

Emerging Priorities in Health Promotion Programs

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Health Promotion in People with Disabilities

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OBJECTIVES

After reading this chapter, you should

- Understand the concept of disability and the ways that disability is defined
- Recognize the importance of understanding the specific disabilities included in a population for planning health promotion programs
- Know how to identify the particular population of people with disabilities represented in a study in order to compare results of different studies
- Be aware of the similarities and differences in cardiovascular health and risk factors between the general population and groups of people with particular disabilities
- Understand how to apply public health strategies to health promotion issues for populations of people with disabilities using existing systems

KEY TERMS

Americans with Disabilities Act
Developmental disabilities

Disabilities
Healthy People 2010

Introduction

Health promotion is an important concept for all populations of individuals. A great deal is known about how to reach the general population through public awareness campaigns and other public health strategies. Less is known about how to reach certain subgroups of the general population, such as the group of people with **disabilities**. Often public health looks at people with disabilities as a single group, when in fact, there are many different groups of people with disabilities. Knowing more about specific disabilities

and understanding how to modify approaches to public health activities, such as those to address health promotion, will help health departments and public health professionals more effectively reach these populations in order to impact their quality of health. This chapter outlines the differences in the categorization of different disabilities, what is known about disease and health conditions—in particular cardiovascular risks—in the populations of people with disabilities, and features some examples of how public health strategies addressing health promotion can be used to not only reach these populations but also to effectively influence health behavior.

Definition of Disability

Disability is a term frequently used but not always understood in its complexity. There are multiple definitions of the term, and it is used one way in public health—looking at the health issues affecting the population—and another in public welfare—determining the appropriate set of services for an individual person. The task at hand is to illustrate the diversity of the population of people with disabilities and to focus on how this population cannot be reached as a single unit.

Accardo et al. define a disability as “any restriction or lack of ability (resulting from an impairment) to perform an activity in a manner or within the range considered usual for a human being” (1996, p. 92). This definition is not specific to any particular impairment and involves sensory, physical, psychological, and cognitive disorders. It also includes an element of transience in that a disability may be temporary or permanent. This makes defining the population of people with disabilities for the purpose of studying its health and finding ways to establish health promotion programs difficult.

The World Health Organization (WHO) defines disability as part of a continuum involving impairment, disability, and handicap as illustrated in Figure 7-1 (Barbotte et al., 2001).

As the second level of this continuum, disability is usually referred to in the context of health and a health experience. It encompasses not only the person’s individual characteristics but also the society or culture in which that person lives (World Health Organization, 2007). This creates the possibility that what is considered a disability by one person or culture may not be in another, potentially making the comparison of health issues among people with disabilities difficult. Handicap, the third level of the continuum, is defined as a disability that affects the person’s everyday life.

In addition, the concept of handicap complicates the matter as a person with a disability only has a handicap if society or lack of opportunity puts him

Figure 7-1
WHO Definition of
Impairment, Disability,
and Handicap

- An *impairment* is a physiological disorder or injury.
- A *disability* is the inability to do something related to an impairment.
- A *handicap* is the social result of a disability.

or her there. For example, a person who is near sighted and is able to see with glasses would have an impairment but not a handicap, unless he or she wanted to be an airplane pilot and needed to have perfect vision. Thus, one might choose to study the population of people with handicaps rather than those with disabilities.

Heterogeneity of Disability Subgroups

Studying health issues in the population of people with disabilities requires some categorization of different disabilities. While the issues of what is a disability versus a handicap complicate defining a population, variability in categorization and definitions of specific disability groups also make determining the size of the population of people with disabilities difficult. Different groups categorize disabilities in different ways, and public health professionals group disabilities differently from professionals involved in health care. Identifying what population group is being studied is important for both learning about the health conditions within that population and for applying health promotion strategies to what is learned in order to change health behaviors.

Medicine or health care divides disabilities into two broad categories: developmental disabilities and acquired ones. **Developmental disabilities** occur in the *developmental period*, which is defined by the Diagnostic and Statistical Manual of Mental Disorders published by the American Psychological Association in 1994 (DSM IV, 2000) as birth (or prebirth) to age 18 years, and by entities like the Commonwealth of Pennsylvania Office of Developmental Programs as birth to age 22 years (Office of Mental Retardation, 2002).

Developmental disabilities generally involve learning or cognition, movement, and/or behavior (Accardo et al., 1996; Batshaw & Perret, 1992). These include conditions like intellectual disabilities, cerebral palsy, learning disabilities, autism, and attention disorders. Developmental disabilities are mostly characterized by abnormalities in the brain, usually in the formation of the brain in utero caused by chromosomal abnormalities like Down syndrome (trisomy 21), exposure to toxins such as alcohol, or infections such as that caused by cytomegalovirus.

To further complicate things, different nomenclature is used for some developmental disabilities depending on the geographical area or time in history. For example, what is currently being called *intellectual disabilities* was called *mental retardation* a few years ago. Go back a few more decades in time and people with these disabilities were referred to as *imbecile* or *idiot*, obsolete terms that now have pejorative connotations (Accardo et al., 1996; Mondofacto, n.d.). Cross the Atlantic Ocean, and in England it is called a *learning disability*. The plurality of terms used for intellectual disabilities makes it difficult to compare populations in various geographic areas and from different time frames (O'Brien, 2001).

There are also disabilities that occur during the developmental period, such as the congenital lack of an extremity or phocomelia (Mondofacto,

n.d.). This can result in a disability but does not involve a congenital brain abnormality. These might also be considered developmental disabilities, although they are not generally included with the disorders typically called developmental disabilities.

Acquired disabilities often result from an injury or a progressive neurologic condition. These include conditions like brain injury, spinal cord injuries, dementia, or Parkinsonism. Generally, these individuals were neurodevelopmentally normal prior to either an injury or the onset of a particular disease or infection (Accardo et al., 1996). Some injuries, like strokes, result in multiple disabilities, including speech and language problems and hemiplegias or paralysis of one side of the body, and most often affect older people.

In terms of definitions of disabilities, there is some overlap between developmental disabilities and acquired ones. For example, a child with typical development that contracts a viral encephalitis may incur a brain injury resulting in lowered cognitive functioning in the range of an intellectual disability or mental retardation. In this case, the child is considered to have an intellectual disability because the condition occurred during the developmental period even though it comes from an acquired condition.

