisans without disability.
- Illinois adults with disability are **more likely to be obese** than those without disability.
- The rate of adults with **high blood pressure** is more than double among adults with disability than those without disability.
- **High blood cholesterol** is more common among Illinoisans with disability than those without disability.

People with disabilities can benefit from disease prevention and health promotion efforts as much as those without disability. Often, community health services are not developed with the needs of people with disabilities in mind. Thus, people with disabilities who want to use these services often experience access barriers including inaccessible medical offices and equipment, transportation barriers, communication barriers, and attitudinal barriers. Because people with disabilities are at an increased risk of developing additional health conditions, health promotion programs must be developed and refined to be more inclusive for people with disabilities to ensure that they have equal access to health care services. Reducing barriers and expanding access to health services and health promotion programs is critical in supporting the independence of people with disabilities.

Part 3

Goals, Objectives and Strategies

Health Promotion

Focus Area #1: Health Promotion

Existing Capacity
The Illinois Disability and Health Program and its program partners, have considerably increased the availability of health promotion opportunities and information for people with disabilities and the inclusion of people with disabilities in existing programs over the past five years.

Collaborating with the Illinois Disability and Health Program, partners who have been offering health promotion opportunities have specifically marketed their programs and services to people with disabilities during this period. Examples include blood pressure education, smoking cessation services, the Chronic Disease Self-Management Program (CDSMP) and the Arthritis Foundation Exercise Program. People with disabilities also have been included in ongoing health promotion programs such as diabetes awareness programs, senior abuse and neglect prevention programs, and a fall prevention program.

Programs designed for people with disability also have been promoted more widely through partner collaborations. The program and partners have marketed a physical activity and nutrition program developed specifically for people with disability, the National Center on Physical Activity and Disability's "14-Weeks to a Healthier You" program, through the networks of Centers for Independent Living (CILs) and other partners in state. These efforts by the Illinois Disability and Health Program and its partners created awareness about the health promotion needs of people with disability among people with disability themselves, their families, caregivers and service providers.

The Illinois Disability and Health Program and partners have developed health promotion information in accessible and culturally appropriate format, and distributed it to people with disability in the state. Examples of such information include factsheets on arthritis, diabetes, fall prevention, blood pressure, healthy eating, chronic disease, and preparation for doctor's visit as well as a blood pressure training video and video logs (VLOGs) to reach people who use sign language with smoking cessation messages and education about resources.

Goal: Increase health promotion and disease prevention opportunities and resources for people with disabilities.

Health Promotion — Continued

Rationale: Health promotion and chronic disease prevention are as important for people with disabilities as they are for those without disability. The presence of disability increases the risk of developing chronic health conditions. Risk factors for chronic diseases such as physical inactivity, obesity, hypertension, and high cholesterol, are more prevalent among people with disabilities than those without disabilities. Thus, promotion of health and wellness is critical for people with disabilities in terms of living longer and healthier lives in the community.

Reducing barriers and expanding access to various health services and health promotion programs in the community are critical issues in supporting the independence of people with disabilities. Traditionally, community health services have not been developed with the many needs of people with disabilities in mind. Thus, people with disabilities who want to utilize these services often experience access barriers including inaccessible medical facilities and equipment, transportation barriers and communication barriers. In addition, preventing chronic disease through health promotion activities can be more cost effective than treating a chronic condition once it develops. Objectives and strategies recommended in this plan focus on increasing accessibility to health promotion services and resources for people with disabilities.

Long-Term Objective: Facilitate utilization of health care and health promotion services among people with disability and their caregivers by increasing their awareness about health risks and expanding existing health promotion resources to include people with disabilities.

Objective 1: By December 2017, identify and disseminate consistent health messages in accessible and culturally appropriate format to people with disability and their caregivers.

Strategy 1: Identify health messages that address important issues as perceived by public health and the disability community in the state, and ensure that they are accessible and culturally appropriate.

