Health-Related Quality of Life, Part II — State and Local Applications

Massachusetts’ FamilyConnection

Using Healthy Days Measures Improves Women’s Quality of Life

The Behavioral Risk Factor Surveillance System (BRFSS) Healthy Days measures have been used to identify health disparities, track trends in population health, and monitor progress toward meeting public health goals. But health officials in Massachusetts found that the measures can also be a useful screening tool for identifying problems such as depression and domestic violence that can reduce a person’s quality of life and result in health-damaging behaviors, including substance abuse. Massachusetts’ FamilyConnection is an excellent example of how states are adapting and using these measures to identify underlying problems and develop interventions to improve the quality of life of their residents.

Attempting to Pinpoint Risk Factors Among Underserved Women

FamilyConnection grew out of a 1998 project funded by the Health Resources and Services Administration (HRSA) and conducted by the Massachusetts Department of Public Health (DPH) to explore issues related to screening and interventions to prevent alcohol use during pregnancy. Lessons learned from the screening program were incorporated into another grant from HRSA in 1999 to examine risk behaviors such as substance abuse, tobacco use, and unprotected sex among women who weren’t pregnant. From this HRSA grant, FamilyConnection was born.

“Women, particularly new mothers, often do not seek care for themselves,” said Steve Shuman, Assistant Director of the Division of Perinatal and Early Childhood Health at the Massachusetts DPH and coauthor of the project’s final report. “Instead, they cope with relationship issues, stress, anxiety, and depression in whatever way they have learned. For too many, this may be with alcohol, tobacco, drugs, or other behaviors that affect quality of life.”

FamilyConnection started in 1999 in three family planning clinics and in FIRSTLink, which links families with needed services and support. All sites were within a 50-mile radius of Boston. In the first year of this 3-year project, the study used a tool that screened for risk behaviors (e.g., Do you smoke cigarettes?). Although these questions could pinpoint specific risk factors, they...
Commentary

Live Better, Live Longer

In this issue of CDN, we look at the many ways in which state and local health departments are beginning to use health-related quality of life (HRQOL) measures to identify populations hurt the most by chronic diseases, to strengthen health promotion programs, and to support environmental and policy changes that will have lasting, broad benefits to the population.

CDC’s Healthy Days measures are fairly simple questions that have real value in helping to track HRQOL outcomes. It is about time that we as a society recognize and begin to keep score of this fundamental component of health.

In a recent issue of the New England Journal of Medicine, investigators found that people at age 70 who had no activity limitations lived about 3 years longer than people who had one or more limitations in a variety of activities associated with daily living.* This finding was not surprising. What was surprising to the authors was that after age 70, initially healthy people had slightly lower total lifetime health expenditures despite living 3 years longer. Although the initially healthy people did eventually become ill and incur expense, their health care expenditures per year of life were about 25% less than those of people with activity limitations.

So arriving at age 70 relatively well, without limitations in health-related quality of life, was associated with not only longer life but also lower health care costs. Also, people who reached age 70 in good health spent fewer years substantially disabled than people who had activity limitations at 70.

This is important because much of our total health care spending occurs in the last few years of life. Moreover, this study and others dispel notions that helping people live longer would increase total health care costs. While this is good news, it is even better news in terms of the aging baby boomer generation. Even moderate delays in disability will give us more time as a society to adjust to the health care costs that boomers will incur and more time to work out solutions to deal with these costs. Substantial delays in the onset of serious disabilities will decrease the total costs even more, meaning that a portion of projected health care costs might be avoided completely.

As the number of older adults increases, many older people will need to work to maintain a good standard of living. Some will want to work because they find it fulfilling and enjoyable. Others may want to volunteer or to take care of grandchildren while the parents go to work. Regardless, they can work only if they are healthy.

A critically important part of older life is not just its length, but its quality and enjoyability. We emphasize health-related quality of life so that older individuals can work if they choose, stay connected with their families and friends, and not be in pain or consider themselves a burden. The goal of public health is to increase the duration of that high-quality fulfilling life.


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Centers for Disease Control and Prevention
did not encourage women to recognize problems and seek further help, according to Jean Mahoney, BSN, the project’s first supervisor who currently works for the American College of Obstetricians and Gynecologists.

The first year produced very few positive results, especially at the FIRSTLink site. Judy Hause, LN, Health and Human Service Coordinator for the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) Program, Massachusetts DPH, believes that these disappointing results were probably caused by the nature of the questions and the relationship between the woman and the home visitor. At the end of first year, the project stayed in the family planning sites but pulled out of the family home visiting program and added one WIC site.

Adopting (and Adapting) the Healthy Days Measures

Because the risk factor questions were not eliciting the kinds of responses from women that could be used as a starting point for counseling, the researchers began to look for a tool that asked women how they were doing rather than what they were doing. Ms. Mahoney saw the Healthy Days measures in the BRFSS and called CDC’s health-related quality of life assessment program, which not only allowed her to use these measures but also worked with her to modify them to suit the purposes of the FamilyConnection project. Changes that were made included adding a question about whether the woman was considering changes to make her lifestyle healthier and simplifying the wording of the questions.

The biggest advantage of the Healthy Days measures for FamilyConnection is their breadth. “For our purposes, our screening tool had to be broad to capture a woman’s wide range of issues. Otherwise, only one issue—such as drug abuse or smoking—would receive concentrated focus,” Ms. Mahoney said. “Unfortunately, that one issue may not be the most important, or it may be only a symptom of a greater underlying problem.”

Ms. Hause agrees: “Staff at the initial site loved the screening tool because of how it could open the door to conversation. The quality of life measures were ideal for our purposes because they cast a wide net. Because of the broadness of the tool, there were some fish we had to throw out, but we caught a whole lot more fish than we ever expected.”

Core Healthy Days Measures

1. Would you say that in general your health is excellent, good, fair, or poor?

2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?

3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?

4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities such as self-care, work, or recreation?
Ms. Hause also noted that another advantage of the tool was that it was unremarkable to participants. “Women didn’t have a strong reaction to the screening questions. For them, talking about how they felt was easier and less invasive than being asked directly if they used drugs or alcohol.”

Helping Women Get the Help They Need

The Healthy Days measures were used first at only one WIC site but eventually expanded to the family planning sites and two additional WIC sites. At all sites, staff members were carefully trained on how to use the screening tool and how to do a brief intervention. In the brief intervention, case managers used responses to uncover underlying problems by following up on why women felt a particular way. If this brief counseling session turned up a potential problem, women were asked if they would like to talk to someone. Those who accepted were referred directly to an on-site case manager who administered other questionnaires and discussed issues. If specific issues such as depression, domestic violence, tobacco use, and alcohol abuse surfaced in these sessions, women were asked if they would like to be referred to treatment services to help them deal with these problems.

According to Mr. Shuman, use of the Healthy Days measures met with amazing success in WIC. “We learned that WIC, with its holistic approach to health care, was the ideal place to engage, screen, and refer women to case management or treatment,” he said. The overwhelming percentage of those who were screened (86%) reported an impaired quality of life. Of these women, 95% agreed to the brief intervention, and of those, 99% were referred to case management. More than half of those referred (56%) enrolled in case management for stage-based motivational counseling. Of those who enrolled in case management, 79% were referred to treatment programs. The case manager determined whether a participant was ready for treatment, which could include mental health counseling, smoking cessation, alcohol or drug abuse counseling, and protection from domestic violence. At the WIC sites, 69% of women screened positive for depression. “We weren’t surprised that so many women were depressed,” Ms. Hause remarked. “Living at 185% of the poverty level and having a new baby is depressing. What surprised us was the number of women who were willing to accept case management and work on making a change.”

FamilyConnection ended in March 2003, when its HRSA funding expired. Ms. Hause is continuing to look for funding opportunities. “We were really disappointed to have to let our case managers go,” she said. “We hope to get the project funded and up and running again.” In the meantime, the project serves as a model for using the Healthy Days measures to ensure that underserved women get the care and treatment they need to improve their overall quality of life.

For further information on the FamilyConnection project, contact Judy Hause at judy.hause@state.ma.us.
Missouri

Leading the Way in Testing and Using HRQOL Measures

When questions about health-related quality of life (HRQOL) were first added to CDC’s Behavioral Risk Factor Surveillance System (BRFSS) in 1993, Missouri lived up to its reputation as the “show me” state. The state BRFSS coordinator was very skeptical that people would stay on the phone if you asked them right up front about their mental health. So state officials put the HRQOL questions later in the survey the first year. The next year, they put the questions back at the front of the survey like the other states. Then they compared the responses for the 2 years and did not find significant differences. CDC benefited from that experiment.

The four core HRQOL questions ask people to rate their general health and estimate how many days in the past 30 they have experienced poor physical health, poor mental health, or limitations in their usual activities.

Besides helping to prove that people will answer questions about their mental health at the beginning of a survey, Missouri has played an integral part in helping CDC develop, test, and promote the HRQOL measures. The productive relationships between the state’s health department, universities, and Prevention Research Center are a model for other states.