Public services for people with disabilities organize types of disabilities in different categories from medicine. The Centers for Medicare and Medicaid Services (CMS) provides funding for groups of people with disabilities through 1915c waivers (Centers for Medicare and Medicaid Services [CMS], 2006), which require that the person have a condition that qualifies him or her to receive institutional services either in a nursing home or an intermediate care facility for people with mental retardation (ICF/MR) or other related conditions (ICF/ORC). Waivers offer people the opportunity to have supportive services in their home rather than an institution. These services include things like assistance with activities of daily living (ADLs), such as dressing, feeding, and grooming, as well as any specialized therapies, such as physical therapy to help with walking or mobility. Waivers are specific to individual states, and the specifics of a waiver are defined by the state. A state can define the population of people to receive funding from the waiver, i.e., which disability group to address as well as the particular services that are eligible to be paid for by the waiver (CMS, 2006). For example, Iowa's physical disability waiver provides funding for services for people with physical disabilities and who meet criteria for placement in a nursing home or an ICF (Iowa Department of Human Services, 2005). Physical disabilities can be developmental, like cerebral palsy or muscular dystrophy, or acquired, like a quadriplegia from a spinal cord injury of the cervical vertebra.

National programs like *Healthy People 2010* (Center for Disease Control and Prevention [CDC], 2000) put disability groups into different categories from the above. The *Healthy People 2010* goals for people with disabilities describe two groups in particular. One is adults living in large, out-of-home facilities (congregate or institutional care), and the second is children with disabilities in regular classrooms. Neither of these two groups would easily be identified using any of the previously defined categories. Adults in congregate

care might be elderly adults living in a nursing home or young adults with intellectual disabilities living in an ICF/MR. From the vantage point of health and health needs, these two groups do not have similar requirements.

The **Americans with Disabilities Act** (ADA, 1990) sets yet another definition for a disability—a legal one. The ADA defines a disability as “a physical or mental impairment that substantially limits one or more major life activities.” This definition would include people that might not fit into some of the other categories or rubrics used. Other public health initiatives developed for the purpose of gathering health information about people with disabilities, such as the Survey of Income and Program Participation (SIPP; U.S. Census Bureau, 1994), define disabilities by functional level and not specific diagnosis or living arrangement. Functional activities in the SIPP include abilities to do things like walk 3 city blocks or carry 10 pounds. Difficulty with functional ability does not map to a particular clinical or programmatic diagnosis. A person with cerebral palsy clinically has a physical and developmental disability, but that person may be able to walk a mile and therefore would not meet the criteria for the functional limitations defined in the SIPP. Thus, information gathered about people fitting the legal definition of disability may differ from that derived from populations with clinical or programmatic definitions.

Evaluating literature studies involving populations of people with disabilities requires understanding the nature of the disability being studied. Health promotion will differ depending on the population that is being targeted, whether that is based on age or presence of cognitive disorders that interfere with the individual’s ability to acquire and use health knowledge. Understanding the heterogeneity of disabilities allows for the study of different groups separately and identifies successful ways of reaching them to help maximize their health.

Demographics of Populations of People with Disabilities

Understanding the subpopulations of people with disabilities is instrumental to developing and implementing a public health promotion program. One set of important information includes the demographic characteristics of the group. Demographic characteristics consist of age, number of people estimated in the population, and health conditions important to the group. These characteristics help define who the populations are, which assists with determining the best way to reach each subpopulation.

Census Numbers

In 2000, the population of people with a disability over the age of 5 years from the U.S. Census Bureau was 49,746,248, which represented about 17.6% of the population (2000). These numbers exclude people living in institutions as well as people in the armed forces and children under the age of 5 years. In addition, the criteria for this data requires that 1 of the following 3 criteria be met: (1) They were 5 years old and over and reported a long-lasting sensory, physical, mental, or self-care disability; (2) they were 16 years old and over and reported difficulty going outside the home because of a physical, mental, or emotional condition lasting 6 months or more; or (3) they were 16 to 64 years

old and reported difficulty working at a job or business because of a physical, mental, or emotional condition lasting 6 months or more.

The first census information about people with disabilities comes from the 1994 SIPP survey (U.S. Census Bureau, 1994). Comparing that data to the most recent census numbers from 2002, the proportion of the U.S. population with a disability as defined above is 18%. That proportion has remained stable over that 18-year period. In addition, the number of people with a severe disability as defined by the responding individual has changed slightly from 9% in 1994 to 11.5% in 2002. The SIPP acknowledges that it uses different definitions of disability when looking at populations of people with disabilities.

Age

The rates of disabilities increase with age and about 70% of people aged 80 years have a disability (U.S. Census Bureau, 2002). This is illustrated in Figure 7-2.

For children under age 15 years, the rates of disabilities are estimated to be 2% for children under age 3 years, 5% for children 3 to 5 years, and 6% for children 6 to 14 years of age. This likely reflects not only the development of disability related to acquired conditions like meningitis or traumatic brain injury but also the definitive diagnosis of disability in young children. Making a definitive diagnosis of a developmental disability is more difficult in younger children as the testing measures are less accurate and the less severe developmental disabilities are often not apparent at younger ages. For example, in the United States, the average age of diagnosis of a congenital hearing impairment of 50 dB or greater has been about 3 years of age, until recently (National Institutes of Health, 1993). The implementation of universal newborn hearing screening in many states has the potential to identify this hearing loss within the first year of life, possibly within the first few months (McCormick, 1995). This would increase the numbers of children

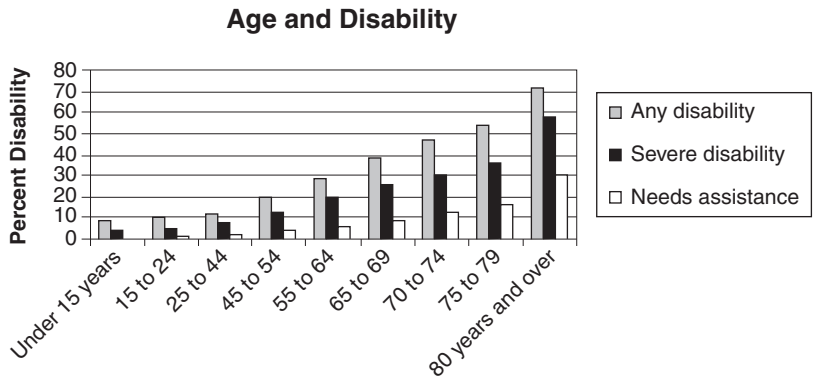


Figure 7-2
Prevalence of Disability
in Different Age Groups

identified as having a disability before age 3 years and change the rates of disabilities for particular age groups.

