

# **Disability and Health in Kansas**

An informational and state capacity  
planning document for addressing  
secondary conditions related to  
disability in Kansas

This document was created as a result of collaboration among the  
Kansas Disability and Health Steering Committee and the  
Kansas Department of Health and Environment's  
Disability and Health Program

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The Kansas Disability and Health Steering Committee, 1) developed goals and objectives for Disability and Health in Kansas and 2) provided guidance and support to the emerging Disability and Health Program at Kansas Department of Health and Environment. The Steering Committee provided a variety of perspectives from the individual, community and state levels to the planning process of this document.

### **Kansas Disability and Health Steering Committee Membership Includes:**

Kansas Association for the Medically Underserved

Kansas Coalition Against Sexual and Domestic Violence

Kansas Council on Developmental Disabilities

Kansas Department of Health and Environment

Kansas Department of Social and Rehabilitation Services

Kansas Foundation for Medical Care

Kansas State Department of Education

Statewide Independent Living Council of Kansas

The University of Kansas

The University of Kansas Medical Center

Wichita State University

And others (50 percent of the membership comprises people with disabilities and parents of children with disabilities.)

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## **Section 1**

### **Executive Summary**

The overriding theme of Disability and Health in Kansas is that individuals with disabilities can have good health and lead full and happy lives. This concept resonates with persons with disabilities because it recognizes that persons who live with a disability can experience a quality of life comparable to persons without a disability. In Kansas, the Disability and Health Program asked persons with disabilities in focus groups, “What are the risk and protective factors for secondary conditions that influence your health?” Secondary conditions included: physical factors, such as pressure sores; psychological factors, such as depression; and environmental factors, such as steps into the doctor’s office.

Results from the focus groups along with statewide data from the Behavioral Risk Factor Surveillance System (BRFSS), Kansas Special Disability Survey - 1997, The University of Kansas Physical Disability Waiver Project, Wichita State University’s Children’s Fitness Project, The Kansas Disability Caucus, Healthy People 2010 Document, and individual expertise from the Disability and Health Steering Committee led to the identification of five priority areas to address the influence of secondary conditions related to the health of people with disabilities in Kansas.

These five priority areas for Disability and Health are:

- Abuse and Violence
- Access to health and wellness services
- Surveillance and Evaluation
- Mental Health/Depression
- Physical Activity

The Disability and Health Program steering committee and subcommittees met to develop goals, objectives and activities to address each of the priority areas. Kansas Department of Health and Environment’s Disability and Health Program used these goal-directed ideas for program guidance recognizing that implementing all the issues are beyond the scope of this program. Other agencies, such as The Kansas Coalition Against Sexual and Domestic Violence, have taken the lead on securing resources to implement other plan objectives. The approval of this state-planning document will assure that the disability issues, reflected in the goals and objectives of this plan, are included in the public health agenda of Kansas.

## **Section 2**

### **Background and History**

#### **Introduction**

The intent of this planning document is to provide a framework for understanding assessment and prevention of the health impact of secondary conditions associated with disability and health among Kansans. This document represents an update of the state disability and health planning process reflected in the 1997 Kansas State Plan for Disability and Health. The identification of state priorities in disability and the need for additional data, as defined in the 1997 Kansas State Plan, serve as the foundation for developing this current document. The paradigm of Prevention of Primary and Secondary Disabling Conditions (adapted from Pope & Tarlov 1991) were integrated throughout the 1997 and current planning processes. This paradigm recognizes the role of social and physical environments in resulting disability. The Disability and Health Steering Committee affirmed this approach and the mission of the group, “health and wellness for all people” to move disability beyond the “illness” or medical model to one that integrates social and physical environmental factors into approaches for health and wellness for people with disabilities. Addressing health disparities in people with disabilities (as with minority groups with health disparities) is necessary for equal status and dignity for this population, which comprises 16% of the Kansas population.

In 1997, the focus of Disability and Health at the Centers for Disease Control and Prevention shifted nationally and in Kansas. The focus narrowed, moving away from primary prevention to concentrate on the prevention of secondary conditions resulting from primary disabilities. The public health approach to disability involves assessment, assurance and policy activities to support the inclusion of people with disabilities in home and community settings. Achieving health and wellness for people with disabilities in the community settings necessitates the identification of environmental barriers to community access that limit the quality of life of people with disabilities. The Kansas Disability and Health Steering Committee developed goals and objectives that will address the identified barriers, support future community-based interventions, and engage persons with disabilities in developing interventions.

## **Eliminating Disparities**

Kansans with disabilities are a diverse group as is the general population of Kansas. *Healthy People 2010* (HP 2010) has a major goal of eliminating health disparities on a national level. KDHE's 1997 Kansas Disability Survey found that significant health disparities were reported by people with disabilities in minority populations.

The 1997 Kansas Disability Survey indicated people of minority status with disabilities, as a group (including African American and Hispanic), reported experiencing significant disparities in health conditions. Identifying health disparities for minority populations is important to understand areas of greatest need and to target interventions where the greatest improvement is possible. In setting goals and objectives to eliminate these disparities this plan considers the same benchmarks as those for the general population.