Examples of health topics include, but are not limited to:

- Early signs of common chronic diseases (i.e., diabetes, arthritis, obesity, cardiovascular disease)
- Risk factors for and prevention of common chronic diseases
- Physical activity and nutrition
- Tobacco cessation
- Maintaining oral health
- Emotional wellness, mental health and suicide prevention
- Fall prevention
- Prevention of violence against people with disabilities
- Emergency preparedness
- Communicating with health service providers

Health Promotion — Continued

Strategy 2: Utilize generic and targeted dissemination mechanisms that are most often used by people with disability and their caregivers.

Examples of the dissemination mechanisms include, but are not limited to:

- Printed and electronic materials, and websites produced by disability specific organizations, health care and public health organizations and others (e.g., E-mail, list serves, social media, VLOGs for deaf and hard of hearing populations, CIL newsletters, fact sheets, flyers)
- Mass media that influences the community (e.g., public service announcements, media campaigns, press releases, "health channels" at physician offices, billboards, and radio, television and newspaper advertisements and articles)
- Events and conferences targeting people with disability and their caregivers (e.g., health fairs, workshops, disability conferences, CIL quarterly consumer meetings)

Objective 2: By December 2017, facilitate inclusion of health promotion activities in disability organizations' strategic plans and/or daily activities.

Examples of activities include but are not limited to:

- Smoking cessation
- Evidence-based and promising practice health promotion interventions
- Self-management programs
- Stress management, meditation, relaxation and yoga
- In-person and on-line physical activity/exercise and nutrition programs

Strategy 1: Utilize "health champions" within disability service organizations to model and encourage others to include health promotion activities in their services.

Strategy 2: Provide technical assistance on how to include health promotion in daily activities.

Strategy 3: Provide trainings on leading specific health promotion interventions.

Health Promotion — Continued

Objective 3: By December 2017, assist statewide public and private health agencies, organizations and associations and programs to include people with disability as one of their target population groups.

Examples of entities include but are not limited to:

- Chronic disease prevention programs
- Recreational venues (e.g., gyms, fitness centers, YMCAs, parks)
- Health voluntaries
- Agencies who serve senior citizens

Strategy 1: Provide technical assistance on how to market health promotion interventions to people with disabilities.

Strategy 2: Provide technical assistance on how to make existing health promotion interventions accessible.

Strategy 3: Provide technical assistance on how to communicate more effectively with people with disabilities.

Professional Development/ Health Service Accessibility

Focus Area #2: Professional Development/Health Service Accessibility

Existing Capacity
The Illinois Disability and Health Program, along with many of its partners and key stakeholders in the state, have on-going activities to increase health care accessibility by educating health care and service providers, including hospital administrators and staff; physicians, nurses and allied health professionals; oral health providers; emergency planners and first responders; ophthalmologists; and medical and allied health students. During the past three years, disability awareness has been adopted as a regular part of the curriculum of three medical schools and one physician assistant program. Professional development activities address general topics that cover large populations with disabilities such as cultural sensitivity, the social model of disability, and ADA mandates, as well as needs and barriers specific to sub-populations with disability such as those with sensory disabilities (deaf/hard of hearing, visual impairment), intellectual/developmental disabilities, and physical disabilities. Topics of communication, medical facility and equipment accessibility, transportation, oral health, fall prevention, genetics, and screenings continue to be addressed.

The Illinois Disability and Health Program, along with many of its program partners, have been working toward breaking down attitudinal barriers and raising awareness of the needs of people with disabilities. Disability awareness trainings are available through Centers for Independent Living and other stakeholders. The program continues to educate health professionals through professional conferences. Local health departments are included in on-going information dissemination and training opportunities. Professional education webinars have been developed and continue to be available online.

Goal: Reduce barriers in accessing health care and health promotion services among people with disabilities.

Rationale: When striving to improve or maintain their own health, people with disabilities often experience a range of barriers in accessing health care, preventive and supportive health services. Some of the major barriers, identified by stakeholders in Illinois, include lack of service providers trained to work with people with disabilities, lack of or inadequate public policies/services addressing their health needs, and lack of information sharing among agencies and health providers about disability issues and available resources. These barriers often hinder people with disabilities from accessing health services and contribute negatively to health disparities between people with and without disabilities. Objectives and strategies are recommended in this plan that increase access to such services for people with disabilities by reducing these barriers.