Many people with developmental disabilities are living longer as are people in the general population. Medical technology has also changed the survival rates for some individuals with disabilities, resulting in more older people with disabilities than ever before. The CDC studied causes and ages of death for people with trisomy 21 (Down syndrome), a common chromosomal problem associated with intellectual disabilities and congenital heart disease. The average age of death in this group rose from age 25 years in 1983 to age 49 years in 1997 (Roizen & Patterson, 2003). Contributing to this are the advances in treatment for congenital heart disease, as 40% to 50% of people with Down syndrome have some type of congenital heart disease. Other medical technology, such as feeding tubes for individuals with cerebral palsy who are unable to take in enough nutrition by mouth, has improved health as well as increased the life span for many people with disabilities (Sullivan et al., 2005).

Conventional wisdom often advised that many people with severe disabilities, especially those with severe cerebral palsy and/or intellectual disabilities, would not survive into adulthood. In addition to the data for people with Down syndrome, there is other data to show that many people do survive into adulthood (Hayden, 1998; Janicki et al., 1999; O'Brien, Tate, & Zaharia, 1991). Unpublished data from Pennsylvania (2001) reveals that the average age of death not adjusted for population for people receiving services in the mental retardation system was 56 years of age. The most common causes of death for people with intellectual disabilities were noncongenital or acquired heart disease (e.g., coronary heart disease), cancer, influenza, and pneumonia. The first two of these parallel exactly the causes of death for the general population (CDC, 2000). Chronic lung disease was lower on the list, but for those individuals dying of a respiratory cause, the average age was also lower at 45 years of age. Thus, people with disabilities have a greater life span than in the past, and many people are living to the age where they are at risk for acquiring additional disabilities related to chronic diseases, such as coronary heart disease, that are common in the general population as people age.

Specific Versus General Health Needs

Historically, health care for people with disabilities has targeted the specific needs of populations such as treatment of seizure disorders or orthopedic surgery for complications of cerebral palsy. Specialty medical care often included single condition, multispecialty clinics staffed by specific medical and surgical specialties. For example, health care for people with spina bifida, a disorder with spinal cord malformations and often hydrocephalous, includes neurosurgery, urology, orthopedics, various therapies such as physical therapy, and pediatrics to follow development. The goal is to address surgical shunt

placement and management for the hydrocephalous as well as the initial repair of the spinal cord and back, urologic management of the neurogenic bladder, and orthopedic management of the spine and lower extremities. Therapies addressed the functional motor needs of individuals, and pediatrics typically looked at development and any acute health needs such as infections. If seizures were present, they might also be addressed through this venue.

Most states, including Pennsylvania, have specialty clinics for spina bifida located either in children's hospitals or at university settings. Various options for payment, including private insurance, public insurance, and services funded through grant money, make medical services for treatment of spina bifida and its complications accessible to most citizens (Spina Bifida Association, 2007a).

While these health care settings often address chronic medical problems, they may not provide health promotion or primary care. These centers tend to be regional in nature, often located in urban areas, and not convenient for primary care, such as immunizations or treatment of acute illnesses like ear and throat infections. This means that most primary care is more likely to be obtained closer to the home of the people rather at the urban clinic. Coordination of care between these two entities is often limited by time and distance constraints, sometimes leading to each assuming that the other is providing a particular service when in fact no one is doing it. This leads to holes in the medical care of people with disabilities because sometimes the less acute things, like screening hearing, get missed. As well, many people with chronic medical problems may have more physician visits for and more attention paid to the care of their chronic medical problems than they have for health promotion. Therefore, the health promotion may take a back seat to the other health issues even though people with disabilities and chronic medical problems can benefit from participation in health promotion activities. To combat this issue, the concept of a medical home for children and adults with special health care needs, including disabilities as well as some chronic conditions, has been developed to provide not only primary care but also care management to coordinate care between all of the health professionals involved in a person's medical care.

One example of where the medical home concept might be helpful is the monitoring of weight for individuals with spina bifida. In the model of health care before the medical home concept, monitoring the growth of children with spina bifida may be one of the things that takes a back seat to the ongoing urology treatment of bladder infections and other problems or neurosurgical management of their shunted hydrocephalous. Literature (Spina Bifida Association, 2007b) shows that children with spina bifida develop obesity at a higher rate than typical children. That proportion of obese individuals with spina bifida remains into adulthood. Obesity comes with substantial health risks for all individuals but has an additional impact on people with spina bifida. Extra weight tends to make walking more difficult in people with spina bifida, which in turn leads many to use a wheelchair for mobility. This serves

to decrease the number of calories used and contributes to increased weight gain. An important goal in health promotion for the population of people with spina bifida should be the prevention and treatment of obesity to avoid its health complications. Until recently, however, there was little data to guide such health promotion recommendations.

Basic Health Information About People with Disabilities

The field obtains basic health information in two manners: surveys of health generally done through health departments and specific studies done by researchers to be published in the literature. Health information is an important driver of public health policy and programming as it allows targeting of funding and efforts toward those health issues with the most detrimental effects or toward those that have the highest prevalence. While much data is available for the general population, the body of knowledge for the population of people with disabilities and for specific disabilities is less robust. The next section looks at what is gathered and known about health for people with disabilities with a focus on health promotion related to prevention of obesity and promotion of physical activity.

General Population Surveys

A great deal is known about health and the prevalence of chronic disease in the general population. The CDC has studied not only the increase in life expectancy in the general population but also the impact of chronic disease, life style, and health behaviors on people as they age. The National Center for Health Statistics (CDC, 2007b) contains a plethora of data about all aspects of health including births, deaths, nutrition, hospital discharge, and ambulatory health data. The information for this data center comes from many different surveys that assess the health and nutrition of the general population as well as information from hospitals about utilization of health care services.