An important aspect of this planning process was the identification of disparity groups in Kansas and addressing their needs with health promotion activities designed for all Kansans. Objectives and activities address the goal of each of the priority areas (access to health care, violence/abuse, mental health issues, physical activity and data). The data for African American and Hispanic respondents can be found in the BRFSS, the Kansas Disability Survey and qualitative data, although the low numbers make analysis tentative. There is a need to gather additional data on all racial/ethnic groups with disabilities, especially Native Americans and Asians to determine the intensity and prevalence of disability-related health issues in disparate populations and reflects the shifting demographics of the state.

## **Section 3**

### **State Assessment of Disability (1997-2001)**

The following sections describe data and informational sources that were used to guide the advisory process in developing the priority areas for disability and health in Kansas. The use of both qualitative and quantitative data was valuable in this process as well as the use of national and statewide data.

#### **Kansas Special Disability Survey-1997**

The purpose of the 1997 Kansas Disability Survey was to estimate the prevalence of disability in adults residing in Kansas and to identify health disparities. The Survey was conducted by the Health Risk Studies Program within the Office of Health Promotion. Adult Kansans across the state were surveyed using a random digit dial telephone process. Participants with disabilities were defined as those who answered yes to one or more of the following questions regarding limitations;

- 1) Are you limited in any way in any activities because of any impairment or health problem?
- 2) Does any impairment or health problem now keep you from working at a job or business?
- 3) Do you currently use any assistive devices such as a wheelchair, cane, braces, or prosthesis?

This survey focused on the prevalence of primary and secondary disability-associated conditions in Kansans, aged 18 and older. Of the 3300 Kansans screened, 520 met the definition of disability reflecting disability prevalence of 16% (n=520), similar to the national prevalence.

The 1997 Kansas Disability Survey included questions about children with disabilities living in the household. Approximately one in five Kansas households reported at least one child meeting the child definition of disability. This proportion roughly reflects the national prevalence. Our criteria for determining disability in a child included meeting one of the following as reported by the adult respondent:

- Children needing services or treatment for a health problem beyond what is needed for most children their own age.
- Children who have problems or delays in physical development, speech/language development, or difficulties doing activities that are normal for other children their own age.
- Children who regularly take prescription medication, require a special diet, or use assistive devices due to a health condition.

A summary of the findings of the 1997 study is being prepared and will soon be available for use in directing policy and helping to measure health related quality of life indicators for people with disabilities in Kansas. Some significant findings from the Kansas Department of Health and Environment, Kansas Disability Survey of Adult Kansans, 1997 study follow in the tables below:

<b>Adults With Disabilities Aged 18 and Older</b>
Approximately <b>16%</b> of Adult Kansans report having a physical or developmental disability. This is similar to national disability figures.
One in ten Kansans with disabilities said that in times of need they received little or no emotional support.
<p><b>Adult Kansans with disabilities compared to adult Kansans without disabilities:</b></p> <ul style="list-style-type: none"> <li>• are at substantially higher risk for poor physical health, based on self-report measures.</li> <li>• are <b>twice</b> as likely to report being overweight;</li> <li>• are <b>three times</b> as likely not to have enough food for their families;</li> <li>• are at substantially higher risk for depression, based on self-report measures;</li> <li>• are <b>four times</b> as likely to report 14 or more days in the past month where they did not feel healthy or full of energy;</li> <li>• are <b>nine times</b> more likely to report 14 or more days of activity-limiting pain in the past month; and</li> <li>• are <b>six times</b> more likely to report 14 or more days in the past month where poor physical or mental health kept them from doing usual activities, such as self-care, work, or recreation.</li> </ul>

<b>Minority Kansans With Disabilities</b>
Minority Kansans with disabilities are nearly three times more likely to report not finding needed health care compared to white non-Hispanic Kansans with disabilities.
Minority Kansans with disabilities are three times more likely to report being dissatisfied with their health care as white non-Hispanic Kansans with disabilities.
The likelihood that minority Kansans with disabilities experienced 14 or more days in the last month where they did not feel healthy or full of energy is three times as great as for white non-Hispanic Kansans with disabilities, according to self-report measures.
The likelihood that minority Kansans with disabilities reported 14 or more days in the last month feeling anxious, tense, or worried is twice as great as for white non-Hispanic Kansans with disabilities.
The likelihood that minority Kansans with disabilities reported feelings of depression or emotional problems 14 or more days in the past month is twice as great as for white non-Hispanic Kansans with disabilities.
Substantially more minority Kansans with disabilities reported feeling unsafe in their neighborhoods than white non-Hispanic Kansans with disabilities.
Substantially more minority Kansans with disabilities have reported not having enough food for their families compared to white non-Hispanic Kansans with disabilities.
Minority Kansans with disabilities were at three times higher risk to report not having sufficient emotional support in times of need from their friends or family compared to white non-Hispanic Kansans with disabilities, according to self-report measures.
Minority Kansans over 40 years of age with disabilities were at 13 times higher risk to report not receiving a procedure to test for colorectal cancer compared to white non-Hispanic Kansans with disabilities, according to self-report.
The likelihood that minority Kansans with disabilities reported being current smokers is twice that of white non-Hispanic Kansans without disabilities.