Professional Development/Health Service Accessibility — Continued

Long-Term Objective: Increase the availability and accessibility of health care and health promotion services among people with disabilities through education, information dissemination and communication.

Objective 1: By December 2017, educate the health service workforce to improve access to health care and health promotion services for people with disabilities.

Strategy 1: Increase disability education/training opportunities for the health service workforce with an emphasis on unique barriers experienced by the following sub-groups identified by disability and public health stakeholders as having a higher risk of health disparities:

- People with sensory limitations
- People with intellectual/developmental disabilities
- People with mental illness
- Children with disabilities
- People with physical/mobility disability

Strategy 2: Develop new or identify existing resources and/or training materials/ programs on the following topics to assist the health service workforce to better accommodate the health needs of people with disability including but not limited to:

- Disability, not as an outcome of disease, but as one of the patient's demographic characteristics, and its application to the patient-centered model of medical practice and treatment of chronic diseases
- Health promotion as an integral component of health care
- Americans with Disability Act guidelines
- Injury prevention for providers and people with disabilities including safe transfer techniques
- Etiquette in interacting with people with disability
- Developing health information in accessible formats
- Identifying mental health service needs of people with disabilities
- Assisting people with disabilities in improving and maintaining their oral health
- Providing clinical services to people with intellectual/developmental disabilities
- Including people with disabilities in on-going emergency preparedness planning

Professional Development/Health Service Accessibility — Continued

Objective 2: By December 2017, educate policy-makers about health care needs/barriers of people with disabilities to increase access to health care.

Strategy 1: Educate policy-makers about implications for people with disability of changes in state health insurance policies.

Strategy 2: Educate hospital policy-makers about the need for policy changes to better accommodate patients with disabilities.

Strategy 3: Educate policy-makers about the need for state and local policies for stronger enforcement of Americans with Disability Act laws to improve physical accessibility to buildings and medical equipment.

Strategy 4: Educate insurance company policy-makers about the need for better insurance coverage for health promotion activities, screening tests, vision and dental services that are important for people with disabilities due to their increased risk for chronic diseases.

Strategy 5: Educate policy-makers about the need for expanded community-based options for people with disabilities.

Strategy 6: Educate policy-makers about the need for increased access to mental health services among people with disabilities, especially in rural areas.

Strategy 7: Educate policy-makers about the importance of accessible transportation services for people with disabilities, specifically in relation to their access to health services.

"The greatest barrier faced is the attitudes of those thinking that people with disabilities are "less than whole" and, therefore, deserve fewer opportunities than mainstream Americans. Attitudinal barriers are so ingrained in society that only a sustained and high profile effort, reaching all constituencies simultaneously, can have any measure of success."

— Illinois Network of Centers for Independent Living

Surveillance and Data

Focus Area #3: Surveillance and Data

Existing Capacity
The Illinois Department of Public Health's Behavioral Risk Factor Surveillance System (ILBRFSS) and the Illinois County Behavioral Risk Factor Survey (ICBRFS) (http://app.idph.state.il.us/brfss/), along with the Department's Disability and Health Program (http://www.idph.state.il.us/idhp/) that produces data products on disability and health from these surveillance systems, constitute the primary surveillance and data capacity existing in Illinois.

Data Capacity
The Illinois Department of Public Health has been fielding two surveillance programs that continue to provide health information on people with disabilities in the state. The Illinois Behavioral Risk Factor Surveillance System is an annual population-based survey that monitors the health of Illinoisans, age 18 and older. The Illinois County-based Behavioral Risk Factor Survey is similar to the ILBRFSS, but designed to collect health information of adults at the county-level. These two surveillance programs constitute the primary data sources for tracking and monitoring the health status of people with disabilities in Illinois.