Missouri Offers Skills, Motivation, and Vision

Before the core HRQOL questions were added to the BRFSS, Missouri’s state coordinator, Jeannette Jackson-Thompson, MSPH, PhD, offered to pilot test them in a 1992 county survey. The results gave CDC its first real HRQOL data and marked the first community use of these measures anywhere in the country. Since then, Missouri researchers have used HRQOL data in several studies, focusing on topics such as arthritis, disability, and unmet service needs in elderly populations. They also have helped test and prove the measures’ validity and reliability. In 1994, they pilot tested CDC’s optional quality of life module, which asks additional questions on activity limitation and symptoms of pain, depression, anxiety, sleeplessness, and vitality.

Missouri’s seven Regional Arthritis Centers (RACs) support individuals and families affected by arthritis. For more information, visit http://www.muhealth.org/~arthritis/ractp.html.
The Missouri researchers were instrumental in helping CDC refine the questions. They have also been a close partner in developing, validating, and applying the HRQOL measures. They are among the leaders of the state health departments in terms of their ability to analyze survey data.

David Moriarty, a CDC program analyst, also credits the state health department with “leadership and skills at the top and a vision of how these measures and the resulting data can be used for population health assessment and surveillance.”

In 1994, CDC asked Missouri officials to help develop and pilot test an optional arthritis module because it was the only state routinely collecting arthritis data on its BRFSS survey (Arizona and Ohio collected data periodically). Arthritis is the leading cause of disability in the United States and contributes significantly to poor HRQOL.

Missouri also was the first state to establish a statewide arthritis program. Today, it boasts seven Regional Arthritis Centers (RACs) that offer arthritis-related education, resources, and intervention services such as self-help courses and exercise classes geared toward people with arthritis (see map, page 5).

“The RACs are a huge part of our program, and they represent how we’re responding to the needs of our population based on the data that have been collected,” said Beth Richards, manager of the Arthritis and Osteoporosis Program in the Missouri Department of Health and Senior Services (DHSS).

In Missouri, about one in three adults have arthritis, and nearly half report joint pain, stiffness, or swelling, according to the 2001 Missouri BRFSS. Arthritis and its related activity limitations contribute significantly to mental distress and poor perceived health, and people with arthritis report a higher prevalence of other chronic diseases such as asthma, cardiovascular disease, diabetes, and osteoporosis.

Maintaining appropriate weight, seeking early treatment, and participating in self-management courses can reduce the impact of arthritis and improve the quality of life of people with the disease. Unfortunately, many people don’t know that they can prevent or offset the effects of arthritis or that help is available.

“Ten years ago, the message was, if you have arthritis, you really can’t do anything about it,” Ms. Richards said. “The leaders in the RACs are still struggling to convince people that physical exercise is definitely going to help them. The quality of life data are important because they will help us know where to go with this message and how to target people who are not taking advantage of the available resources.”

County Data Prompt More Money for Programs

When the HRQOL measures were first used in a 1992 survey in Boone County, the results helped guide services at a newly opened Family Health Center in Columbia. This clinic serves mainly low-income, uninsured, and underinsured people, and focuses on providing primary care and
referrals to other health care and community services.

In 1995, the Boone County Commission asked the Missouri DHSS (then the Department of Health) to conduct a broader survey because the first one included mainly residents of the city of Columbia (where most of the county’s population lives).

The new data collected for the 1995 Boone County Health and Human Services Needs Assessment brought in more than $6 million in additional funding for county programs, according to Dr. Jackson-Thompson.

The Family Health Center used the data to win several new grants, including funding as a Federally Qualified Community Health Center from the Health Resources and Services Administration.

The data also prompted the county’s Chamber of Commerce to establish the Boone County Health Report Card, a project designed to identify and improve specific health problems. Community teams were established to address these problems, which included rising health care costs, low childhood immunization rates, and barriers to health and dental care.

Since the early 1990s, Missouri has continued to expand its use of HRQOL measures in state, regional, and local surveys. Four other counties have conducted health surveys, and in 1998, Boone County conducted a third needs assessment. The results of these surveys will help county officials plan and develop programs and services.

For example, concerns about the health and social impact of high school dropout rates in Boone County led to a major effort to hire more literacy specialists, according to Bill Elder, PhD, interim director of the Office of Social and Economic Data Analysis (OSEDA) at the University of Missouri. OSEDA works with state and local groups to collect, analyze, and translate data to help educate community leaders and citizens about public policy issues.

More recently, the HRQOL measures were included in a survey of key chronic disease indicators conducted in all 114 Missouri counties and the City of St. Louis in 2002. This study marks the first time that all four HRQOL measures have been used anywhere in the country to produce such a large amount of local data.

Public health officials will now have a sharper, more focused picture of the health of state residents, as well as baseline measures to track progress in health interventions. The data also should help educate local policy makers who sometimes dismiss state or national data as not reflecting their communities.

“Data talk in this era of accountability,” said Bert Malone, MPA, former director of the chronic disease division of the Missouri DHSS. “When you can provide sufficient numbers of county surveys, people sit up and pay attention.”

Mr. Malone, who is now the director of environmental health in the Kansas City Health Department, added that HRQOL data collected in the early 1990s helped prevent
drastic cuts in the state’s arthritis program.

“We were able to use that data to sustain the program with only marginal cuts in an environment where programs were getting whacked right and left, mainly because we could adequately define the burden of disability and convince policy makers that this was a significant health condition that warranted funding,” Mr. Malone said.

“When you can provide sufficient numbers of county surveys, people sit up and pay attention.”

Collaborative Relationships Offer Key Support

In addition to their own collaborations, CDC and Missouri state officials have forged strong partnerships with the state’s academic institutions, including the University of Missouri and Saint Louis University’s School of Public Health and Prevention Research Center (PRC). Each organization supports the other with funding and personnel, resulting in more research and more state and community services.

Cooperative agreements, particularly with the Saint Louis University PRC, have supported studies to examine the validity and reliability of the HRQOL measures, as well as their ability to measure unmet service needs and disability rates.

“Missouri is a really good example of how the PRC works with the state health department to develop quality of life approaches,” Mr. Moriarty said. “This type of linkage would be particularly valuable for states that don’t have their own in-house capacity for analysis.”

Elena Andresen, PhD, MA, director of the PRC methods core, called the partnerships “a great model that has allowed us to do a lot of practice-based work in public health,” adding, “You can’t start these relationships easily, so if you have the foundation already, and you have funds and projects going back and forth, adding new projects becomes much easier.”

Dr. Andresen, who also is an associate professor and director of the epidemiology division at Saint Louis University’s School of Public Health,
believes the HRQOL measures can serve as broad indicators of community health problems that crosscut risk factors, diseases, and health programs.

Although HRQOL data cannot help you identify a specific problem or know exactly how to change an intervention, they can be a red flag that a program is not working. If your targeted population—or a subgroup of that population—is still reporting poor quality of life or limitations in their activities, you know to dig deeper to find out why.

“HRQOL measures are not used as much as they could be,” Dr. Andresen said. “I think people often look at very specific behaviors, risks, and outcomes, and they neglect to consider general health status. I think that’s unfortunate because you can get an additional piece of information that gives you a broader picture of what interventions and programs are doing.”

Dr. Jackson-Thompson agreed. “One of the big advantages of these measures is that you don’t have to be an epidemiologist to understand them,” she said. “There’s virtually no program that wouldn’t find them useful. And they’re something the public can relate to because everybody wants good health.”

### Hennepin County, Minnesota

#### County-Level Data Key to Effective Public Health Practice

Comprehensive county-level health assessments are uncommon. Hennepin County, Minnesota, is one of four counties in the United States identified by CDC for their exemplary reports on local health-related quality of life (HRQOL) data. Most counties lack the resources to do their own surveys. Mostly larger entities such as cities or states conduct them. The advantage of communities doing their own survey is that they can look at their population subgroups, both geographic and demographic, and identify unmet health needs.

Hennepin County is thoroughly researching and reporting on community health not only to determine the health status of its residents and assess their health needs, but also to identify community factors (e.g., access to care, social support, social connectedness, economic distress) that affect the physical and mental health of the population. The goal is to obtain information for program planning and policy development.

The largest of Minnesota’s 87 counties, Hennepin comprises urban, suburban, and rural communities. It is home to about one-fourth of the state’s population (more than 1 million people) and half of the state’s racial/ethnic minority population.
Hennepin County recently published data from its Survey of the Health of Adults, the Population, and the Environment (SHAPE) for 2002. The SHAPE project is a collaborative effort of the Hennepin County Community Health Department, the Minneapolis Department of Health and Family Support, and the Bloomington Division of Public Health. SHAPE uses the core Healthy Days measures to rate overall health in Hennepin County. An initial survey conducted in 1998, SHAPE 2002, and future surveys will allow Hennepin County to assess the health status of residents, track health indicators and other measures, and identify trends in the population.

SHAPE 2002 data are also used to compare county health rates with those of Minneapolis, the state, and the nation (see figure). “It’s important to us to track and meet the national Healthy People 2010 goals, especially the HRQOL goals, at the county level,” explained Margaret Hargreaves, MPP, SHAPE project director. Hennepin County has gathered solid baseline data and is poised to develop appropriate and targeted interventions because of its clear understanding of where problems exist.

General Findings and Specific Results

According to SHAPE 2002 data, Hennepin County residents rate their health as being better than that of other adults in the general U.S. population. More than 90% consider their health good, very good, or excellent, compared with the national rate of 85%. SHAPE 2002 documented some encouraging findings, including a dramatic decrease in the smoking rate for adults aged 18–24 years, from more than 36% in 1998, to 23% in 2002.
“This is the only group to show a decrease,” noted Ms. Hargreaves, who suggests the decline may be due to increased state and county efforts to reduce tobacco use among young people during the 3 years prior to the survey.