Behavioral Risk Factor Surveillance System (BRFSS)

One such survey, the Behavioral Risk Factor Surveillance System (CDC, 2007a), samples households in all 50 states as well as the District of Columbia, Puerto Rico, Guam, and the U.S. Virgin Islands. This survey has been used annually since 1984 and is administered by the health departments. The survey assesses information about health behaviors including alcohol and tobacco use, nutrition and physical activity, access to health care, use of screens like cancer screening, and certain disease conditions such as diabetes, asthma, and high blood pressure. This information is used to track and identify emerging trends in order to intervene and try to improve the health of the population. The data also provides information about the treatment of some conditions, which allows a look at the adequacy of the health care system as well as the presence of health risks. Some of the surveys described below accommodate and include people with disabilities, while others use methods that relative undersample that population. In addition, there are now surveys that concentrate on certain populations of people with disabilities.

The BRFSS is conducted by telephone and samples about 350,000 people per year, making it the largest health telephone survey in the world. The BRFSS (CDC, 2007a) was developed in 1984 by the CDC to provide a mechanism to gather information about personal health behaviors that research has shown contribute to premature mortality and morbidity. Demographic details gathered include age, gender, race and ethnicity, education level, marital status, employment, and number of children living in the household. The person answering the phone provides the information for the survey. States can add questions to the survey, and some include questions about disability and limitations of mobility in the survey. North Carolina includes a question about disability and uses that information to determine the prevalence of disability among adults living in that state. The prevalence of disabilities can assist in planning for services to support people with disabilities to live more independent lives.

In general, most surveys do not include information about people with disabilities and those that do generally use a single category labeled disability rather than looking at any of the subsets of people with disabilities. Phone surveys that capture information from the first person that answers the phone in private residences may not access people with disabilities, especially those with intellectual disabilities, deafness, or difficulties with speech. None of the survey strategies will access people living in other kinds of community living settings, like group homes or environments that provide support for people with intellectual or physical disabilities. These surveys also do not access health information about people living in institutions even though identifying the differences or lack of differences might help people live in more independent environments.

Behavior of School-Aged Children Survey

Kalnins et al. (1999) studied health behaviors in children with physical disabilities by using the Health Behavior of School-aged Children survey, which is a WHO survey. In completing the survey, they noted that they needed to modify the recommended protocol for administration of the instrument. The authors note that children with physical disabilities in Canada are rarely included in health behavior surveys; however, knowledge about risks for the development of secondary health conditions, especially those related to behavior, would contribute to the prevention of those secondary conditions. The prevention of obesity in children with spina bifida is one such area of health promotion that can prevent such secondary health conditions. The authors conclude that while there is a need for separate surveys of health behavior in children with physical disabilities, there is also a need to include questions about disabilities routinely in surveys used in the general population.

Survey of Income and Program Participation (SIPP)

The U.S. Census Bureau (1994) conducts SIPP, which includes a section that delineates disability using the ADA definition, on the general population. However, this survey does not include any information about health or health behaviors. Another survey conducted through the NCHS (CDC,

2007b)—the National Health Interview Survey (NHIS)—has periodically included special sections related to certain disabilities. In 1989, the survey collected data using a special questionnaire on mental health. A special questionnaire on disability was included in 1994 and 1995, which assessed limitations in activities and work and the need for personal assistance in activities of daily living. In the other years, the NHIS included information about chronic disease and limitations in activity.

In addition to population level surveys collecting information related to disabilities, there are some surveys that have been used with populations of people with specific disabilities. In the example given above, Kalnins et al. (1999) modified the Health Behavior of School-aged Children survey to apply to children with physical disabilities, like spina bifida or cerebral palsy. They conclude that not only can such surveys be applied to populations of children with disabilities, but the information derived from them can be used to reduce the risks of developing secondary conditions and to promote health and well-being as well. Steele et al. (1996) used the same survey and concluded that while children with physical disabilities were less likely than their peers to use alcohol, tobacco, or marijuana, they had less healthy diets and participated in less physical activity. The later behaviors put them at greater risk for obesity and the health risks for secondary conditions such as heart disease, diabetes, arthritis, and stroke, which come with obesity.

Disability Specific Surveys

National Core Indicators Project (NCI)

Other surveys were specifically designed for people with specific disabilities. The National Core Indicators project (NCI) was developed in 1997 by the Human Services Research Institute (HSRI), an organization developed in the 1970s to enhance the quality of services and supports for people with mental retardation and mental illness, in conjunction with the National Association of State Developmental Disability Directors (NASDDDS, 2007) to measure performance across the services offered to people with intellectual and other developmental disabilities. It targets states and the services provided by and/or funded by government entities with a goal not only to assess the quality of those services but also to gain knowledge about how to improve them and directions for future service development. Currently, 26 states and parts of another participate in the surveys collecting data about common performance indicators in the same manner. Participants work in a collaborative manner to identify important areas to survey and to modify the instrument to meet those information needs. Data collected includes information about consumer and family outcomes such as choice in a variety of aspects of life, cost, and health and safety outcomes and is analyzed to provide information that will help states and provider entities address the weaknesses in their programs.

NCI surveys are completed in a face-to-face interview on a sample of people within the service system (HSRI, 2006). Multiple surveys exist including consumer, family, and provider versions. Depending on the ability of the

consumer to answer, some questions may not be used. Only a few health indicators exist, and they include the number of consumers that have had the following examinations in the last year: physical exam, women with an ob-gyn exam, and dental exam. Another health indicator looks at the number of people taking medication for anxiety or mood or behavior problems. Proposed indicators include a wellness measurement to assess the number of people with healthy behaviors in areas such as weight, physical activity, and unhealthy habits such as smoking. Another question in the current survey relates to participation in exercise or sports in the past month and does allow comparison to national public health data about the lack of participation in leisure-time physical activity, which is a Healthy People 2010 goal.

Pennsylvania Health Risk Profile (HRP)

Pennsylvania uses a unique electronic survey to assess health indicators in the population of people receiving mental retardation services in a licensed residential setting. This instrument, called Health Risk Profile (HRP; Office of Mental Retardation, 2001), collects health information annually on a random sample of people across the state. In the 2006–2007 fiscal year, 1,346 people were sampled—a number close to 10% of the residential population. Registered nurses visit the home and collect the information using the record from the residential provider agency. Questions cover three areas: (1) access to health care, (2) health promotion and disease prevention, and (3) disease management. Data from this instrument is used locally to address individual health issues and statewide to address broader health issues. Many of the questions asked directly relate to areas identified by the CDC's *Healthy People 2010* initiatives for the general population and include information about weight, nutrition, physical activity, and cancer screening as well as disease conditions and their treatment.