**Please note:** The number of minority Kansans in the total number of surveys was small. Much of the difference between minority Kansans and white non-Hispanic Kansans were accounted for by African Americans. Other categories include groups such as Asian and Native American.

## **Kansas Focus Groups**

In 1998, six focus groups of parents of children with disabilities and adults with disabilities were conducted by the Kansas Disability and Health Program staff in various communities in Kansas. The communities which were chosen represented the rural, urban and mid-sized Kansas community perspectives. Groups were asked about risk and protective factors to prevent secondary conditions in their lives or the lives of their children with disabilities. The definition of secondary conditions included things that were physical, such as pressure sores; psychological, such as depression; and environmental, such as steps into their doctor's office.

Participant statements were categorized into several broad priority areas: transportation, access to health and wellness, community attitudes, mental health/depression, prevention of abuse/violence, physical activity, Surveillance and Evaluation, community attitudes, advocacy, housing, employment, community services and supports, physical activity, and education. Participants with disabilities and parents of children with disabilities shared their individual and community health needs when asked. Some statement examples included;

Physical Activity: *"There is not an accessible playground in my community"*

Transportation: *"The costs of accessible transportation keep me from making and getting to medical appointments"*

Employment: *"Employers don't always understand my potential"*

Accessibility: *"My community needs curb cuts and street crossings so that I can travel safely to work and other activities."*

## **The University of Kansas Physical Disability Medicaid Waiver Project**

According to the 1997 Kansas Disability Survey, more than three quarters of the Kansas population with disabilities are at risk for a sedentary lifestyle, as compared to 58% of the general population. For survey purposes, at risk for a sedentary lifestyle included anyone who reported that they did not engage in at least 20 minutes of physical activity three times a week. The staff at the University of Kansas Research and Training Center on Independent Living have studied health outcomes and satisfaction with services of participants enrolled in the Physical Disability Waiver Program under the Kansas Department of Social and Rehabilitation Services. Participants of the waiver program must be Medicaid eligible, and must experience a disability significant enough that they are threatened with institutionalization. The program offers support that enables participants to remain in their communities.

A telephone survey of 150 Physical Disability Waiver Program participants provided rich information regarding barriers to being physically active. In-depth

home interviews supplied information about their definitions of health, their perceptions of their own ability to be healthy, and how the waiver services support their health in order to better understand how people with disabilities view their health, what role physical activity plays in their lives, and how they perceive the value of health promotion efforts. Many reported that they enjoyed some level of health as long as they could maintain a routine of at least a few daily and weekly activities, such as participating in their household, maintaining relationships, going shopping, and attending church. A majority of participants in the Kansas Physical Disability Waiver Program reported that they are “homebound” but still interested in ways to maintain or improve their health.

### **Wichita State University Children with Disabilities Fitness Project**

The purpose of the Children with Disabilities Fitness Project was to improve the physical fitness profiles of children with developmental disabilities, and prevent secondary conditions associated with poor profiles (e.g., coronary heart disease, obesity, or type two diabetes). Dr. Ken Pitetti and his research staff evaluated the exercise capacity, cardiovascular fitness, muscle strength, and motor skills of school aged students with developmental disabilities and found that youth with disabilities are at greater risk for developing secondary conditions than students without disabilities.

Dr. Pitetti and his staff have conducted studies of students with developmental disabilities in the Wichita School District. Their observations indicate that the most challenging aspect of the exercise program is ensuring that the conditioning levels of his students are maintained over time. This research has led to the development of a physical fitness curriculum for middle and high school students primarily with cognitive disabilities.

## **Section 4**

### **Ongoing Assessment of Disability**

#### **Disability and Health Steering Committee and Individual Expertise**

The Disability and Health Steering Committee members comprise state and local disability agency staff, parents of children with disabilities, and persons with disabilities. They bring their collective group wisdom to the Disability and Health Steering Committee meetings.

Guidance from the Disability and Health Steering Committee led to a strong collaboration with the Statewide Independent Living Council of Kansas (SILCK). Through the Kansas Disability Caucus, SILCK generated a list of priority areas for people with disabilities associated with risk and protective factors to living independently in the community. The focus group information gathered by Disability and Health Program which examined risk and protective factors of secondary health of people with disabilities matched the SILCK list. The same things that people with disabilities need to live independently in the community are the same things they need to live healthy lives. By working cooperatively, the Kansas Disability and Health program and SILCK can offer strategies that address the critical health and independent living needs of people with disabilities in Kansas.

#### **Kansas Disability Caucus**

The Kansas Disability Caucus is held every other year in Kansas. The Caucus brings together people with disabilities from every county in Kansas, of many ages, with many types of disabilities. The purpose of the caucus is:

- To develop new disability leadership in Kansas
- To educate Kansans with disabilities about the mechanics of the policy making process and encourage their participation in it.
- To determine major issues facing Kansans with disabilities and to elicit solutions for issues identified.