Also, seniors (aged 65 or older) reported surprisingly good health. Ms. Hargreaves noted that the self-reported rate of good to excellent health was roughly the same for residents aged 65–84 years as for those aged 84 years or older. “We are not sure why we do not see the same sharp decline in health among older adults that is seen nationwide,” she said.

Although Hennepin County residents reported generally better health than other U.S. residents, SHAPE 2002 data did identify health disparities associated with race/ethnicity and place of residence. Not only did SHAPE 2002 gather data on five racial and ethnic groups (American Indians, Asians/Pacific Islanders, African Americans/blacks, Hispanics/Latinos, and whites), but the survey also distinguished between U.S.-born blacks and African-born blacks and looked at Southeast Asians as a distinct group.

Ms. Hargreaves pointed out one finding unique to a specific subgroup when looking at which residents obtained recommended health screenings. “We found that among nonimmigrant groups, the differences among racial/ethnic populations were surprisingly small; however, among immigrants (e.g., foreign-born Latinos, African-born blacks), particularly new immigrants, there were large differences in getting preventive health care services.” Ms. Hargreaves explained the importance of not lumping members of various races and ethnic groups into the same category. “Generic racial/ethnic rates mask significant differences in [rates among] racial/ethnic subgroups,” she said.

Investments in Local Data Charged by County Support and Community Needs

The county’s extensive focus on gathering, analyzing, and reporting local data can be partially attributed to local support including that of community health boards, community organizations, and county commissioners. The missions and strategic plans of these local entities prioritize health, safety, and quality of life for their constituents. The concept of quality of life is well received by local and business communities. Mayors and other local officials take pride in the fact that their community is identified as a good place in which to live and where residents feel good about their health and well-being.

In addition to receiving civic backing, including state-appropriated funds and core public health grants, Hennepin County receives technical support for public health surveillance from the Minnesota Department of Health, the University of Minnesota School of Public Health, and local and national health experts. “We have a highly rated hospital—the Hennepin County Medical Center—which is an anchor to our local health efforts,” explained Ms. Hargreaves. “SHAPE data are also extremely helpful because we are coordinating the
Local data are not the same as national data.

Distributing the Data and Reaching Out

By sharing its data and methods with other counties and on state and national levels, Hennepin County is serving as a model for others who want to conduct comprehensive local public health assessments. SHAPE 2002 data were presented to more than 600 attendees at the Health Disparities Summit held in January 2003. “We presented SHAPE data at health services research, local, and statewide conferences, including recent diabetes and cancer conferences,” said Ms. Hargreaves. “In fact, SHAPE data were featured at the Hennepin County SHAPE Up Conference in October 2003 that focused on exercise, nutrition, and obesity.”

Although Hennepin County is in the early stages of applying the findings of SHAPE 2002, many in the public health community have taken notice. The SHAPE survey questionnaire is being used in the development of other health surveys by the Winnipeg Regional Health Authority; by counties in Michigan, Ohio, and Connecticut; and by other counties in Minnesota. “The six other counties in the metropolitan area are preparing to conduct surveys and are working on getting funding,” Ms. Hargreaves said.

In addition, Hennepin County provides data and technical assistance to other county programs. Hennepin County helps county public health workers prepare grant applications, obtain other types of funding, and plan evaluations for projects designed to improve public health or reduce racial/ethnic health disparities.

“We also work with community groups to analyze data and answer questions,” said Ms. Hargreaves. “For example, we are working on an analysis of mental health among African American men, asthma among adults, and data for an American Indian family project,” she said. Other county projects include looking at how traditional and complementary health care varies among different populations and how alternative medicine affects quality of life. The county is also working with a health committee in North Minneapolis to identify ways to improve the health of high-risk populations.

Key Approaches to Collecting Local Data

When asked what advice she would give to other local health departments in collecting data, Ms. Hargreaves recommended some key strategies. “It is important to involve many partners to shoulder the load and get buy-in,” she said. She also emphasized the collaborative approach as a way to pool resources (e.g., expertise, funding, staff) and avoid duplication of efforts. Ms. Hargreaves advised conducting one thorough survey instead of over-researching certain racial/ethnic communities with limited, disjointed studies and suggested investing more time upfront on survey development and planning before gathering data.

“Engage community members and
get their input on what needs to be researched or added to your survey,” she said. “It is important to listen to your target audience and to be flexible.” After hearing that getting phone interviews might be difficult in some communities, SHAPE researchers arranged to speak with respondents in person. “We conducted 9,782 telephone surveys and did 178 face-to-face interviews, and it was a great help to be prepared to conduct in-person surveys,” said Ms. Hargreaves.

To get statistically reliable data for certain racial/ethnic populations, researchers oversampled some neighborhoods with large racial/ethnic minority populations and conducted the survey in five languages (English, Spanish, Somali, Hmong, and Vietnamese). “Translating the survey into other languages was extremely beneficial,” said Ms. Hargreaves. Before translated versions of the survey were finalized, back-translations were done and members of the target communities reviewed the translations to be sure they were understandable. “Don’t skip this step,” Ms. Hargreaves warned. “The survey firm hired bilingual and bicultural interviewers, and it helped when the interviewer began the conversation in the language of the respondent.”

Finally, Ms. Hargreaves emphasized that although gathering local public health data is time-consuming and expensive, it is well worth the effort. “It’s difficult, but it’s not impossible,” she said. “Local data are not the same as national data, and it’s important to look at what’s going on locally.”

Building on the Foundation

SHAPE is an ongoing survey, which Hennepin County plans to conduct every 4 to 5 years. “Our goal is to look at trends over time,” said Ms. Hargreaves. The county will use a core set of surveillance questions and incorporate new questions as needed to identify emerging health issues and gather information of special interest to specific populations. After evaluating the SHAPE questionnaire conducted in 1998, Hennepin County made strategic changes to the next survey. “For example, some key differences between our 1998 and 2002 questionnaires are that in 2002, we had more questions about men’s health, mental health, and cultural factors and their influence on health,” she said. Hennepin County also plans to conduct additional surveillance to fill gaps in information on the health of its children. “Before we conduct the next adult survey [SHAPE in 2006], we hope to do an assessment of the health of our population that is under 18,” Ms. Hargreaves said.

National Support for Local Public Health Assessments

Because of its size and its racial/ethnic and geographic diversity, Hennepin County needs the sort of local stratified data that SHAPE provides to identify health problems within specific population subgroups. The Behavioral Risk Factor Surveillance System (BRFSS) provides state data; however, public health planning differs across states. Ms. Hargreaves noted, “Some states administer services predominantly at the county level, and this is especially true for states in the Midwest.”
Recognizing the need for local data, the National Association of County and City Health Officials (NACCHO) developed an initiative called Mobilizing for Action through Planning and Partnerships (MAPP) that outlines a comprehensive approach to community health by assessing four community components: community themes and strengths, the local public health system, community health status, and the forces of change. (For more information, visit http://www.naccho.org/PROJECT77.cfm.) The MAPP strategy is to identify positive assets as well as public health problems and outline a comprehensive and systematic plan to improve community health.

CDC supports NACCHO’s initiative and is promoting the collection of local HRQOL data. These data are critical to public health because they give a broader and more timely measure of health than has been used in the past and are specific to the community. Data collected directly in a survey can be used to identify and prioritize current problems, develop a strategy, and make improvements.

Hennepin County is establishing a wealth of useful data that can be applied to improving the physical and mental health of its residents, as well as their overall quality of life. “Communities don’t do enough community health assessment, and that is the most fundamental role of public health—to track the health of the population,” stated Ms. Hargreaves. “You need local data to effectively improve public health.”

For More Information

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Hennepin County Reports (partial list)
SHAPE 2002 and other reports are available at the following Web site: http://www.co.hennepin.mn.us Scroll to Reports, Plans, and Studies
SHAPE 2002: A Preview
January 2003
SHAPE 2002: Racial and Ethnic Data Book
March 2003
SHAPE 2002: Geographic Data Book
July 2003
SHAPE 2002: Methodology Report
November 2003
Senior Health Report Card
November 2003
Community Health Services Plan Assessment
Fact Sheets
January 2003
How Are California Counties Using HRQOL Data?

In two of California’s more populous counties, the Behavioral Risk Factor Surveillance System’s Healthy Days measures have been used to assess the impact of chronic physical and mental health conditions on people’s daily lives and estimate the economic burden of chronic disease in the county.

Los Angeles County

CDC’s Healthy Days questions (see sidebar, page 16) were used in the 1999–2000 Los Angeles County Health Survey (a random-digit-dialed telephone survey of 8,354 noninstitutionalized adult residents) to assess the substantial toll that chronic health conditions impose at both the personal and societal level.

“Our leadership has been a strong supporter of adding health-related quality of life questions to this survey,” said Paul Simon, MD, MPH, director of L.A. County’s Office of Health Assessment and Epidemiology. “Our health officer has really pushed our department to develop a more active presence [in this area].”

