DISABILITY

NATIONALLY, WE KNOW:

- People with disabilities are generally identified as persons having an activity limitation, who use assistance, or who perceive themselves as having a disability. An estimated 21% of the population has some level of disability using this definition. The most common conditions or impairments that limit activity in descending order of frequency are: heart disease (13%), back problems (13%), arthritis, orthopedic conditions, asthma and diabetes, mental disorders, visual impairments, learning disabilities, and mental retardation. (National Health Interview Survey = DMMS, 2000.)

Dennis Fitzgibbons, Director of Operations, ALPHA ONE, South Portland, Maine

"Public policy leaders first need to get their hands around who the disabled community includes. It's not just people with physical disabilities, but those with brain injuries, mental health disabilities, and sensory impairment … there's quite a range."

"Most health professionals lack a basic understanding of the health issues people with disabilities face. Medical students across the country receive little education in what it means to have a disability. As a result, people with disabilities often have to educate their own physicians. There is a great opportunity for a person who is knowledgeable about his or her own disability to work with a provider who is willing to listen and learn. They could build a partnership that is much more effective in maintaining that patient's health."

- Defining disability is a challenge, especially for health data systems that measure the health impact of disabilities. Different data systems classify disabilities differently. Examples include:

  The Americans with Disabilities Act of 1990 (ADA) defines a disability as a "physical or mental impairment that substantially limits one or more major life activities."

  Social Security Administration, through which services such as Medicaid Health Insurance and financial resources are obtained, defines a disability as a physical or mental impairment that substantially impairs the person's ability to perform work (substantial gainful activity), and the condition must have existed or is expected to continue to exist for at least one year.

- Other challenges in defining disabilities include:

  Some disabilities, such as mental disorders, may be only temporary, yet others are lifelong.

  Often, people in the deaf culture who use American Sign Language do not consider themselves disabled, yet deafness is often included in measurement tools as a disability.

- Rates of disability for both sexes increase with age.

- Rates of disability are rising for people under 45 years.

- Disability and underlying conditions disproportionately affect women, partially due to a longer life expectancy.
- Having a disability is associated with higher rates of poverty, living alone, unemployment, low education, physical inactivity, obesity, pain, sleeplessness, depression, and anxiety, even when disability rates are adjusted for age.
- Many people with disabilities lack access to health services and medical care.

Meryl Troop, Office of Deaf and Multicultural Services, Maine Dept. of Behavioral and Developmental Services, and (in mirror) Romy Spitz, Ph.D., Technical Consultant on Deafness, Mobius Inc., and researcher at USM

"Communication with health care professionals is a special challenge for people who are deaf and hard of hearing. Very few providers in Maine use sign language and professional interpreters are rarely hired. There is also a shortage of assistive listening devices, TTY equipment, and training on relay services. Deaf people need to be better accommodated in visiting nurse programs, nursing homes, and all facets of health care."

IN MAINE, WE KNOW:

- There is no consistent statewide system for measuring how many Maine people have disabilities, and what the impact of their disabilities is on their health. Existing data systems are primarily those that serve different populations with disabilities such as MaineCare and Maine's Division of Vocational Rehabilitation.
- The Behavioral Risk Factor Surveillance System (BRFSS) has recently started asking disability-related questions, but there are not yet enough data to assess the impact these disabilities have on health:

  In 2000 and 2001, Maine BRFSS asked: "During the past 30 days, did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?"
  None: 80%
  20% replied "yes," with a median of 5 days (both in 2000 and 2001) out of 30.

  In 2001, Maine BRFSS asked: "Are you limited in any way in any activities because of physical, mental, or emotional problems?"
  Preliminary results show: 19% Yes

  In 2001, Maine BRFSS asked "Do you now have any health problems that require you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?"
  Preliminary results show: 5.7% Yes
- MaineCare insures about 35,000 disabled low income people. (See Access Chapter *Healthy Maine 2010: Living Longer and Healthier Lives* for additional information.)

- The Division of Vocational Rehabilitation served 5,379 people in 2000, one-third (1,790) of whom were clients with a mental illness, one-quarter of whom were diagnosed with an orthopedic condition, and nearly one quarter of whom were diagnosed with other physical disabilities.
- The US Census defines a person as having a disability when he or she is identified as having blindness, deafness, severe vision or hearing impairment; or a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying. According to the 2000 Census, an estimated 141,000 Maine people age 21–64, or approximately 19% of that population, are disabled. This is the same as the national rate for this age group.

  In Maine, 42% of non-institutionalized people with disabilities are employed, compared with 33% nationally.
  (US Census Bureau and Maine Economic Growth Council, 2002 Measures of Growth report. Summary and analysis done by the Maine Development Foundation.)

  According to the 2000 Census, an estimated 25,000 Maine children ages 5–20 years are disabled, approximately 9% of that population. By comparison, 8% of the US population ages 5–20 are disabled.

  According to the 2000 Census, an estimated 72,000 Maine people over the age of 64 are disabled, which is approximately 41% of this population.

  The total population in Maine with a disability is estimated to be 325,500 by the 2000 Census, which is approximately 26%, or one in four, of the population.
- Eight and a half percent (8.5%) of Maine's population (just over 100,000 people) are deaf or hard of hearing. Of this number, 10% (about 10,200 people) are profoundly deaf.
  (Source: Maine Department of Behavioral and Developmental Services.)
- Hearing aids are not covered by MaineCare or by most insurers.
- Only about 35% of English is visible through lip reading; therefore, it is difficult if not impossible for the deaf to communicate with health care providers without an interpreter. However, the hourly rate for a sign language interpreter in Maine is $50, including travel time. Four Maine counties have no interpreter at all. Partial payment for interpreting services is reimbursed through MaineCare, and Maine is only one of three states that have any reimbursement. University of Southern Maine is graduating its first class in sign language interpretation in 2003.

CHALLENGES

- There is a need to develop consistent and concise ways to determine and define disability status so that it can be measured by more health data systems in Maine; yet also be comparable, as much as possible, with national health data systems.
- The Bureau of Health is expanding its questions on disability status through BRFSS. This will eventually provide some statewide estimates that can give some additional characterizations such as age, gender, and geographical distributions of people living with disabilities in Maine. This will also be comparable with national BRFSS data.
- The Bureau of Health lost ground in addressing some of these challenges when its Disability Program was de-funded in the 1990's. However, the Bureau hopes to move forward in improving health measurements regarding disability status.