Healthy People 2010

In addition to its goals for health for the general population, *Healthy People 2010* (CDC, 2000) has specific goals for people with disabilities and secondary conditions, namely to eliminate disparities between people with and without disabilities, and to target these activities toward certain populations of people with disabilities. A sample of the groups described includes adults living in large, out-of-home facilities (congregate care) and children with disabilities in regular classrooms. *Healthy People 2010* uses existing sources of health data from established surveys such as NHIS and BRFSS. In the discussion of looking at data to determine disparities in groups of people with disabilities, the *Healthy People 2010* publication notes that few data systems identify people with disabilities. Some of the issues that have been identified to have disparities between the population of people with disabilities and those without are similar to those described by other authors, namely increased obesity and decreased physical activity. In addition, *Healthy People 2010* also found

increased stress in people with disabilities and a lower proportion of women over 55 years of age who had an annual mammogram. In general, this initiative groups all individuals with disabilities into a single subpopulation of the general population, although there are specific goals related to certain subgroups of people with disabilities. These subgroups are often defined by where people live, such as adults living in congregate care (usually institutional living either in a nursing facility or an intermediate care facility), or children with disabilities that are in a regular classroom. These groupings will allow identification of some kinds of risks and some remedies based on the location of people but will not allow for looking at particular groups of disabilities.

Survey Methods

Surveys employ multiple methods to gather the needed health information. Phone surveys are common and generally use local phone listings to draw a random sample of the population in order to survey a statistically significant number of respondents. Some surveys are done with a combination of methods, such as phone and face-to-face interviews. Yet other surveys use a paper document that is sent through the mail, completed, and then returned by the recipient. Each of these methods has strengths and weaknesses. As well, some of them are more or less accessible to people with disabilities. The impact of these issues can determine whether or not a survey instrument will reach the population of people that is desired.

Phone Surveys

Phone surveys, like the BRFSS, have become a staple in the toolbox of health departments for monitoring health indicators in the population. Traditionally, these surveys have relied on landlines and accessing numbers that are published and public in nature. Emerging changes in technology may impact the ability to use this strategy to reach both the general population and the populations of people with disabilities. Estimates show that 25% of people aged 18 to 25 years and almost 33% of people aged 25 to 29 years live in a household without a landline (Landers, 2007). In addition, 32% of low-income young adults have only cell phones. These numbers do not appear in the local phone books making them more difficult to reach. This is also true for some populations of people with disabilities, especially those that live in small group homes in the community or people living in institutions that also do not typically have a phone number that is listed in the local phone directory. The lack of a listed phone number serves to bias the results of surveys that are done using randomly selected phone numbers, as these populations will not be surveyed. Given the prevalence of this in particular subpopulations, this could serve to underestimate behaviors that are more common in these age groups. These surveys also likely underestimate behaviors and conditions that are more prevalent in the populations of people with disabilities that make up almost 18% of the U.S. population, a substantial portion of the population (U.S. Census Bureau, 2000).

Face-to-Face Surveys

Most of the disability specific surveys, like the NCI project, use a face-to-face technique. This avoids the issues of people with intellectual disabilities not having the ability to read or write. It also avoids missing sampling people with physical disabilities that may not be able to answer the phone because of mobility limitations and therefore would not be the primary respondent to a phone survey. Even these methods cannot overcome the issues of the lack of ability to communicate—either to understand the question or to be able to answer—that impact some people with severe intellectual disabilities, despite special equipment or communication devices, to say the words for them. Instead, NCI uses surveys for caregivers and families to complete about the individual. This limits the ability to question about a number of things that are common questions used in health surveys in the general population, such as perceptions of health.

Mail Surveys

Postal questionnaires represent another strategy employed to monitor health indicators and risk factors. Mail surveys must be completed and returned by participants. The SF-36, or Short Form Health Survey, was developed for the Medical Outcomes Study and has been widely used to survey health status (Brazier et al., 1992). It has been used to estimate disease burden in specific diseases compared to the general population as well as to compare one disease to another. Application of the tool generally occurs by completing the written questionnaire in the physician or other health practitioner's office. For individuals that cannot self-administer the test because of a condition that prohibits them from being able to complete the forms, it may be administered verbally by a professional, such as a social worker (University of California at Los Angeles, 2007). Other researchers have applied the questionnaire by using it in a phone interview format. Interestingly, these interviews showed more positive impressions of the health quality of life questions than the written survey indicating a possible bias introduced by using a person to administer it. Garratt et al. (1993) assessed the possibility of using the SF-36 by mail instead of an in-person written format or a verbally administered questionnaire either by phone or in person. A Dutch study (Picavet, 2001) looked at the response rate between a survey done by interview and one done by mail. It discovered that the interview survey had a higher response rate, 58.5% to 46.9%, and women were more likely to respond to the mail survey. In addition, individuals with lower education levels did not respond as frequently to the mail survey.

The comparison of response rates as well as types of responses for surveys administered in different modalities adds an additional level of complexity and uncertainty in evaluating the results of different health surveys. In addition, some populations of people with disabilities will be unable to participate in some of the potential formats of surveys, which either leaves them out of the data pool altogether or uses a modification for them that might result in a

different result than had they been able to use the same format. Individuals with disabilities have a lower education rate than their age peers without disabilities and are less likely to be employed. *Healthy People 2010* data (CDC, 2000) indicates that only 52% of people in the broad disability category are employed compared with 82% of the general population. Educational outcomes for youth with disabilities, as measured through the National Longitudinal Transition Study (Wagner et al., 2006), consistently show that individuals with disabilities achieve less educationally than youth in the general population. The subgroup of youth with intellectual disabilities and multiple disabilities typically score the lowest on all testing. This is consistent with their diagnosis of an intellectual disability but creates a barrier to using standard questionnaires about health related to lower abilities to either read or understand spoken language or to be able to communicate an answer. Therefore, measures that require giving a perception of health or using a multipoint, interval response scale, such as a Likert scale, may also be more difficult to administer to individuals that do not have the cognitive capacity to understand gradations of response related to a particular question. This makes comparison of some measures of health that are standard for the general population difficult with some subpopulations of people with disabilities.