After adding CDC’s Healthy Days questions to its biannual survey, researchers found that county residents reported higher average numbers of both unhealthy and activity limitation days than were reported overall in California and in the United States. However, it was unclear whether these differences reflected true disparities in health status or demographic variations between the populations.

The survey findings also reinforced a large body of research linking poor health outcomes with lower socioeco-
L.A. COUNTY Healthy Days Measures

The following questions were asked in the 1999–2000 Los Angeles County Health Survey (random-digit-dialed telephone survey of 8,354 adult residents):

1. Would you say that in general your health is excellent, very good, good, fair, or poor?
2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

Responses to the second and third questions were added together to estimate the total number of days in the past month that the respondent felt that either his or her physical or mental health was not good, a summary measure referred to as “unhealthy days.” Responses to question four were used to estimate the number of days in the past month that activity was limited because of poor physical or mental health, referred to as “activity limitation days.”

Available information generally includes mortality statistics and not much more.
To address some of the knowledge gaps in this area, Los Angeles County conducted a study to explore the combined impact of multiple chronic conditions on functional status and health-related quality of life (HRQOL).

The county limited its study to nonelderly adult residents (18 to 64 years of age) and assessed the impact in this population of selected chronic health conditions on people’s functional status based on activity limitation days (ALDs), a validated measure of HRQOL. Researchers also examined countywide variation in chronic disease impact by age, sex, and race/ethnicity. The analysis was restricted to 1999 survey data from 7,121 adults in the selected age group who reported that they had ever been diagnosed by a health care provider with heart disease, diabetes, arthritis, depression, or asthma, conditions that cause the most ALDs in the county.

Based on their analysis, researchers concluded that at least one in four nonelderly adults in Los Angeles County has been diagnosed with a chronic disease and that the five chronic conditions included in the analysis account for at least 40% of all ALDs in this population. Furthermore, they found that although the prevalence of adults with multiple chronic conditions is relatively low, this group accounts for a disproportionately high burden of ALDs.

As might be expected, the study confirmed that chronic disease impact increases with age. Investigators also found a higher impact among women than men, and a lower impact among Hispanics (possibly reflecting a younger age distribution and higher level of undiagnosed disease) than among whites and blacks.

Dr. Simon reported that such findings present significant opportunities for reducing the burden of chronic diseases in the nonelderly adult population. For more information about study findings, call the Los Angeles County Office of Health Assessment and Epidemiology at 213/240-7785 or visit its Web site at http://www.lapublichealth.org/ha/.

San Diego County

The United Way of San Diego County established the Outcomes and Community Impact Measurement Program after eight task forces representing county residents and community leaders developed the following list of desired countywide outcomes in 1995:

- **Access.** People have access to a full range of effective community services.
- **Self-Sufficiency.** People reach and maintain an optimal level of independence and health.
- **Civic Solutions.** People live in, participate in, and are supported by diverse, economically sound communities.
- **Educational Success.** People have the necessary life-long educational support to reach their potential as productive and contributing community members.
- **Public Safety.** People feel safe from the threat of crime and violence in their homes, neighborhoods, and communities.
- **Well-Being.** People are emotionally self-sufficient and able to cope with
the stressors in their lives.

Based on these desired outcomes, the United Way designed a program to examine the impact of community assets and services on meeting people’s needs and expectations. This program, the Outcomes and Community Impact Program, then conducted a health survey among 3,711 randomly selected county residents. Part of the survey focused on the perceived general health status and quality of life of county residents. Findings were examined by the respondents’ geographic location, age, race and ethnicity, educational level, income, and other characteristics, and projections based on these findings were made for the entire current population of San Diego County.

Overall findings from the survey revealed that within each demographic subgroup, from 37.4% to 82.1% of respondents reported their perceived level of health as very good or excellent. Hispanic residents were the least likely to report very good or excellent health, whereas whites were significantly more likely than either Hispanics or blacks to report very good or excellent health.

Other groups more likely to report very good or excellent health were college graduates and persons with commercial or military insurance coverage. The percentage of those reporting their health as very good or excellent increased with annual household income, ranging from 44.5% for those with incomes of $20,000 or less to 82.1% for those with incomes of $100,000 or more annually.

The majority of county residents (59.8%) reported no days of poor physical health in the 30 days preceding the survey, but 4.8% said their physical health had not been good for the entire past month. By demographic subgroup, the average number of days respondents reported their physical health as not good ranged from 2.0 days for persons with $100,000 or more in annual household income to 6.2 days for those covered by the state’s Medi-Cal health insurance program. Persons who were widowed reported a significantly higher mean number of days in poor physical health than persons of other marital status.

Overall, survey respondents reported an average of 3.0 days of poor mental health and an average of 1.9 days when they were prevented from doing their usual activities due to poor physical or mental health within the past 30 days. Nearly 7% reported being physically disabled.

Findings such as these help policy makers determine whether the large
annual investment in improving the health and well-being of San Diego County residents is making a difference.

Future Directions
Other large California counties are expressing interest in using CDC’s Healthy Days measures. In a 2001 Orange County Health Department newsletter, Health Officer Mark Horton, MD, MSPH, wrote:

HRQOL expands the statistical toolbox we use to measure individual and community health to compare communities and regions, and to plan and gauge the impact of our health services and public health programs. It complements our measures of disease burden with a measure of perceived healthiness and will allow us to assess to what extent our health care services and public health programs are working to increase the number of days individuals feel healthy and able to perform their usual activities.’ I expect HRQOL will soon be included in major health indicator reports which draw upon [Behavioral Risk Factor Surveillance System] data at the local, state, and national levels.

According to Holly Hoegh, Director, California Behavioral Risk Factor Survey, most California counties have not used BRFSS data for Healthy Days measures to date because of the small sample sizes. Instead, they rely on findings from the biannual California Health Interview Survey (CHIS), a collaborative project of the UCLA Center for Health Policy Research, the California Department of Health Services, and the Public Health Institute.

Surveying more than 55,000 Californians in 2001, CHIS is the largest health survey ever conducted in any state, and one of the largest health surveys in the country. Its find-
assumption that the social and economic well-being of Oregonians depends on the interconnectedness of quality jobs, a sustainable environment, and caring communities” (Figure 1).

Oregon has proven the worth of using benchmarks to track and improve quality of life of an entire state’s population. In 2002, the Institute for Government Innovation, part of the John F. Kennedy School of Government at Harvard University, recognized the Oregon Progress Board and its benchmarks as one of the 15 most effective public sector programs of the previous 15 years. In a statement announcing the award, Executive Director Gail Christopher said, “The Oregon Benchmarks model has been replicated by other states and has informed both practice and policy debates at the federal level of government and within nonprofit and private sectors.”

One key area of overall QOL is health. In the dozen years since their inception, the benchmarks have gained respect and legitimacy. Kathy Pickle, Oregon’s Behavioral Risk Factor Surveillance Survey Coordinator, says, “There is value in benchmarks. Health care isn’t just an abstract thing. Not only are people getting screened, but what happens next? What should be done for individuals?” Benchmark data give policy makers, health care providers, civic and business leaders, and all Oregonians a report card on and a guide to improving quality of life.

Challenges to Health-Related Quality of Life
As with most broad measures of large groups of people, over time some categories improve, some hold steady, and some worsen. Although Oregonians’ self-rated health is at the national average, the 2003 benchmark report indicates that those who consider their health very good or excellent has fallen from 63% in 1993 to 55% in 2001. Targets for this measure are 65% by 2005 and 72% by 2010.

Oregon is using its Behavioral Risk Factor Surveillance System to track HRQOL for people with chronic conditions such as diabetes, arthritis, and asthma. “We use [the data] to understand which of our populations are bearing the greatest burdens from these conditions and to help tease out some of the causes and related factors,” said Nancy Clark, Health Systems Liaison in the Oregon Department of Human Services. “We are performing surveillance on
those things that affect quality of life.”

One program working to reverse the downward health trend is the Oregon Diabetes Program (ODP). The number of Oregonians reporting diagnosed diabetes increased from 4% in 1995 to 6% in 2001. People over age 65 are particularly at risk: 14% have diagnosed diabetes. The ODP uses the Healthy Days measures to compare the HRQOL of Oregonians with diabetes to that of Oregonians without diabetes. The 2002 Report Card of the Oregon Diabetes Program indicates that in the previous 30 days Oregonians with diabetes had 5 fewer physically healthy days and one less mentally healthy day than Oregonians without diabetes.

The 2001 Oregon Behavioral Risk Factor Surveillance Survey indicates that 36% of Oregonians have some type of arthritis. Those with arthritis were also more likely to report being inactive and obese.

Oregon asthma programs are also using HRQOL research. “In the asthma program, we have made an effort to look specifically in surveys among people with asthma to determine if their limited activity is, in their view, a consequence of their asthma,” said Richard Leman, MD, Oregon’s Chronic Disease Epidemiologist. “Our role is to educate, to conduct surveillance, and we feel it is useful to look at quality of life and degree of disability. The next part of our role is education of people who can do something about that. It’s part of the partnership between the public health department and people in the community.”

Benchmarking Smaller Populations

Benchmarking at the state level has proven so useful that local government and business leaders are applying the concept to counties and cities. An example is the Portland Multnomah Progress Board (PMRB), modeled after Oregon’s Progress Board. The PMRB benchmarks the city of Portland and its surrounding county, Multnomah. The PMRB’s mission statement summarizes their goals: “The Portland Multnomah Progress Board identifies, monitors, and reports on indicators (named Benchmarks) for important community-wide goals. The Board identifies major trends in the community and acts as a catalyst for government, business, and community groups to improve the performance of the benchmarks.”