Program/Product Capacity
The existence of surveillance data alone is not sufficient. Health related data pertaining to people with disabilities need to be extracted from the surveillance programs and presented to end users in a user-friendly manner. The Illinois Disability and Health Program has been a primary source of data products related to the health status of people with disabilities in the state. Using data from the ILBRFSS, the program has published five Illinois Disability and Health Data Reports (http://www.idph.state.il.us/idhp/publications.htm) that present empirical data on demography, prevalence of chronic health conditions and their risk factors, and health service access of people with disabilities in Illinois. Each report consists of a series of bar-charts to underscore the potential health disparities between Illinoisans with and without disability for each health topic in order to facilitate its use by end users who are unfamiliar with data and statistics. To further facilitate use by end users with disability, the accessibility of the reports has been rigorously tested. The reports are intended to facilitate dialogue among key stakeholders who are interested in promoting the health and wellness of Illinois citizens with disabilities. The reports have been frequently utilized by state-level chronic disease prevention programs (e.g., Tobacco, Cardiovascular, and Arthritis) and their program partners to facilitate inclusion of people with disabilities in their own programs.

Surveillance and Data — Continued

In addition to the data reports, the program also publishes data briefs that capture health information at the sub-state level utilizing data from the ICBRFS. The health status data of people with disabilities presented in the data reports likely obscure variations across different sub-state geographic areas. Lack of health information specific to certain sub-state areas is one of the potential reasons that local programs fail to recognize the health needs of people with disability and include them in their ongoing program activities. In each of the data briefs published by the program, data were aggregated into the service areas of 23 Centers for Independent Living, which are local disability advocacy organizations, to facilitate the utilization of local disability data. Each data brief addresses a specific topic pertaining to the health of people with disabilities (e.g., disability prevalence, obesity, exercise and smoking), uses GIS maps to contrast the health status difference across various geographic areas and presents tables to contrast gaps between people with and without disability in each area. The data briefs can be found at http://www.idph.state.il.us/idhp/publications.htm.

Goal: Data pertaining to the health of people with disabilities throughout their lifespan will be collected, analyzed, monitored, and made available to partners and stakeholders.

Rationale: Collecting, analyzing, monitoring, and disseminating data related to the health of people with disabilities in a user-friendly manner are important steps to inform policy and educate policy-makers, advocate for funding, evaluate existing programs and policies and plan new initiatives to address improving the health and quality of life and reduce the risk for chronic and secondary conditions among people with disabilities. The current void of population-based health information on children with disabilities and people with mental illness needs to be addressed in order to respond to the emerging health care and health promotion service needs of this segment of state population with disabilities.

Long-Term Objective: Enhance the existing surveillance capacity by capturing additional health data on persons with disability, producing data products, and promoting utilization by stakeholders to increase health promotion opportunities addressing the health needs of people with disabilities.

Surveillance and Data — Continued

Objective 1: By December 2017, enhance the existing surveillance capacity by including information addressing the health status of people with disabilities and their sub-groups in ongoing surveillance and data efforts.

Strategy 1: Support inclusion of more detailed race/ethnic variables in ongoing surveillance and administrative data efforts in the state.

Strategy 2: Advocate for inclusion of the health status data on people with mental illness in the ongoing surveillance and data efforts in the state.

Strategy 3: Advocate for inclusion of the health status data on children with disabilities in the existing surveillance programs in the state.

Strategy 4: Facilitate inclusion of *disability* as one of the demographic variables into existing data efforts.

Strategy 5: Examine health data on people with disabilities living in rural areas.

Strategy 6: Monitor health data on people with disabilities across 23 Centers for Independent Living service areas.

Objective 2: By December 2017, produce data products that are accessible to and easy to understand by end users.

Strategy 1: Update the *Illinois Disability and Health Data Report,* which documents the health status and health risk factors of Illinoisans with disabilities, using ILBRFSS data annually through 2017.

Strategy 2: Update the *Illinois Disability and Health Data Briefs,* which document the health status and health risk factors of Illinoisans with disabilities across sub-state geographic areas, using ICBRFS data through 2017.

Strategy 3: Ensure each data product presents data in a simple and easily understandable manner for end users and is provided in an accessible format.

Surveillance and Data — Continued

Objective 3: By December 2017, facilitate the utilization of disability and health data products by other programs and stakeholders in the state.

Strategy 1: Encourage statewide disability organizations to include health objectives in their state plans through sharing disability and health data products with them.

Strategy 2: Actively promote disability and health data products to other state programs, agencies and policy-makers who work on health policies and services to raise their awareness on the health needs of people with disabilities in the state.