Literature and Research

Research is another way that information is developed about health for people. Most research involves either the general population or groups of people with the same health conditions. Consequently, there is a relative paucity of research and information about health for many populations of people with disabilities. Many studies do not indicate whether or not the people in the study had any type of disability if the disability is not related to the health condition and not part of the study. The history of involving people with disabilities in medical research is a dark one, as illustrated by a CBS news article about Sonoma State Hospital. The report outlines a period in the late 1950s and early 1960s when children institutionalized there were reported to have been used in experiments involving radiation. This story is not unique and contributes to the barriers of researching health issues in this population (Mabrey, 2005). In addition, research assumes some risk, and informed consent related to those risks is difficult in some populations of people with disabilities who are unable to understand those risks.

Types of Research Studies

Information about health in people with disabilities comes from a variety of studies. Some are larger in size, involving thousands of individuals, and serve primarily to provide descriptive information about a particular population of people. Examples of this type of study are the mortality studies done in California by a variety of authors related to identifying risk factors for mortality in the population of people with intellectual disabilities living either in an institutional or a community setting (Chaney & Eyman, 2000; Eyman,

Call, & White, 1991; O'Brien et al., 1991). Others are relatively small in size and may study a single aspect of a particular disorder, such as a study of sleep disorders in individuals with neurofibromatosis type 1 done by Johnson, Wiggs, and Huson (2005). Most of the research is found in specialty journals, such as the journals published by the American Association on Intellectual and Developmental Disabilities (AAIDD formerly known as AAMR, the American Association on Mental Retardation) or *Developmental Medicine and Child Neurology*, the official journal of the American Academy for Cerebral Palsy and Developmental Medicine and the British Pediatric Neurology Association.

Cardiovascular Risks in Particular Populations of People with Disabilities

Although current knowledge about health conditions is limited, findings show some similarities to the general population. For instance, most studies of causes of mortality show that the causes of death for people with intellectual disabilities mirror those of the general population (Janicki et al., 1999; Patja, Molsa, & Iivanainen, 2001). The top cause of death is cardiovascular disease followed by cancer and respiratory diseases. Some studies have also shown a higher rate of cardiovascular disease in this population than in the general population (O'Brien, 1991; Pitetti, Campbell, 1991). Pitetti and Campbell (1991) relate this to the adoption of a sedentary lifestyle and eating patterns. As in the general population, lifestyle and health behaviors primarily related to nutrition and physical activity contribute greatly to the development of cardiovascular disease.

Other groups of people with disabilities have increased risks for cardiovascular disease. Individuals with spinal cord injuries have cardiac complications that occur early after their injury but also tend to have higher blood lipids, which are associated with cardiovascular disease leading to death (McKinley & Garstang, 2006). Approximately 20% of deaths of individuals with spinal cord injuries are due to cardiovascular disease. Increased incidences of not only high blood lipids but also obesity, physical inactivity, insulin resistance, and diabetes contribute to the higher risk for heart disease. Individuals with spina bifida have a similar pattern of increased risk factors for heart disease.

Certain disease conditions that put people at risk for disabilities may also bring risks of other disease conditions. Rheumatoid arthritis (RA) is one of these conditions in that it causes inflammation of joints that can lead to limitation in movement and difficulty with ambulation. A study done at the Mayo Clinic shows that people with RA have a higher risk for heart disease than the general population (Kaplan, 2006). Other researchers (Bacon et al., 2002; Kaplan, 2006) have corroborated this finding. Although some of this risk is likely specific to the inflammatory etiology of RA, traditional risk factors for cardiovascular disease do play some role (Del Rincon et al., 2001). Minimizing the general risks of heart disease as well as the disease-specific

risks could help contribute to better health and to decreased mortality and morbidity due to heart disease in this group.

Two risk factors for heart disease include obesity and lack of physical activity (Hahn et al., 1986; McGinnis & Foege, 1993). Obesity contributes heavily to heart disease risk as well as predisposing an individual for diabetes, high blood pressure, and increased lipids, all of which are also risks for heart disease (Mensah & Brown, 2007; Pearson, 2007). In addition, obesity is a risk for the development of arthritis and orthopedic problems that may limit the ability to walk, providing an additional contribution to heart disease risk. On the other hand, physical activity reduces the risk of heart disease as well as reduces blood pressure, blood lipids, and obesity. (Kaplan et al., 1996; Kushi et al., 1997; Lee, Blair, & Jackson, 1999; Paffenbarger et al., 1993; Sherman, D'Agostino, & Cobb, 1994; Wei et al., 1999).

Obesity in People with Disabilities

Data about obesity and physical activity is more available for populations of people with disabilities than some of the other health measures used in the general population. Obesity is not only a risk for heart disease but also a contributor to disability in that it causes or complicates arthritis and diabetes (Iezzoni, 2003). This in turn complicates the use of physical activity to ameliorate obesity and to control weight. Obesity has been identified as a significant issue in a number of populations including people with Down syndrome or trisomy 21. Rubin et al. (1998) found that 45% of the men and 56% of the women followed in a large specialty clinic in the Chicago area were overweight. Other studies, including ones by Braunschweig et al. (2004) and Rimmer, Braddock, and Fujiura (1993), corroborate these results in the broader population of people with developmental disabilities.

Rhode Island has reported on their obesity results from the BRFSS surveys for the years 1998 to 2000 (Rhode Island Department of Health, 2000). Comparing the levels of overweight and obesity in the population of people with disabilities to those without reveals that the differences are minor (see Figure 7-2). As well, more than 50% of both populations are either overweight or obese. In a British study, Wannamethee et al. (2004) showed that the prevalence of overweight and obesity in a population of elderly men between ages 60 and 79 years was about 69%. The group of overweight and obese men had twice the risk of cardiovascular disease and twice the risk of mobility problems as the group that had weight in the normal range. A study of obesity in a cohort of people with spina bifida followed from birth to 35 years of age showed a 56% rate of obesity (Hunt & Oakeshott, 2003). In comparison to the prevalence of overweight and obesity within the general population, these results are not different and the problem of obesity is one that affects all members of industrialized society.