Oregonians take their benchmarks seriously and intend them to be drivers of change, rather than just more compiled data. A Brief History of the Portland Multnomah Progress Board states, “Benchmarks place a priority on measuring results, such as adult literacy, rather than efforts. Community indicators are more meaningful signs of achievement than are the expenditures on programs. They tell us whether our strategies are working to get results. By focusing on and monitoring the outcomes, community leaders and citizens can reset priorities and adapt and modify programs as they learn what works.”

Benchmarking the Future

Oregon is proving the benchmark concept useful in monitoring and
trying to improve HRQOL. “We report HRQOL data for advocacy, to show we need to do more as a community and state. We need to find ways to deal with health problems so they don’t interfere with people’s activities,” says Dr. Leman. “We use the data as a tool to educate health care providers and others about how much these issues affect people, and to promote coalitions in the community to improve quality of life.”

North Carolina
How Many Years of Your Life Will You Enjoy Good Health?

Life tables have been around for decades, projecting how long we can expect to live. North Carolina has gone a step further by estimating how many years its residents can expect to enjoy good health. The findings are described in the report Healthy Life Expectancy in North Carolina, 1996–2000 (http://www.schs.state.nc.us/SCHS/pdf/SCHS-129.pdf).

Health statisticians used 1996–2000 mortality data to calculate life expectancies. They then used 1993–2000 data from the state Behavioral Risk Factor Surveillance System (BRFSS) to estimate, by age, the average years of life remaining in good perceived health, in good physical health, in good mental health, and without activity limitation (based on responses to CDC’s four Healthy Days questions).

These combined measures—of death and nonfatal health outcomes—are also known as summary measures of population health. Summary measures are of great interest around the world because public health agencies can use them to identify problems, strengthen programs, and guide policies.

North Carolina’s summary measures have revealed some significant health disparities. For example, even though minority men and women don’t live as long as whites, they spend more years with physical or mental health problems or limitations in activity than white men (see graph, page 23).

As the state’s population ages, the burden of chronic and disabling diseases will only increase, predicted Ziya Gizlice, PhD, North Carolina’s BRFSS project director and a coauthor of the healthy life expectancy report. Having the BRFSS Healthy Days survey data each year will allow the state to regularly update its healthy life expectancy estimates and use the information to strengthen public health efforts.

“We work closely with the state’s Division of Aging and Disability programs,” said Dr. Gizlice. “They use these questions to raise awareness about quality of life issues.” These measures are pretty easy to communicate with people—for example, people with arthritis. They can easily see this information as being relevant to them.”
Governor James B. Hunt made increasing the span of healthy life of North Carolinians the first of the state’s 2010 health objectives. In the future, Dr. Gizlice hopes that state legislators will also keep a keen interest in the healthy life expectancy data. “I think our report is getting the attention of legislators, especially now that baby boomers are getting older. We need to be on top of these measures in terms of quality of life. Yes, we want to live longer, but do we want our last 10 to 15 years to be miserable or healthy?”

Reaction to Race
North Carolina is also using the Healthy Days measures to see how a variety of factors might be affecting people’s health. “In 2002, we included the reaction to race questions on our BRFSS survey,” Dr. Gizlice said. “We also had the Healthy Days measures. It was interesting to see how people who reported being treated unfairly in the health care setting perceived their quality of life to be.

“The difference was stunning,” he noted. “People who reported being treated worse said that out of the past 30 days, they had 14.4 physically unhealthy days and 8.6 mentally unhealthy days. But people who did not say they were treated unfairly reported only 3.6 physically unhealthy days and 2.8 mentally unhealthy days.”

Visitors to the North Carolina Department of Health and Human Services Web site can cross-tabulate almost every question on the BRFSS with the first health status question, he said, “so they can see how the different risk factors and health problems affect people’s perceived general health.”

Dr. Gizlice encourages other states to consider setting up similar Web sites to help the public gain a deeper understanding of health-related
quality of life. “We’re giving people the opportunity to look at the data in a different way. We have over 10,000 tables on our Web site, and we get over 5,000–6,000 hits per month, excluding robots and search engines.”

North Carolina also posts national data and some county-level data on its Web site so that visitors can see how the larger counties compare with each other and with the state and nation in terms of risk behaviors. “In Rick County, where I live, 5.8% of the people reported 8 or more poor physical health days vs. 16.5% in Eastern North Carolina—one of the most impoverished regions of the state,” he noted. “So these data are helping us see where our biggest problems are in North Carolina.”

Healthy Days Measures Shape
A Portrait of the Chronically Ill

The burden of chronic disease in the United States can be calculated using estimates of the number of people affected or in terms of costs or long-term outcomes. Another way to assess chronic disease outcomes is through the patient’s eyes. This was the goal of an online survey conducted by The Robert Wood Johnson Foundation (RWJF) and the Foundation for Accountability (FACCT). CDC’s Healthy Days measures were a key tool used to assess the perceived health burden of Americans with various chronic conditions. To create A Portrait of the Chronically Ill in America, 2001, the report of this study’s findings, FACCT surveyed more than 6,000 people with arthritis, asthma, coronary artery disease, diabetes, depression, and hypertension.

In 1996, FACCT President David Lansky, PhD, contacted CDC and other organizations and individuals with expertise in widely used quality of life measures for advice in identifying standard population health outcome measures. FACCT is a national organization committed to improving health care for Americans by advocating for an accountable and accessible system in which consumers are partners in their care and help shape the delivery of care. To achieve this goal, FACCT wanted to develop consumer-focused quality measures. FACCT was established with support from a broad coalition of public and private partners to address a critical need for standard health outcome measures that could be used to track population health and assess the effectiveness of public health and medical care.

The report’s conclusions are sobering, but they also illustrate the power of quality of life measures. The survey is a good example of how the core Healthy Days measures can be effectively used to illustrate the physical and mental health burden of chronic disease. Including CDC’s core quality of life measures with other disease-oriented measures helps the public health community communicate better with the health care community about desired patient outcomes. “The Healthy Days measures turned out to be an important com-
ponent of the survey,” said Dr. Lansky. The survey overview begins with an observation based on the Healthy Days concept: “People with chronic illnesses are about twice as likely to ‘have a bad day’ as other Americans. They report twice as many days when they could not function normally, and are twice as likely to say they are in poor or fair health.”

What the Survey Found

Alarmingly, the survey showed that underserved and uninsured people experience even greater gaps in health care if they have a chronic illness. People with chronic diseases also report 4 more days a month when they are unable to function normally than people without chronic diseases. FACCT found that one-third of those surveyed do not receive the information and services they need to manage their illnesses successfully.

By identifying similar characteristics of people with and without chronic diseases, the results of the survey clearly suggest that chronically ill people could have better quality of life. People with chronic diseases are less likely to say that they have the support they need to successfully care for themselves. For example, some people with coronary artery disease said they had not been told how to lower their blood pressure, and some people with diabetes reported being unable to master self-care routines.

Public domain FACCT and RWJF health survey measures on general health, caregiver health, end of life issues, depression, arthritis, asthma, diabetes, and heart care include one or more Healthy Days measures and are accessible through the FACCT Web site at http://facct.org/facct/site/facct/facct/measures. For more information, visit http://www.facct.org/facct/site/facct/facct/home. The report, A Portrait of the Chronically Ill in America, 2001, is available at http://www.facct.org/facct/doclibFiles/documentFile_287.pdf.

The findings reported in A Portrait of the Chronically Ill in America, 2001, were used to answer four questions:

1. What is the impact of chronic illness on the overall health, behavior, and quality of life of those affected?

2. Can people with chronic illness get access to needed medical care and related services?

3. Is the U.S. health system providing the appropriate, recommended services to people with chronic illness?

4. Are people with chronic illness working effectively as partners with health professionals in managing their illness?
“In our increasingly secular society, what seems to matter most are economic indicators.”


We know how America’s gross national product compares with Japan’s, but what about the social health of the nation? How does America compare with other industrial countries in such areas as poverty among older adults, access to health care, and youth suicide? That’s what Marc L. Miringoff, PhD, has been asking. Dr. Miringoff, co-author with Marque-Luisa Miringoff and Sandra Opdycke of Social Health of the Nation: How America Is Really Doing, founded and directs the Fordham Institute for Innovation in Social Policy and is associate professor of Social Policy at Fordham University Graduate School of Social Service in Tarrytown, New York.

Noting the lack of a U.S. social index, the Miringoffs developed the Fordham Index of Social Health in 1987, using 16 indicators of social health. They needed a threshold for measuring social progress, so they picked the best performances from the past 30 years of data (for example, in 1973, child poverty was at its lowest level). The index is modeled on economic indicators’ thresholds, and the national media are beginning to recognize it as an analogue to economic indicators.

Dr. Miringoff’s work also interests CDC researchers who are measuring health-related quality of life (HRQOL) because it is important to know what is going on in the community that affects physical and mental health. These factors, called social determinants of health, include the rates of poverty, employment, literacy, and education in a community. One of the purposes of CDC’s Healthy Days measures is to look at the relation between social factors like those included in the Miringoffs’ index and perceptions of health.