Strategy 3: Share data products with the State Health Improvement Plan (SHIP) Committee to ensure that people with disability are represented in the plan.

"Understanding the extent of disability and the life circumstances facing our citizens with disability are critical steps to planning effective health promotion and disease prevention strategies for this large, but under-studied sub-population in the state."

— Illinois Disability and Health Data Report, 2009

Part 4

Call to Action

Call to Action

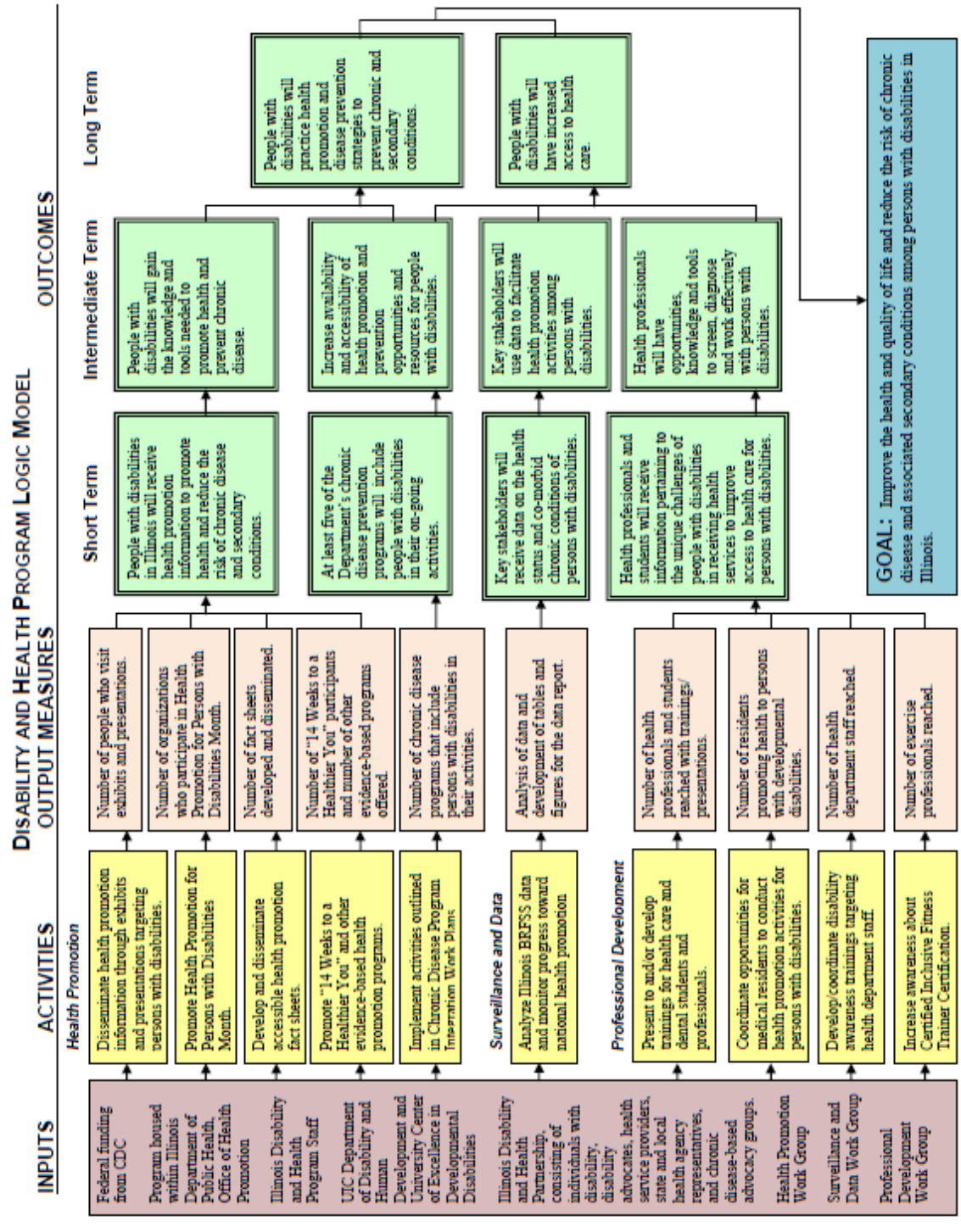
People with disabilities continue to comprise a major portion of the population base in Illinois. Available data suggest that people with disabilities in Illinois have elevated health risks and increased rates of chronic disease relative to those without disability. While public health services in the state have been designed to promote the health and well-being of all residents, existing social, economic, physical and communication barriers hinder their access to such services and have potentially contributed to health disparities between people with and without disability. Despite federal and state initiatives in the last decade to improve access and reduce barriers for people with disabilities, significant disparities between the health of people with and without disabilities continue to exist in Illinois.