Participation in Physical Activity

One of the other components of risk for heart disease is lack of physical activity. Various authors have studied participation in physical activity in populations of people with disabilities. Physical activity is more difficult to study as it involves not only whether or not someone participates but also at what

level of exertion and what frequency. The CDC has set guidelines for recommended amounts of physical activity (CDC, 2008); however, those are not necessarily the criteria used for participation in the research literature. Thus, rates of participation in the research literature may not reflect the recommended goals for physical activity. McGuire et al. (2007) note that physical activity is not very common in the population of adults with disabilities. *Healthy People 2010* data (CDC, 2000) indicates that slightly less than half of all people follow the CDC recommendations for physical activity. About 49% of people without a disability met the physical activity criteria compared to 37.7% of people with a disability. Multiple researchers have shown that rates of nonparticipation in physical activity for people with intellectual and developmental disabilities are similar to that of sedentary people without disabilities (Draheim, Williams, & McCubbin, 2002; Temple, Anderson, & Walkley, 2000). Messent, Cooke, and Long (1999) defined some barriers to participation for people with disabilities including limited access to activities and opportunities in the community.

Thus, there are two components of prevention for heart disease: normal weight and physical activity. Baseline data about the prevalence of both obesity and participation in physical activity for people with disabilities exists in the literature. Changes in personal behavior can impact both obesity and lack of physical activity, minimizing heart disease risk related to those factors. Changes in levels of obesity and physical activity in the population can measure the impact of public health interventions, making this a good example to illustrate how public health strategies can be used to improve health for populations of people with disabilities.

Using Public Health Strategies to Impact Obesity and Levels of Physical Activity for People with Disabilities

Public health has three core functions: assessment, policy development, and assurance (Figure 7-3).

Policy development provides a way to take scientific findings from the research studies to the real world to make meaningful improvements to the health of people. Policy development tools include public health law and voluntary practices and partnerships. These focus on development of systems and organizational change as well as changes in individual behavior. Although legislation often brings to mind Congress and the federal government, state and local legislation and regulation has a role in changing behavior and improving the health of the public. Partnerships for voluntary

Figure 7-3
Core Functions of
Public Health

1. Assessment
 2. Policy development
 3. Assurance

activities may also include state and local governmental entities in addition to academia and community groups. The case studies that follow focus on health promotion activities related to the issues around prevention of cardiovascular disease that were discussed in the last section. This section uses these cases to outline how public health tools can be used to impact people with disabilities.

National Initiatives

In general, all health promotion activities strive to move the science of the issue into practical application in the community or for the population to be able to change behavior. The CDC (2002) has identified prevention of cardiovascular disease as a national priority. Therefore, it is important to look at what is happening at the national level before discussing local initiatives in order to put the local activities in the context of the national ones. In 2002, the CDC developed a national public health action plan to prevent and decrease the rate of heart disease in this country. This plan takes a comprehensive approach to the issue in order to move the nation forward toward meeting the goals around prevention for heart disease and stroke set out in *Healthy People 2010* (CDC, 2000). The public health approach to this issue thus far has included assessment to identify the magnitude of the problem, policy development to address the knowledge gained from assessment, and assurance to continue to measure the impact and any changes in the magnitude of the problem. Citing the statistics that 39% of all deaths in Americans are due to heart disease and that there is growing disparities in people from racial or ethnic minorities and with lower income and education levels, the CDC (2002) has set out five areas to focus their activities. Figure 7-4 shows the five areas of focus outlined by the CDC.

Public Health Strategies

Public Awareness Campaigns

Numerous public health strategies have been used to address the epidemic of heart disease. These include public awareness campaigns, health information and education, materials that guide participation in activities, and

- **Taking action**, which turns current knowledge into effective actions from a public health vantage point to address the issues.
- **Strengthening capacity** by building and expanding partnerships and developing and sharing resources to implement and maintain the actions.
- **Evaluating impact** to monitor the prevalence of the disorders and to communicate the interventions that produce the best responses.
- **Advancing policy** to identify the most crucial issues, support the research to identify how to approach the issues, and develop the policies to support the findings of the research.
- **Engaging in regional and global partnerships** to share successes and failures and therefore to more effectively use resources.

Figure 7-4
CDC Five Areas
of Focus

development of partnerships including those between community organizations and government. Public awareness campaigns are a common tool used by public health not only to increase awareness of a particular health issue but also to generate interest in the issues. Radio and television spots about nutrition, articles in local newspapers and newsletters outlining local resources for obesity prevention, as well as the use of other paper media such as handouts, can generate interest in the need to both prevent and treat obesity. Some of the materials used in public awareness campaigns can also provide some health information to increase people's knowledge about the issue. For example, health information about the prevention of heart disease would include information about the relationship between obesity and sedentary lifestyle to the development of heart disease as well as its role in decreasing life expectancy. It also could include information about how to prevent obesity, such as ways to increase physical activity and improve eating habits. More detailed information would be included in a specific program that might be developed to address the needs of a particular population. For example, a program developed to prevent obesity in people with spina bifida would need to take into account the need to modify physical activities for people that either use a wheelchair for mobility or walk with crutches and braces. A partnership between a local department of health and a local chapter of the Spina Bifida Association could be used to create a program to prevent obesity in people with spina bifida. In this way, government and community can partner to address a common health issue.

Legislation and Regulation

In addition to the strategies above, the public health professionals also have legislation and regulation to add to their armamentarium related to health promotion. Although the concept of legislation often brings up the role of the federal Congress, there are multiple other layers of legislation and regulation that can have an impact on communities. State government has the ability to create legislation or regulation that assists in the monitoring of health problems such as obesity or to limit the access of the population to things that cause obesity. In addition, local ordinances can also be used to change behavior. One of the following case studies looks at a situation where a city health department with the ability to write legislation created a law to impact the intake of a particular type of fat in an attempt to decrease the problem of obesity and the risk of heart disease in that city.

Case Studies

Groups working with people with disabilities use the public health strategies to address the increasing problems of obesity and sedentary lifestyle with its increased risk of heart disease for people with disabilities. These strategies have been implemented in parallel with the national goals related to the

prevention of heart disease through the prevention of obesity and increased physical activity. The strategies chosen represent different types of public health interventions to achieve the same result. Some of the strategies impact only people with disabilities, while other interventions address the general population and will impact people with and without disabilities. Each of the strategies provides a real life example of how public health interventions can be used to target certain populations of individuals to impact a public health problem such as the epidemic of heart disease

Case Study on Local Legislation

In October 2003, the Food and Drug Administration (FDA) published an edition of its consumer magazine noting that scientific evidence shows that not only saturated fat but also trans or partially hydrogenated fat contribute to heart disease. These compounds created by adding hydrogen to vegetable oil are found in margarines, cakes, cookies, french fries, and other foods made with vegetable oil. Trans fat increases the levels of low density lipoproteins, or LDLs, which increase the risk of developing heart disease. As of January 1, 2006, the FDA requires that the amount of trans fat in a food be included on the label on the nutrition facts panel. The scientific community recommends that people, especially those with heart disease or risk factors for heart disease, limit their intake of fat including trans fat in order to decrease their heart disease risk. Americans typically consume more fat than they need and on average consume 6 grams of trans fat although the American Heart Association (2007) recommends 2 grams per day. Because scientific evidence has shown a relationship between heart disease and trans fat, a diet that is low in fat is recommended to prevent the development of heart disease.