Marilyn Metzler, RN, is a co-chair of the CDC/ATSDR working group on social determinants of health, which is composed of interested employees with expertise in this area. “The ultimate goal,” she said, “is to develop methods and measures that we can use to assess the conditions that support health. With such measures, we will be able to describe communities that are sick or healthy in order to expand our understanding of what causes individuals to be sick or healthy.”

CDC research shows that social determinants of health in a community are related to individuals’ perceptions of their health. For example, CDC data show that people in areas of high poverty and unemployment report more unhealthy days than people in areas where fewer are poor and jobs are more abundant. According to Dr. Miringoff’s findings, the three variables with the greatest effect on his index are child poverty,
high school completion, and access to health care.

Americans have a long history of monitoring the “health” of the economy. As a result, most of us are familiar with terms like gross domestic product and recession, which are defined by business and economic indicators and indexes. We are also accustomed to the idea that the nation’s well-being is somehow measured by such indicators. We expect that certain conditions will bring specific consequences; when the economy stalls, for instance, the Federal Reserve may lower interest rates.

“Economic indexes are institutionalized; they trigger action,” noted Dr. Miringoff.

But despite their strengths, economic indicators are not the only valid measures of how the nation is doing. They do not describe the nation’s quality of life. Many people do not find them relevant to their daily life.

Why We Need a National Social Report

Dr. Miringoff envisioned a different type of national index—one based on social data. Such an index “would provide a very different picture from what is conveyed by traditional business and economic barometers,” he wrote in Social Health of the Nation. Social data are not collected as frequently as economic data, nor are they commonly treated as indicators of how the nation is doing. The findings of a particular study or survey may create public interest briefly, but they seldom attract the kind of media analysis that economic reports receive. Social data may be less accessible to the public and media because they are issued discretely, without common definitions.

Social determinants of health are rarely discussed in terms of their interrelationships. Dr. Miringoff argues that analyzing social issues in relation to each other, rather than in isolation, will promote public understanding of our strengths and weaknesses. “The lack of context and regularity in the reporting of social issues, and the absence of the kind of familiarity that an ongoing narrative, grounded in fact and interpretation, could provide, have made public deliberation about social issues more vulnerable to the politics of the moment,” he wrote.

In contrast, the last 12 years of index data clearly show areas in which the nation’s performance is improving (infant mortality, high school completion, poverty among older adults, and life expectancy); areas of worsening performance (child abuse, child poverty, youth suicide, and others), and areas for which trends are shifting (adolescent drug use and adolescent birth rates).

Social reporting can benefit every level of government. Under Dr. Miringoff’s direction, The Fordham Institute for Innovation in Social Policy produces The Social State of Connecticut, a report used by the governor’s office and the state legislature to assess the social well-being of the citizens of Connecticut. The goals of the project are to focus public attention on the issue of social health in the state, inform public
policy, and create an accessible information source. The document brings together diverse information regarding a number of critical social problems over an extended period of time. It has made a difference in Connecticut. After noting an increase in child abuse one year, Dr. Miringoff met with legislators, who redirected funds to address the problem. Connecticut has shown overall improvement in all categories 6 years in a row.

The indicators included in the Index of Social Health offer warning signs that significant sectors of our national life are in decline or crisis. The data indicate that the nation’s social health was stronger in the 1970s than it is today. Dr. Miringoff is particularly concerned about rising youth suicide rates.

Dr. Miringoff would like to see a government organization that would function as a Council of Social Advisors to the President (like the Council of Economic Advisors). Among other duties, this group would produce an annual social report that would combine state data with national survey data to offer a comprehensive picture of the social health of the nation. It will address the nation’s need for a yearly benchmark of social performance—something that is already available in every other industrial country, but is lacking in the United States.

Current Status of Social Reporting in the United States
You might call health-related quality of life the place where social health intersects with physical and mental health. This intersection is becoming obvious in the many surveys and report cards being used across the nation to measure key health and social factors at various levels (see page 30, “Measuring Quality of Life in the World, Nation, States, and Local Areas”). Some of them combine both social determinants of health and quality of life measures like CDC’s Healthy Days measures.

The CDC Perspective
Whereas Dr. Miringoff wants to stimulate public discourse and shape public policy, CDC has a different perspective. It wants to distinguish between community health outcomes and their social and environmental determinants.

If potential social determinants of health such as community poverty rates truly influence population
health, the effect should be seen in surveys using well-designed HRQOL measures, which track people’s health perceptions over time. CDC researchers want to use continuously collected Healthy Days surveillance data to validate such determinants.

They also want to work with Dr. Miringoff to examine how his index might help to explain variable patterns of response to CDC’s HRQOL measures. Population HRQOL surveillance may be complementary to tracking community indicators of health. The HRQOL surveillance strategy is to track perceived physical and mental health over time in adult populations, identify potential community-level indicators of HRQOL, and analyze ties between survey-based HRQOL data and the indicators.

Although the annual release of the index is covered by national media, including The New York Times and The Washington Post, the public remains less familiar with findings on social health than with economic indexes. Will a national social index improve our quality of life? “We can only hope,” said Dr. Miringoff. ☎
Measuring Quality of Life in the World, Nation, States, and Local Areas

Interest in CDC’s Healthy Days measures has grown as health-related quality of life indicators are recognized as useful tools for identifying populations at risk, health disparities among subgroups, and resource needs in public health planning. Here are some reports that use these or similar measures.

World


Nation and States

America’s Health: State Health Rankings (2003 Edition). Produced by the United Health Foundation in partnership with the American Public Health Association (APHA) and the Partnership for Prevention, the report ranks the healthiness of each state’s population based on 16 measures of health, including the recent activity limitation days data from CDC’s Behavioral Risk Factor Surveillance System (BRFSS). Visit http://www.unitedhealthfoundation.org/shr2003/.

2000 and 2001 State Women’s Health Report Cards

Making the Grade on Women’s Health: A National and State-by-State Report Card is the first report to assess comprehensively the overall health of women at the state and national levels. Visit the National Women’s Law Center Web site at http://www.nwlc.org/display.cfm?section=health.

Kaiser Family Foundation’s State Health Facts Online. This new resource contains the latest state-level data on demographics, health, and health policy, including health coverage, access, financing, and state legislation. Data on all 50 states can be compared by 11 topics, which include demographics, health status, health coverage, managed care, and health costs. To view a profile of a particular state, click on a map, then select a topic. The information is user-friendly and comprehensive. See state comparisons on mental health, including data from the BRFSS on recent mental health. Visit http://www.statehealthfacts.kff.org/.

Cities, Counties, and Communities

Improving Health in the Community. This important publication from the Institute of Medicine (IOM) describes the use of community indicators and performance monitoring to improve community health. The guide also provides tools to help communities develop their own performance indicators. CDC’s Healthy Days measures are included among the IOM’s...

Community Health Status Indicators Project
(http://www.phf.org/data-infra.htm)
The Community Health Status Indicators (CHSI) Project has produced a county-specific report of community health status for local jurisdictions across the United States. The project’s goal was to provide important health and health-related data, presented in a way that makes them useful to communities. This collaborative activity of the Association of State and Territorial Health Officials, the National Association of County and City Health Officials, and the Public Health Foundation was initially funded by the Health Resources and Services Administration (HRSA) and is currently being updated with additional support from CDC and the Agency for Toxic Substances and Disease Registry (ATSDR).

National Neighborhood Indicators Partnership
This collaborative effort by the Urban Institute and local partners is intended to improve neighborhood-level information systems for use in local policy making and community building. The Web site (http://www.urban.org/nnip/) also provides a number of useful publications and links to other sites related to indicators and community building.

Knox County, Tennessee, Health-Related Quality of Life Report (July 2003)
This state of the county report highlights mental health as an area with possibilities for public health intervention. Visit http://www.knoxcounty.org/health/hrql03.pdf.

CDC Offers Resources on Conducting and Interpreting Economic Evaluations
Whether you plan to conduct your own economic evaluations or interpret the results of evaluations done by experts in the field, CDC offers assistance.

Interactive Course
CDC has developed a free, interactive, Web-based course on economic evaluations. Prevention Effectiveness: Decision Analysis and Economic Evaluation covers the basics of decision analysis and economic evaluation methods, using case studies and modules focusing on topics such as cost-benefit analysis, cost-utility analysis, cost-effectiveness analysis, and sensitivity analysis. The goals of the course are to help practitioners plan and conduct their own prevention-effectiveness studies and interpret the results of studies conducted by others.

“We hope that taking this course will lead to more states collecting cost data,” noted Vilma G. Carande-Kulis, PhD, lead economist and chief...
of CDC’s Prevention Effectiveness Branch. “States have to know not only how effective the interventions are but how efficient they are. And if you’re going to measure economic efficiency, you have to not only measure health-related quality of life but also start measuring costs. That, in turn, would help states make better use of the resources they have.” For more information about the course, contact Dr. Carande-Kulis at VCarande-Kulis@cdc.gov.

Checklist for Assessing Studies
For states that don’t plan to conduct their own economic evaluations but simply want to be better able to scrutinize the studies already out there, some advice and resources are available from Ping Zhang, PhD, and Michael M. Engelgau, MD, of CDC’s diabetes program. They suggest questions state health departments ask the following to determine if an economic analysis was well conducted and its results are valid and reliable.