This revised action plan is an outcome of a robust partnership between the Illinois Disability and Health Program and more than 60 program partners and other stakeholders. The plan reflects their dedication in ensuring better quality of life of people with disabilities in the state through the maintenance and improvement of their health and well -being. The plan purposefully provides a broad framework which allows current and future efforts in the state to address specific health topics important to people with disabilities (e.g., mental health, women's health, reproductive health) and the unique health and wellness needs of sub-groups of people with disabilities (e.g., minorities with disabilities, veterans, people with specific types of disabilities that have unique needs) to be aggregated into this framework. This approach signifies that the task of promoting the health and well-being of people with disabilities in the state is not a job for a single state or local agency or program, a community-based service provider, or a health advocacy organization. Rather, it requires the collaborative efforts of all committed organizations and their members in the state including people with disabilities and their advocates.

To learn more about the Illinois Disability and Health Program and how to become involved, contact the Illinois Department of Public Health, Disability and Health Program at 217-557-2939, TTY 800-547-0466.

Logic Model

Appendix A



Appendix B

Agencies Participating in State Plan Development

* Indicates Key Informant

Access Living of Metropolitan Chicago – Judy Panko Reis*, Marilyn Martin*, Tom Wilson*
Age Options Area Agency on Aging – Maria D. Oquendo-Scharneck*
American Heart Association – Heather Gavras*
American Lung Association – Lori Younker*
Anixter Center – Emily Lucena
Arthritis Foundation – Michele Pfeilschifter*
Asian Human Services, Inc. – Jing Zhang*
Chicago Lighthouse – Greg Polman*, Jim Pagani*
Coalition of Citizens with Disabilities in Illinois – Ruth Burgess Thompson*
Evanston Northwestern – Susan Magasi
Illinois Chapter of the American Academy of Pediatrics – Jennie Pinkwater*
Illinois Council on Developmental Disabilities – Sandy Ryan*
Illinois Deaf and Hard of Hearing Commission – John Miller*
Illinois Department of Human Services, Illinois Imagines Project – Teresa Tudor
Illinois Department of Public Health
- Asthma Program – Nancy Amerson*
- Cardiovascular Health Program – Lynette Shaw*
- Center for Health Statistics – Bruce Steiner
- Division of Disaster Planning and Readiness – Cheryl Miles*, Cory Ryan
- Division of Injury and Violence Prevention – Jennifer Martin*
- Genetics/Newborn Screening Program – Claudia Nash*, Brook Crock
- Healthy Aging/Arthritis/Alzheimer Programs – Rhonda Clancy*
- Office of Minority Health – Marbella Marsh
- Office of Women's Health – Sandra Goodner
- Physical Activity, Nutrition and Obesity Program – Margie Harris*, Kalea Engel
- Tobacco Program – Kristen Nolen*, Lynda Preckwinkle
- Vision and Hearing Program – Gail Tanner*

Illinois Department on Aging – Ross Grove*, Jan Cichowlas
JoDaviess County Health Department -- Peggy Murphy*
LIFE Center for Independent Living – Dana Craig*
Midwest Asian Health Association – Hong Liu*
NorthPointe Resources – Kirsten Krok*, Dina Donahue-Chase
Options Center for Independent Living – Kathy Petersen
PACE Inc. Center for Independent Living – J. Hadley Ravencroft*