At the caucus, expert speakers educate and inspire the participants, and regional caucus sessions develop a list of issues and solution statements that provide the content and direction of the state plan for SILCK. These issue and solution statements have influenced the work of the Disability and Health program in developing goals and objectives included in this plan. The Caucus provides a forum for the voice of people with disabilities in planning and policy activities.

## **Healthy People 2010**

*Healthy People 2010* (HP 2010) is a national consensus document that articulates the what, when and where of our national public health agenda. Increasing the quality of life for Americans and eliminating the disparities in health are the two overarching goals of HP 2010. For the first time, Healthy People includes a separate chapter of disability objectives (chapter 6). Disability objectives are also included in other chapters with topic issues of breast and cervical cancer prevention, tobacco use prevention, and injury prevention to ensure that disability is part of the national public health agenda. HP 2010 supports Kansas' efforts to include disability in our state public health agenda.

*Disability and Health in Kansas* is part of our statewide response to including disability in our state public health agenda. By serving as a state consensus document, it is intended to promote the development of interventions on a local level that include disability as part of the local community public health agenda. The partnership of the national, state and local community promotes efforts to insure maximum impact and efficient utilization of resources.

The disability priority areas of access, violence/abuse, mental health, physical activity and data identified in Kansas are also included in chapter 6 (disability objectives) and/or as objectives in other chapters in HP 2010. Some of the HP 2010 disability objectives are developmental because they do not yet have established baseline data. A lack of baseline data for disability issues is also true in Kansas. A four-year review of developmental objectives in HP 2010 will determine if baseline data has been established. Disability objectives that do not have baseline data will be deleted from HP 2010. Qualitative and quantitative data collection in Kansas, including intervention evaluations, will provide state baseline data to support the objectives in this plan and in HP 2010.

## **Section 5**

### **Priority Areas**

Priority areas in Kansas were identified by the advisory process of the Disability and Health Steering Committee. The compilation of information on factors that affect secondary conditions of Kansans with disabilities was facilitated by Bureau of Health Program staff. The advisory committee reviewed data from the 1997 Kansas Disability Survey, Kansas Focus Groups, KU Physical Disability Waiver Project, WSU Children's Fitness Project, Kansas Disability Caucus, and Healthy People 2010 and used the collective group wisdom, experience, and expertise to identify the following priority areas:

Abuse and violence

Access to health and wellness services

Surveillance and Evaluation

Mental Health/Depression

Physical activity

Members of the steering committee and others whose participation is integral to the further development and implementation of work plans continue to meet. The Kansas Department of Health and Environment's Disability and Health program will use this document for guidance, however implementing program activity to address all the identified issues is beyond the scope of a single agency. The adoption of this plan by other entities is vital to the assurance of achieving the goals and objectives selected by the steering committee. For example: agencies such as; the Kansas Coalition Against Sexual and Domestic Violence, Washburn University's Center on Violence and Victim Services have taken the initiative to secure resources and are prepared to play a lead role in the implementation of some objectives. The goals and objectives which were developed through the advisory process for each of the five priority areas are discussed in this section.

## **Abuse and Violence**

### **Background**

Abuse and violence in the lives of people with disabilities was identified as a priority area in the planning process. People with disabilities participating in focus groups identified abuse and violence as a health risk factor and were concerned with abuse and violence as a secondary condition as well as the reason for a primary disability. National data on the subject of abuse and violence of people with disabilities is voluminous and wading through it reveals the breadth of the issue. Upon review of currently available data, members of the Kansas Disability and Health Steering Committee recommended narrowing the scope of the issue initially to domestic violence against women with disabilities.

National information regarding abuse and violence against people with disabilities is alarming. The American Congress of Community Supports and Employment Services fact sheet reports that crime strikes individuals with disabilities four (4) times more often than the general public and that sexual assaults and robberies strike individuals with disabilities 13 times more often than the general public (Holding R., 1997). A qualitative research project in Houston, Texas, conducted by Margaret Nosek (Young, M.E., et al, 1997), interviewed women with disabilities who had experienced domestic violence and found that while women with disabilities didn't experience abuse at a higher rate than women without disabilities, they did experience the abuse for a longer period of time before seeking help.

When asked about risk and protective factors that effect their health, people with disabilities and parents of children with disabilities in Kansas voiced their strong support for abuse and violence prevention efforts. Discussions from the focus groups noted a belief that people with disabilities are often at greatest risk from people who are closest to them and who provide needed supports.

Kansas victim services are beginning to address the needs of women with disabilities through increased awareness and accessibility. The Kansas Disability and Health Program brought together victims service providers and disability staff, a rewarding activity as both groups immediately recognized the value of working together. Kansas Coalition Against Sexual and Domestic Violence will survey their member agencies to determine their current levels of service and shelter accessibility for Kansans with disabilities. In Kansas, the results will be used to develop education, training and funding for increased access to services. Nationally, the results will be included in the development of standards for victims' services.

Statistics from the Kansas Attorney General's Office in 1999 offer limited information about the numbers of people with disabilities seeking victim services. What we do know is that 14,065 women sought services during that year. Of that number, 422 were reported to be women with physical disabilities and 575 were women with mental illness.