• Was the study question well defined? The study question should clearly identify the alternatives being compared and the viewpoints from which the comparisons were made.

• Was a comprehensive description of a competing alternative given? A good study should provide a clear and specific statement of the primary objective of each alternative program. This information allows readers to judge the applicability of the program to their own setting.

• Were all the important and relevant costs and consequences for each alternative identified? Even though it might not be possible or necessary to measure and value all of the costs and consequences of the alternatives under comparison, the study should fully identify the important and relevant ones.

• Were costs and consequences adjusted for differential timing? Because a comparison of programs must be made at one point in time (usually the present), the timing of program costs and consequences that do not occur entirely in the present time must be adjusted to reflect current values. Both costs and health consequences such as quality-adjusted life years, which occur in the future, should be discounted back to their present values at the social discount rate. The U.S. Panel on Cost-Effectiveness in Health and Medicine recommends a 3% annual discount rate.

• Was an incremental analysis of costs and consequences of each alternative performed? To allow meaningful comparisons, the study needs to examine the additional costs that one program imposes over another, compared with the additional effects, benefits, or utilities that the program delivers.

• Was allowance made for uncertainty in estimates of costs and consequences? Lack of data, data generated from different settings, and different views on how to handle a study problem are common problems in the economic evaluation of health interventions. Therefore, the study needs to examine how these uncertainties, imprecise uses of data, or method-
ologial controversies might affect the study conclusion.

“We encourage you to use and interpret the studies already out there and use them to make informed decisions about what you’re going to do,” recommended Dr. Engelgau. “They won’t make the decisions for you, but they are a useful tool and just one piece of the puzzle to consider when making decisions about how to allocate resources.”

Population Health and Quality of Life Measures Designed for Different Purposes

Many health-related quality of life measures are available, and each is designed to meet specific purposes:

- To measure the burden of disease, monitor the health status of a population over time, and track progress in meeting health objectives.
- To determine the cost-effectiveness of one intervention or compare the cost-effectiveness of several different interventions.
- To identify populations affected by health disparities.
- To evaluate interventions targeting specific diseases or conditions.
- To identify health priorities and guide the development of health policies.

By measuring and tracking health-related quality of life (HRQOL), researchers can identify people who would benefit the most from healthier environments, early diagnosis of disease, and treatment. The findings are also valuable in predicting which people are most at risk of dying, requiring hospitalization, or needing outpatient services over the next year. Here are just some of the measures being used around the world to collect and analyze data on health status and health-related quality of life.

Quality of Well-Being Scale

The Quality of Well-Being Scale is a self-administered questionnaire that measures how disease and disability affect people’s ability to function physically, take care of themselves, and engage in social activities. People select from various scenarios that describe their function level (mobility, physical activity, social activity) and symptoms or problems that might impair their ability to function. With this scale, preference weights are used to integrate the three function levels as well as the symptoms and problems into a single number, ranging from 0 (death) to 1 (perfect health).

Researchers have used the Quality of Well-Being Scale to evaluate outcomes for people with AIDS, arthritis, diabetes, and many other chronic illnesses. The scale has been used in many large studies, including the Diabetes Prevention Program (DPP) clinical trial.
Health Utility Index

This index is used to measure improvements in health. Like the Quality of Well-Being Scale, the Health Utility Index is preference-based and rates an individual’s health on a scale of 0 (death) to 1 (perfect health). The index also allows researchers to assign negative values to a person with a health status considered worse than death.

The Health Utility Index has been used in population surveys, clinical studies, and cost-effectiveness studies to evaluate public health interventions. This index was one of the tools used in the Action to Control Cardiovascular Risk in Diabetes (ACCORD) study.

EQ-5D (EuroQol) Survey

Developed in Europe, the EQ-5D is a preference-based survey that asks people to rate their current health state on a scale ranging from 0 (the worst they can imagine) to 100 (the best they can imagine). The survey asks about mobility; self-care; usual activities such as work, housework, and leisure activities; pain or discomfort; and anxiety or depression.

The EQ-5D is designed to complement other quality of life surveys such as the SF-36. The survey has been used to measure many different health conditions and treatments. It has been used in population surveys and clinical studies. This was one of the tools used in the Translating Research Into Action for Diabetes (TRIAD) and ACCORD studies.

QALYs

A quality-adjusted life year (QALY) is an aggregate measure that takes into account both length of life and quality of life. This preference-based measure estimates the time a person will live at different levels of health over the remaining years of life, with 1 equaling perfect health, and 0 equaling death.

With QALYs, the goal is to determine how many quality-adjusted life years can be gained through a particular intervention. QALYs are often used in cost-utility studies to assess the economic efficiency of interventions and to compare a person’s quality of life with or without a particular intervention.

“QALY weights are applied to various aspects of a person’s physical and mental health to get an overall estimate of that person’s health,” explained CDC program analyst David G. Moriarty, an aging studies specialist who coordinates CDC’s HRQOL assessment program. “You can then average individuals’ scores to get an overall population estimate—say, the 0.85 level of health. QALYs can also tell you how intervention A costs this much but brings you from the current score of 0.85 to only 0.86. Intervention B, on the other hand, costs more but gives you a greater point gain in the score.”

DALYs

Another preference-based measure is the disability-adjusted life year (DALY), which measures the burden of disease and disability in a population. Preference scores, derived from
experts worldwide, range from 0 (death) through 1 (perfect health). “Whereas QALYs measure what you would gain by conducting a particular intervention, DALYs measure the health gap between the ideal and what the population is actually experiencing,” explained CDC medical geographer James B. Holt, PhD, MPA.

“DALYs allow for broad standardization of measurements of morbidity across a broad spectrum of diseases and socioeconomic conditions,” noted Vilma G. Carande-Kulis, PhD, lead economist and chief of CDC’s Prevention Effectiveness Branch. DALYs can help guide decisions about allocating health care resources, and they are being used in studies both small and large. For instance, the Los Angeles County Department of Health Services analyzes DALYs and includes the results in its report on disability. The World Health Organization is using DALYs in its Global Burden of Disease project to estimate health-related quality of life among countries.

CDC will soon launch a project to look at geographic variations in DALYS from region to region and to examine trends over time and differences in population groups. “So we’ll be looking at DALYs in different ways—geographically, demographically, and over time,” Dr. Holt noted. The work will be done through a cooperative agreement, which will be funded in fiscal year 2004 over a 3-year period.

“The DALY is not a new measure, and, as with other subjective measures, it has its detractors,” said Dr. Holt, pointing out that some researchers interpret the economic valuation methodology as placing different values on older people than on younger people. DALYs also have raised methodological concerns because of the way in which preference weights are set—by experts and not the population. Nevertheless, “DALYs are there waiting for us to use,” he said. “They will help us plan our program interventions and see where the burden is greatest in terms of disease and disability. We feel DALYs are very useful and will give us information we would otherwise not be able to gather.”

Short Form 36

The Short Form 36, developed and validated in the RAND Corporation’s Medical Outcomes Study, is a questionnaire used by clinicians and researchers around the world. Commonly referred to as the SF-36, this tool uses 36 questions, eight subscales, and two summary scales to assess key aspects of people’s physical and mental health. Individuals are asked to rate their general health, vitality, pain, limitations (due to physical and emotional problems), functioning (physical and social), as well as psychological distress and well-being. Recently, shorter forms of this instrument have been developed.

The SF-36 can be used alone or with disease-specific measures in clinical practice, research, and policy analysis, according to Ping Zhang, PhD, a CDC health economist. The survey can be used for both the general population and patients.
Healthy Days

CDC’s Healthy Days measures differ from the preference-based measures because they are direct estimates of people’s perceived physical and mental health over time. They were designed to identify health disparities and trends and to evaluate changes resulting from broad population-based interventions. CDC worked with many partners to develop this standard set of questions.

The Healthy Days measures tally a person’s responses to determine the number of days during the previous month when he or she felt that either physical or mental health was not good (see calendar, page 37). The Healthy Days measures include four core questions that identify trends over time and reveal how population subgroups are doing compared with the general population. Because the core questions do not provide the details needed to identify public health interventions that might help these individuals, the CDC HRQOL-14 was developed. It includes the 4 core questions plus 10 questions that gather more detailed information on activity limitation and quality of life.

“Tools such as Healthy Days allow public health practitioners to use a common measure to prioritize,” said Charles G. Helmick, MD, a CDC medical epidemiologist specializing in arthritis. “If you think HRQOL is important, these measures will help you see where the biggest problems are, by disease. Measuring health-related quality of life is a good way to set priorities from a broad public health perspective. And it’s a good way of getting at the burden and learning how bad a disease is,” he noted. “Ideally, it is a good way to track changes as a result of our interventions.”

“The Healthy Days questions have been useful in collecting data on arthritis because the questions are concise and can be incorporated into existing surveys,” Dr. Helmick noted. “We were looking for a short version that people would use. If we want our constituents—state health departments—to look at other outcome measures, such as quality of life, we have to make it very easy for them to collect the data.”

The Behavioral Risk Factor Surveillance System (BRFSS) and the National Health and Nutrition Examination Survey (NHANES) have both added the core Healthy Days questions to their surveys and can now provide a wealth of quality of life information on adults with arthritis and other chronic diseases. CDC researchers are eager to analyze the 2000 and later NHANES Healthy Days data because NHANES is the premiere survey for assessing the U.S. population’s health status. NHANES includes a national sample of 5,000–6,000 people each year, and its HRQOL findings will complement the state data collected through the BRFSS.