Appendix B — continued

Progress Center for Independent Living – John Jansa*, Sam Knight*
Rush University – Sarah H. Ailey
Salud Latina/Latino Health – Patricia Canessa*
Seguin Services – Terry Porter*
Springfield Area Disability Activists – Tyler McHaley*
Springfield Center for Independent Living – Susanne Cooper*, Karen DeLay*
Starting Point Aging and Disability Resource Center, Macon County Health Department – Becky Gillen*, Amy Reeser*, Julie Peter*
Statewide Independent Living Council – William Gorman*
Stroke Survivors Empowering Each Other – Mickey Clancy*
The ARC of Illinois, Family to Family – Faye Manaster*
United Cerebral Palsy of Illinois Prairieland – Linda O'Neill
University of Illinois at Chicago, Department of Disability and Human Development – Sharon Lamp*, Beth Marks
University of Illinois at Chicago, College of Dentistry – Robert Rada, D.D.S.*
University of Illinois at Chicago, Division of Specialized Care for Children – Bonnie Cohrs*
Western Illinois Area Health Education Consortium (AHEC) -- Kathy Fauble*

Appendix C

Key Informant Interview Survey

Focus Area 1: Health Promotion

1. Looking back at the last five years,
   a) What are two things **ALREADY BEING DONE** by your organization to improve health for people with disabilities in Illinois?
   b) What else **COULD BE DONE** (by your organization or others) to improve the health of people with disabilities?
   c) Of the activities listed above, prioritize what **SHOULD BE DONE** first.

2. In working with the Illinois Disability and Health Program in the next five years, and in alignment with your organization goals, what **CAN BE DONE** (by your organization or others) to:
   a) Identify or distribute information regarding health promotion activities for people with disabilities in Illinois?
   b) Change state/local/organizational policies to support health promotion activities for people with disabilities?
   c) Conduct media or education campaigns to endorse health promotion activities for people with disabilities?
   d) Implement health promotion activities for people with disabilities?
   e) Facilitate changes in physical, social, and psychological environment to improve health promotion activities for people with disabilities?
   f) Market health promotion activities for people with disabilities?

3. **WHAT ELSE** can be done (by your organization or others) to promote access to health services for people with disabilities in Illinois?

Focus Area 2: Professional Development/Service Accessibility

1. Looking back at the last five years,
   a) What are two things **ALREADY BEING DONE** by your organization to improve access to health care for people with disabilities in Illinois?
   b) What else **COULD BE DONE** (by your organization or others) to improve the health of people with disabilities?
   c) Of the activities listed above, prioritize what **SHOULD BE DONE** first.

Appendix C — continued

2. In working with the Illinois Disability and Health Program in the next five years, and in alignment with your organization goals, what **CAN BE DONE** (by your organization or others) to:
   a) Distribute information (e.g., ADA awareness publications, products) regarding access to health care for people with disabilities in Illinois?
   b) Change state/local/organizational policies to improve access to health care for people with disabilities?
   c) Implement health and social interventions to improve access to health care for people with disabilities?
   d) Facilitate changes in physical, social, and psychological environment to improve access to health care for people with disabilities?
   e) Advocate for changes in health services to improve access to health care for people with disabilities?
3. **WHAT ELSE** can be done (by your organization or others) to promote access to health services for persons with disabilities in Illinois?

Focus Area 3: Surveillance and Data

1. Looking back at the past 5 years,
   a) What are two things **ALREADY BEING DONE** to improve surveillance and data collection on the health of people with disabilities in Illinois?
   b) What else **COULD BE DONE** (by your organization or others) to improve surveillance and data collection on the health of people with disabilities in Illinois?
   c) Of the activities listed above, prioritize what **SHOULD BE DONE** first.

2. In working with the Illinois Disability and Health Program in the next five years, and in alignment with your organization goals , what **CAN BE DONE** (by your organization or others) to:
   a) Disseminate disability and health data products, such as a state-level data report and a CIL-level data brief, to stakeholders/policymakers?
   b) Advocate for changes in state/local/organizational policies to support health surveillance of people with disabilities?
   c) Advocate for changes in state/local/organizational policies to support health surveillance of people with disabilities?

3. What data related to the health of persons with disabilities in Illinois would be helpful to your efforts?