The Kansas Disability and Health Steering Committee, as well as victim services and disability agencies strongly support the identification of abuse/violence as a priority area for Kansans with disabilities. A review of best practices from other states indicates that this issue must be addressed with information and support at the individual, community and statewide level.

### **Goal for Abuse/Violence**

- People with disabilities in Kansas will have the same access to violence and abuse services as do people without disabilities.

### **Objectives for Abuse/ Violence**

By 2005, 1) Develop, 2) implement, and 3) evaluate informational materials and activities for victims and community agencies to increase awareness of abuse and violence experienced by women with disabilities by 50 percent. (Baseline: 1 survey to victim service agencies to measure accessibility and raise awareness on the part of respondents)

### **Recommendations**

- Develop and disseminate statewide brochures with general information about abuse and violence and people with disabilities.
- Develop statewide resource materials for community agencies that inform them about local resources that can be used to address barriers such as transportation, housing, medications, etc. for persons with disabilities who are in crisis situations.
- Support of training grants that offer education, consultation, technical assistance, and information.
- Develop, pilot, and disseminate training curriculum about abuse and violence and persons with disabilities to be used by diverse community groups.
- Develop and distribute an accessibility survey to victim service agencies.
- Develop and distribute an abuse/violence survey to disability agencies.

By 2005, Increase by 200% the number of task force and planning groups that specifically address abuse and violence and women with disabilities to further the collaboration among advocates for women with disabilities, domestic violence victim advocates, sexual assault victim advocates, health care providers, women with disabilities who have experienced abuse and violence, university partners, and others. (Baseline: 1 statewide planning group, The Abuse and Violence Task Force)

### **Recommendations**

- Convene and facilitate meetings to develop partnerships and team building opportunities.
- Recruit women with disabilities who have experienced violence and abuse to participate as task force members.
- Participate in other state planning groups to include disability and violence and abuse issues.
- Increase the number of local task force groups to plan, conduct, and evaluate activities related to abuse and violence experienced by women with disabilities.
- Conduct outreach to recruit racial/ethnic minorities with disabilities as representatives on work groups.

## **Access to Health and Wellness**

### **Background**

Access to health and wellness is vital to people with a disabilities seeking to maintain their independence. Developing a secondary condition such as a pressure sore or infection, as well as a chronic condition such as diabetes or heart disease can thwart a person's progress toward their personal health and independent living goals. Significant barriers exist for the health-related quality of life of people with disabilities in Kansas. Qualitative and quantitative research has shown that health risk factors for people with disabilities include access to dental care, adequate health insurance, and inclusion in prevention-focused public health initiatives. Access to primary care, prevention, and health promotion programs are important for people with disabilities. As people with disabilities move out of isolated, institutional settings into communities as active citizens more focus and planning will be required to meet their broad based health needs.

Adult Kansans with a disability are hampered by financial considerations in their quest for health and wellness. Affordable dental care is a significant problem for persons with a disability. The 1997 Kansas Disability survey found that one in three persons (30%) with a disability reported they had not seen a dentist within the last two years. Medicaid insurance does not cover dental services. People with disabilities at the 2001 Kansas Disability Caucus reported difficulty affording dental services. The 2000 Kansas Behavioral Risk Factor Surveillance System (BRFSS) found that of persons with a disability aged 18-24, 40% reported that they had not seen a dentist within the last two years, 20% of persons with a disability aged 25-34 reported that they had not seen a dentist within the last two years; 29% of persons with a disability aged 35-44 reported that they had not seen a dentist within that last two years; 35% of respondents aged 65 and over reported that they had not seen a dentist in the last two years.

Having health insurance does not guarantee access to health care for persons with disabilities in Kansas. An Independent Living Center in western Kansas reported that a significant number of people with disabilities (approximately 500) with Medicaid insurance and are enrolled in the Kansas Physical Disability Waiver Program services did not have a primary care physician. People with disabilities in Kansas who qualify for waiver services are those with the greatest need for support to maintain or improve their independence and health. While current data is not sufficient to define access to health care as a statewide problem, participants in the planning process reported it to be a significant barrier in localized areas of the state. Qualitative data indicates that people with disabilities in these locales lack access to important preventive and primary care due to 1) scarcity of primary care physicians accepting people with Medicaid or 2) inadequate insurance coverage.

It is important to include disability issues in public health programs developed for Kansans. Statewide efforts for prevention programs (tobacco use, sexual assault, and breast and cervical cancer) should address the impact of these issues on persons with disabilities. State level health promotion programs that address disability needs in their state plans by supporting appropriate interventions recognize that people with disabilities can live healthy lives and improve the health-related quality of life for Kansans with disabilities.

Limited access to health and wellness services and education are a significant barrier to a healthy life for people with disabilities in Kansas. Members of the Kansas Disability and Health Steering Committee acknowledged that many groups were individually working on the issue of access to health and wellness and that a more unified approach would provide greater success. Working collaboratively best ensures greater access to dental care, quality mental health care, and access to preventive and primary health care and health promotion messages.

## **Goals for Access to Health and Wellness Services**

- People with disabilities in Kansas will have increased access to community-based, preventive health, and health-related programs and services.