The Healthy Days measures are not typically used in cost-effectiveness studies because health economists prefer preference-based tools, such as the Health Utility Index and Quality of Well-Being Scale, in which each item is weighted. “Those tools are more in concert with economic
theory,” Mr. Moriarty explained. “We’re now trying to gain a better understanding of how our Healthy Days measures are similar to and different from these other measures and how the Healthy Days measures might be adapted for use in cost-effectiveness studies.”

“One of the key advantages of tracking population health-related quality of life is that it tells you things you wouldn’t ordinarily see with a point-in-time survey,” said Mr. Moriarty, who has worked for the past decade to develop and test the validity of methods for measuring health-related quality of life. Measuring how people perceive their physical and mental health over time is important “because it’s the foundation that will allow us to study the effects of public policies and a variety of factors, like the environment,” he noted. “But also it will help us identify health disparities that should be further investigated.”

In the future, CDC plans to study how the weather, climate, and seasons affect people’s perceptions of their health, Mr. Moriarty said. The data can also be analyzed to help determine how the economy, the quality of our health systems, air and water pollution, sprawl, and even traffic affect people’s health and quality of life.

Such information is useful to health planners and legislators. They can use HRQOL data to evaluate and strengthen public health programs, to compare the cost-effectiveness of various interventions, and to guide their decisions about health policies and allocation of scarce public health resources. HRQOL findings are also used to set health objectives for the nation, states, and communities. The ultimate goal of such research is to promote people’s physical and mental well-being, which, in turn, gives individuals the potential to increase their satisfaction with life, ability to take care of themselves, and ability to engage in social activities.

A multitude of other instruments have been developed to measure health-related quality of life. Good sources on the many tools in use around the world are the Compendium of Quality of Life Instruments by Sam Salek (Wiley, 1999) and the Quality of Life Instruments Database (QOLID), available at http://www.qolid.org.
Using Quality of Life to Measure a Program’s Effectiveness and Value

Your chronic disease program is very effective. People are living years longer as a result of your efforts. So what?

When measuring the value of a program, a better question might be, “Are people living better and longer?” said Michael M. Engelgau, MD, a CDC medical epidemiologist. For instance, is your program helping people manage their pain better? Is it allowing them to remain active and independent?

And even if people are living better and longer, are the benefits of your program worth the costs? asked Ping Zhang, PhD, a CDC health economist.

One way to answer these questions is to measure how a program affects both length of life and quality of life. Measures that take length and quality of life into account are known as aggregate or summary measures of health. Quality-adjusted life years (QALYs) are one type of aggregate measure used in economic evaluations (see page 34.)

“The concept of QALYs is fairly straightforward when we think about what chronic diseases do — they shorten your life and make it not as good as it would have been had you not developed the chronic disease,” noted Dr. Engelgau. “With QALYs, you’re trying to quantify that. For example, diabetes can cause blindness, kidney failure, and amputation. Living years with these conditions tends to make the quality of those years less when compared with someone without these conditions.”

Researchers can use measures such as QALYs to estimate how much longer people could live and how much better their lives would be during their remaining years with a health intervention as opposed
Health economists can also calculate the cost per QALY gained to measure a program’s cost-effectiveness. Two programs can then be compared to determine which program adds more QALYs to a person’s life for the same amount of money.

Preference-Based Measures

In cost-effectiveness studies, researchers typically use measures that are preference-based—meaning they use scores or weights based on preferences for various hypothetical health conditions. Preferences can be derived from patients, providers, experts in a particular field, or the community. QALYs and disability-adjusted life years (DALYs) are preference-based. In addition, tools that measure quality—such as the Quality of Well-Being Scale, the Health Utility Index, and the EQ-5D Survey—are preference-based measures (see pages 33 and 34).

“Preference-based utility scores are developed by going to the general population and asking people how undesirable it is to have certain conditions,” Dr. Engelgau explained. Thus, preference-based scores reflect how individuals rate the magnitude of the problem. “One person might say being blind is devastating, but another might say it’s not that bad. Maybe they’ve learned to adapt.”

States probably don’t have the resources to conduct primary research to elicit preferences for health states, noted Vilma G. Carande-Kulis, PhD, a CDC health economist. One option, she said, would be for the federal government to work with communities to elicit preferences through grants and contracts. The states could then coordinate the research. “CDC could lead an initiative to build surveys on the Web,” she suggested. “There are pretty good published results comparing how representative Web, mail, and telephone surveys are.”

Economics Just Part of the Equation

As the U.S. population ages and budget constraints increase, economic factors will play an increasingly important role in decisions about how best to use resources to get the maximum value, Dr. Zhang said. “But you can’t make your decisions about allocating resources just based on this one piece of information,” he cautioned. Public health priorities, community standards, equity, feasibility, and public policy also need to be considered.

Equity and Social Responsibility

Economic evaluations will help us hone in on where we can get our best value, “but we’re not going to walk away from populations that are not a good value,” emphasized Dr. Engelgau.

“On the flip side, in high-risk populations, such as underserved and low-income people with high risks for chronic disease, we don’t know about the economics of treating these populations,” Dr. Engelgau noted. But on the basis of what other economic evaluations have found, interventions targeting these people might be more cost-effective than...
interventions targeting people not at high risk “because they’re in such bad health already,” he said.

As medical technologies advance, more procedures that vastly improve some people’s quality of life—for example, hip replacement surgery and certain cardiovascular disease treatments—will become more available, but these procedures will also be very costly, Dr. Zhang explained. “Society can’t afford for everybody to have these procedures,” he said. “Economic evaluations of these technologies can help us to determine which procedure gives a better value for our money and should be adopted first at the population level.”

Feasibility
Health departments also need to make sure the intervention can be done successfully, advised Dr. Carande-Kulis. “Look at all of the factors that can enhance or completely neutralize the benefits of that intervention,” she said. “Make sure you don’t have incentives at the federal level that will neutralize incentives at the state or local level.”

For example, a county might raise taxes to build more sidewalks and encourage people to walk outdoors. “But you might also have cheap gas and tax breaks to developers, encouraging the building of subdivisions farther and farther out,” away from the parks and shops, Dr. Carande-Kulis explained. “So you’re disconnecting people in the community. They have the sidewalks, but where are they going to walk to?”

Economic consequences also must be considered, noted Steven M. Teutsch, MD, MPH, executive director of outcomes research and management for Merck & Co. in West Point, Pennsylvania. “For example, it’s not expensive to pass a clean air law. It’s cheap for the state, but it imposes huge costs on others,” he pointed out.

In the private sector, most businesses expect a quality-of-life program’s costs to at least be matched by its benefits. “Businesses want to know: What does it mean for them?” Dr. Teutsch said. Will employees have fewer migraines at work because of the program? Will they be more productive on the job? Will insurance claims decline?

Another important question for businesses to ask is this: Will employees take advantage of the program? “No company will put a treadmill in every employee’s office,” Dr. Carande-Kulis pointed out. “It’s not feasible. Some folks might be using them to hang their jackets on and never use them to exercise.”

Getting the Most Value
Learning which types of interventions are most effective and whether they might work in a particular setting is essential for states. “If you’re going to do things, do things that will actually make a difference,” Dr. Teutsch advised.

Rather than conduct their own cost-effectiveness studies, many states rely on expert guidance from sources such as the independent Task Force on Community Preventive Services. The task force conducts systematic reviews of the effectiveness and economic efficiency of various population-based interventions and
Quality-Adjusted Life Years (QALYs) gained from a program

QALYs allow researchers to measure the gains in both years and quality of life resulting from a program.

makes recommendations based on effectiveness. Dr. Teutsch, who is a member of the task force, suggested that health departments learn about the basic questions that are asked in these studies:

- How big is the public health problem you’re trying to address (burden of illness)?
- Can the intervention work (efficacy)?
- Does the intervention, in fact, work (effectiveness)?
- What are the harms and benefits of the intervention (net benefit)?
- How much will the intervention cost?
- How do the costs compare with the benefits (economic evaluation, cost effectiveness, cost benefit)?
- If you had more resources, what additional benefits from this intervention could you expect (incremental cost effectiveness)?

QALYs are an important measure that can be used to answer these questions. Whether your intervention aims to change people’s behaviors, the environment, or systems (such as health care, education, or transportation), the health effects can be assessed in terms of QALYs.

“For instance, we now have evidence that diet and exercise can lower the risk of developing diabetes among people who are at high risk,” Dr. Engelgau explained. “The next questions are how much does it cost?...”
Is it too much? Is it a good investment?” he said. “The cost per QALY will tell you if it’s a good investment or not.”

Dr. Zhang and Dr. Engelgau encourage health department staff to learn more about QALYs and the various other aggregate measures used to assess health-related quality of life. “Take time to understand the concept of an aggregate outcome,” advised Dr. Engelgau. “It provides the answer to the question ‘So what?’”

Suggested Reading


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**ADDENDUM to “Health-Related Quality of Life Among Women” CDNR vol 16, no. 1, Winter 2003**

The following information on Von Willebrand Disease is offered as suggested reading for CDNR readers.