## **Objectives for Access to Health and Wellness Services**

By 2005, increase to 8 the number of state level planning efforts that currently include both disability and public health perspectives. (Baseline: 6; Breast and Cervical Cancer Prevention, Sexual Assault Prevention, Domestic Violence Prevention, Assistive Technology of Kansas, Kansas Brain Injury Waiver Steering Committee, Kansas Disability Caucus)

### **Recommendations**

- Participate in planning activities (agenda development, data presentations, consensus building) for the planning processes of all chronic disease programs at KDHE.
- Work to include disability issues in state level planning documents.
- Support the emerging state oral health office.
- Participate in planning activities (agenda development, data presentations, consensus building) for the planning processes of all chronic disease programs at KDHE.

By 2005, increase by 5% the percentage of persons with a disability who have visited a dentist within the last two years. (Baseline: 30%)

### **Recommendations**

- Work with the new Maternal and Child Dental Health Coordinator to identify barriers to dental care access for children.
- Include people with disabilities as a targeted population for interventions to increase dental care access.
- Support Medicaid policy changes to broaden coverage to include needed dental services.

By 2005, all health promotion programs at KDHE will incorporate disability issues into their program objectives. (Baseline: needed)

### **Recommendations**

- Survey of health promotion programs at KDHE to understand the connections between this programming and disability issues.
- Include disability related objectives in Healthy Kansans 2010 and other state policy documents.

By 2005, determine current level of access to primary health care for people enrolled in the Physical Disability Waiver Program who live in SW Kansas (Garden City area). (Baseline: needed)

**Recommendations**

- Identify funding source for conducting survey of consumers.
- Facilitate listening group of consumers to describe the needs/barriers.
- Develop and implement a consumer survey on Physical Disability Waiver Program through ILC's to determine the level of need.
- Engage providers to evaluate capacity to provide services to people with disabilities who have Medicaid health insurance.
- Expand the access to health and wellness workgroup to include members from statewide agencies who are currently working on addressing the problem and/or who have the ability to affect change (e.g. Kansas Association for Medically Underserved, Kansas Department of Social and Rehabilitation Services, Kansas Association of Centers of Independent Living and others).

## **Surveillance and Evaluation**

### **Background**

People with disabilities have become part of the national and state public health agenda in Healthy People 2010 and significant gains have been made in data gathering for this population. People with disabilities, as other groups with health disparities, are increasingly included in public health surveillance activities. This inclusion allows us to address the most basic systemic access barriers created by the lack of data. Without data, people with disabilities are not included in planning, program development and resource allocation for interventions.

The Kansas Disability and Health Steering Committee recognizes that Kansas needs sufficient disability data to provide a comprehensive and inclusive description and analysis of disability data to provide for adequate public health assessment, policy and program development. This comprehensive panoramic view of disability requires the analysis and integration of three data components: population based data, disability related service data sets, and qualitative data. An accurate description of disability includes not only a panoramic perspective but maintains information related to the specificity of the diverse groups that comprise “people with disabilities”. This balance is achieved through varied data sources on disability in Kansas, which include the Behavioral Risk Factor Surveillance System (BRFSS), the 1997 Kansas Disability Survey, the Disability Data Set Project (service data), Healthy People 2010 and others.

Multiple definitions of disability necessitates an understanding of the specific definition, the intended user and utility of the data be articulated. The Kansas Disability Survey 1997 indicated that about half of the respondents reported they own their own home and have adequate transportation. However, key informant interviews of staff and consumers from Independent Living Centers (ILCs) indicate accessible housing and transportation as major problems for center participants. Reviewing the data from ILCs and the Kansas Disability Survey allows us to analyze housing and transportation from two disability perspectives, each with valid and useable information.

An important tool surveillance and evaluation is the disability module and quality of life questions in BRFSS surveys. Additionally, focus groups, the summary report from the statewide Disability Caucus, research reports from university partners, national survey data and other data sources contribute to our understanding of disability and health in Kansas.

Data sources to set baseline information and measure progress towards objectives presented in this plan will also be developed as will strategies to address emerging issues. As an example, employment issues have emerged as increasingly significant issues for people with disabilities, necessitating the development of the health questions that are pertinent to employment. An adequate data system will be maintained to insure the inclusion of people with disabilities in public health assessment, policy and program development, and resource allocation.

## **Goal for Surveillance and Evaluation**

- Kansas will have sufficient data to provide comprehensive information on the health of Kansans with disabilities.

## **Objectives for Surveillance and Evaluation**

By 2005, maintain disability data collection and analysis. (Baseline: Annual BRFSS disability related questions)

### **Recommendations**

- Participate in annual August BRFSS meetings to request and show support for inclusion of disability questions.
- Disseminate disability and health data in Kansas using current BRFSS data.

By 2005, increase and assess disability specific data pertaining to individual racial/ethnic minority groups with disabilities. (Baseline:0)

### **Recommendations**

- Include disability related questions in data gathering activities specifically targeting racial/ethnic minorities.
- Seek resources to conduct data collection from racial/ethnically diverse populations.
- Invite the participants of racial/ethnic minorities onto planning committee.

By 2005, assess the following emerging issues as they pertain to the health and wellness of Kansans with disabilities. (Baseline: 0)

### **Caregivers**

#### **Recommendations**

- Conduct a literature review and identify existing data sources for caregiver issues in Kansas.
- Gather qualitative data on caregiver issues through focus groups and/or key informant interviews.
- Share results with the Kansas Disability and Health Steering Committee

### **Drug/alcohol**

#### **Recommendations**

- Conduct a literature review and identify existing data sources for drug and alcohol issues in Kansas.
- Gather qualitative data on drug/alcohol issues through focus groups and/or key informant interviews.
- Share results with the Kansas Disability and Health Steering Committee

## **Employment**

### **Recommendations**

- Conduct a literature review and identify existing data sources for employment issues in Kansas.
- Gather qualitative data on employment issues through focus groups and/or key informant interviews.
- Share results with the Kansas Disability and Health Steering Committee

## **Evaluation**

### **Recommendations**

- Conduct a literature review and identify existing data sources for evaluation of issues in Kansas.
- Gather qualitative data on evaluation issues through focus groups and/or key informant interviews.
- Share results with the Kansas Disability and Health Steering Committee

By 2005, identify, increase and enhance disability-related data sets on abuse and violence issues. (Baseline:1) (Kansas Attorney General's yearly PFA Report)

### **Recommendations:**

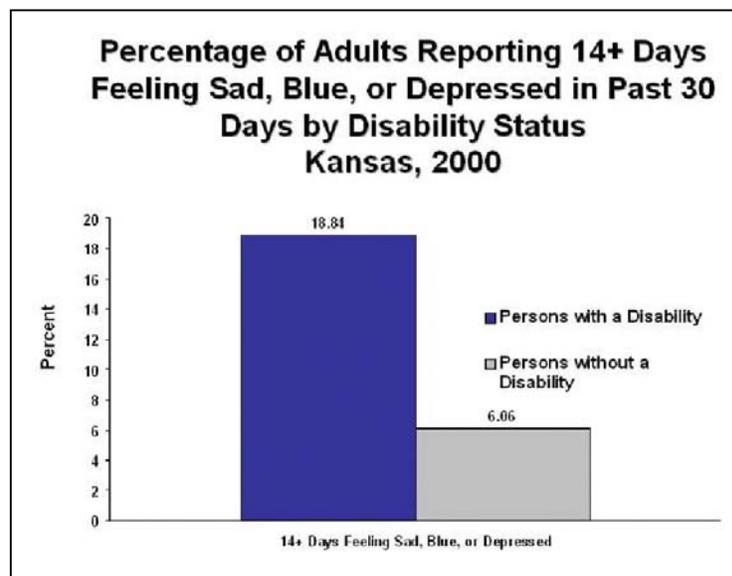
- Meet with Kansas Attorney General's office to review intake forms of victim service agencies.
- Review intake forms and screening tools from other states.
- Share best practice and examples with task force on abuse/violence and people with disabilities.

## Mental Health/Depression

### Background

Health and wellness for people with disabilities includes mental health just as it does for the general population. Many mental health issues were identified in this planning process for people with disabilities in Kansas. Participants in the process included mental health advocacy groups such as NAMI (National Alliance on Mental Illness), Families Together and KEYS (Kansas Educational Youth Services). For the purposes of this document, disability can be defined to include mental illness. Mental health issues for people with disabilities can include depression, suicide, violence/abuse trauma, and dual diagnosis of physical/mental disability. Additionally, a dual diagnosis can include a cognitive disability, such as mental retardation and depression.

Some participants in this planning process strongly identified access to appropriate and competent mental health services as an important priority for health and wellness of Kansans with disabilities. Concerns included the reluctance of some disability agencies to make referrals to community mental health services. Other participants had questions about how well mental health assessments identify disability and its impact. Similar questions arose about treatment. Several participants expressed concern about adequate monitoring of psychiatric drugs. The process raised several questions, including: How do “Disability Agencies” identify who is at risk for mental “illness”? What are appropriate referrals? Once referrals are made, how can we determine long term and short term impacts? The range of services include crisis intervention to respite care. Interest in the mental health care for children with disabilities was expressed.



More Kansans with disabilities rate their mental health to be poor compared to Kansans without disabilities. The 2000 Kansas BRFSS asked respondents the question, “During the past 30 days, for about how many days have you felt sad, blue or depressed?” Almost 19 percent of persons with a disability reported feeling sad, blue, or depressed 14 or more days in the past year compared to 6 percent of persons without a disability.

Understanding access to mental health services for people with disabilities involves an awareness of the history between the independent living movement and traditional mental health providers. Current networking is occurring between disability, mental health, and public health groups such as the National Alliance for the Mentally Ill, KEYS for Networking, Families Together, and Kansas Association for the Medically Underserved, and KDHE. As the foundation is built the dialogue between mental health advocacy groups and the traditional mental health community can be expanded to include independent living centers and mental health centers. Leadership is needed to convene and facilitate the development of a network of public health, traditional mental health providers, mental health advocacy groups and disability agencies. This network would facilitate cross training between members, identify physical and attitudinal access and develop strategies to reach identified goals and objectives.

### **Goal for Mental Health/Depression**

- People with disabilities in Kansas will have access to quality mental health services that is equal to people without disabilities.

### **Objective for Mental Health/Depression**

By 2005, Integrate disability into existing mental health programs and services to impact quality of care for people with disabilities. (Baseline: 0)

#### **Recommendations:**

- Convene and facilitate a network of public health, traditional mental health providers, mental health advocacy groups, consumers, and disability agencies to address mental health access issues for people with disabilities.
- Form collaborative relationships with mental health entities at the state and local level.
- Integrate disability issues into the state's suicide prevention agenda.

## **Physical Activity**

### **Background**

People with disabilities in Kansas are not meeting the national goal set by the Surgeon General, which is to engage in 30 minutes of physical activity on all or most days of the week. The Kansas 2000 BRFSS asked respondents the question, “During the past month, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening or walking for exercise? Almost 40% of persons with a disability reported no leisure physical activity in the past 30 days compared to 28% of persons without a disability.

It is important to note that physical activity goals in the lives of people with disabilities can mean increasing or maintaining self-sufficiency. For example, increased physical activity to maintain range of motion can allow a person to independently put on his/her own socks. In other studies, adults with disabilities indicated that it was important to be able to accomplish physical activities in their homes. Additional Kansas research done by Dr. Ken Pittetti and discussed below has shown that the fitness levels of children with disabilities is poor and many are not active participants in school physical education programs due to a variety of barriers. Increasing students’ opportunities for participation can impact their health now and in the future.

A survey of Physical Disability Waiver participants ages 16 to 64 by the Research and Training Center on Independent Living at The University of Kansas found almost three quarters (73%) reporting that they were “homebound”. When asked to rate their general health status, over one-half (58%) reported that their health was poor to very poor. This group defined health as the ability to be physically active and participate in common everyday activities. An in-home intervention to increase continued physical activity was developed and was successful in increasing awareness of the importance of physical activity and related health benefits in a pilot sample of participants.

Dr. Ken Pitetti, a disability researcher at Wichita State University examined the physical fitness profiles of children with developmental disabilities and found that these youth are at great risk for developing secondary conditions due to poor fitness levels. Dr. Pitetti and his staff have established a physical fitness program that can be integrated into the weekly schedule of students with developmental disabilities. The most challenging aspect of the exercise program is ensuring that the conditioning levels of students are maintained over time.

The Workgroup on Physical Activity, a subcommittee of the Kansas Disability and Health Steering Committee, has recommended the identification of accessible activities in the state. This information on physical activity and disability will be posted on a national website and will offer information to a person with a disability regarding the location of accessible recreation sites. The national website, National Center on Physical Activity and Disability (NCPAD) has a reputation as an excellent source of information and support to positively impact the health of people with disabilities (<http://www.ncpad.org/>). By coordinating with NCPAD Kansas data will be available to all people with disabilities.

## **Goals For Physical Activity**

- People with disabilities in Kansas will sustain levels of physical activity sufficient to achieve and maintain maximum self-sufficiency.

## **Objectives for Physical Activity**

By 2005, increase by 10% the percentage of Kansans with a disability who report participation in physical activity in the past 30 days. (Baseline: 60%)

### **Recommendations:**

- Develop materials, disseminate information, and provide training and technical assistance in cooperation with the National Center for Physical Activity and Disability (NCPAD).
- Review access to health facilities and health-related activities in Kansas and send information to NCPAD for inclusion on Kansas website.
- Support other initiatives that encourage increased physical activity for persons with disabilities, e.g. PACE programs-community based physical activities for persons with arthritis.

By 2005, increase the number of statewide programs, which include people with disabilities as a target population for physical activity interventions. (Baseline: 0)

### **Recommendations:**

- Include both disability and public health perspectives in the following state-level programs:
  - Special Olympics
  - Kansas LEAN 21
  - Kansas KIDS Fitness Day
  - Youth Leadership Forum
- Promote youth involvement in physical activity workgroups

## **Section 6**

### **Summary**

#### **Future Directions**

The five disability and health priority areas of access, mental health, violence/abuse, physical fitness and Surveillance and Evaluation were established through a consensus building process over a four year period. During the last few months of this process, some emerging priorities were identified. These include: role of care givers, drug/alcohol use, employment, and evaluation. Some of these issues are already included as part of current priority areas, but the steering committee recommended that these emerging areas continue to be explored and developed.

The Disability and Health in Kansas Public Health State Capacity Planning Document includes priority areas, baseline data where available, goals and objectives and emerging issues. This document was written from the perspective of people with disabilities who believe that Home and Community Based Services provide the best opportunity to maintain their health and wellness.

It is hoped that this plan will provide participant agencies in the strategic planning process a tool to develop specific program strategies, work plans, and policy and legislative recommendations. Future collaborative efforts of Steering Committee members will insure that disability is part of the state of Kansas' public health agenda and will also support the maintenance of disability in the national public health agenda through HP 2010.

## REFERENCES

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