In New York City, the Board of Health can pass laws for the city related to public health issues. In response to the scientific information about trans fat and the epidemic of heart disease, they passed a law to ban trans fat from all restaurants (University of North Carolina, 2007). Trans fat must be removed from all foods by July 2008. The passing of the law comes after a trial period of voluntary removal of trans fat, which had no impact on the amount of the substance in foods. Although the legislation is controversial, it illustrates one strategy used in public health to effect change in behavior. This particular strategy impacts everyone that eats in a restaurant in New York City, helping to cut down on the amount of trans fat ingested by the general population. This in turn will help individuals with both weight and blood cholesterol control by decreasing the fat intake and decreasing their risk for heart disease based on LDL levels. It also affects all groups of people including those with disabilities that eat in restaurants in the city. It is an example of a way to reach people with disabilities through targeting a broader population.

The ultimate impact of this law on either the heart disease risk of the population or on the restaurant industry in New York City remains to be seen, especially as it relates to populations of people with disabilities. As this law impacts people only when they eat in a public restaurant, it may have more or less of an impact depending on the frequency of meals that are consumed out of the home. Although that is not known, specifically for people with disabilities, the

more that people are out in the community and not in institutions, the more access they will have to the amenities that are used by the general population. This example shows how legislation or regulation offers public health a strategy to effect change in the population with the potential to reach subpopulations of people with disabilities.

Review Questions

1. How can legislation or regulation be used to support public health goals?
2. What populations of people does the New York regulation impact?
3. What other ways could legislation be used to address issues of obesity?
4. Would these have more or less of an impact on the populations of people with disabilities?

Case Study on State Level Program Development

Development of specific programs that target a population is another public health strategy to address a need. In this vein, the University of Illinois at Chicago (UIC) through the Rehabilitation Research and Training Center on Aging with Developmental Disabilities and the Center for Health Promotion used federal grant money to develop an exercise and nutrition program for adults with developmental disabilities (Heller, Marks, & Ailey, 2001). This program was tested using people from six different residential and vocational agencies and showed success in terms of increases in muscle strength and flexibility as well as improved knowledge and attitudes about exercise.

The UIC curriculum was developed by a number of specialists and includes an exercise program developed by an exercise physiologist, nutrition and cooking classes developed by a registered dietician, and health education classes (Heller et al., 2001). The design of the program involves 12 weeks' time and is recommended for 8 to 10 participants with disabilities. Each of the modules can be modified to meet people's specific interests as it is important that people choose what they do for physical activity in order to stick with it. For example, people are offered a choice of aerobic activities from walking or running to various types of cardio workouts available on videotape. They are then encouraged to choose their favorite activities in which to participate. It also includes concepts such as negotiation and compromise as well as social supports. This program provides materials to help people with developmental disabilities begin and maintain an exercise program with other people with developmental disabilities.

Review Questions

1. How might physical activities need to be modified for people with disabilities?
2. How does a state promote participation in a program like this?

Case Study on Local Implementation of Federal Program

The U.S. Department of Health and Human Services (DHHS) Office of Disabilities used another strategy for program development with its I Can Do It, You Can Do It program (Office of Disabilities, 2004). The Secretary

of Health and Human Services, Tommy Thompson, set the goal of encouraging increased physical activity for the nearly 6 million children with disabilities in the country. The strategy pairs children with disabilities with physically fit mentors who may or may not have a disability. The goal of the pairs is to accumulate minutes of physical activity toward the goal of a series of awards starting with a Presidential Active Lifestyle Award (PALA) followed by a Presidential Champions Award with either a bronze, silver, or gold medal depending on the number of points accumulated. The outcomes included having children with disabilities adopt healthy life behaviors, including regular physical activity and health nutrition, and the adults in their lives not only recognizing the importance of this but also actively encouraging it. A long list of partners participates in this program and includes those representing children with a variety of disabilities from cognitive disabilities to physical ones. The program provides a series of materials for use in participation in the program, including daily activity logs.

In an extension of this program, the Adapted Physical Activity Program at Slippery Rock University of Pennsylvania (2007) applied the principle of using a mentor to adults with intellectual disabilities. This pilot, coordinated with the local and state mental retardation program offices, paired senior level undergraduate students studying adapted physical education with an individual with intellectual disabilities living in the area local to the University. The students acted as mentors, and the physical activity portion of the program occurred at local community resources such as the YMCA. Students used their knowledge from their didactic studies to adapt activities for their partners. Included in this was a brief component for education related to nutrition and food choice. Preliminary results of the pilot showed not only active participation throughout the program but also some positive gains in physical fitness for the people with intellectual disabilities.

Review Questions

1. Discuss other ways that the federal government could implement a program like I Can Do It, You Can Do It.
2. What other populations of people could act as mentors for this kind of program?
3. Consider the validity of a program studied in one population and applied to another such as this example where the program was originally designed to be implemented with children with disabilities and was extended to the adult population.

Case Study on Development of a State Level Program for Health Education

Health education such as that provided in the nutrition component of the I Can Do It, You Can Do It program constitutes an important public health tool. That, with the monitoring of a health issue, helps move a population forward to a particular health goal. The Commonwealth of Pennsylvania Office of Developmental Programs (ODP) developed such a program for people with intellectual disabilities receiving services through

the state program. ODP and its stakeholders, including consumers of services, their families, advocates, service providers, and others, identified a lack of knowledge about health issues as a weakness in the program. In response to this realization, ODP developed the concept of Health Care Quality Units (HCQU) designed to provide training and technical assistance about health issues for the stakeholders of the system. The first HCQUs developed under this concept began operation in 2000 with the remainder beginning implementation within the next 2 years. There are 8 of these HCQUs across the state, and in fiscal year 2006–2007 (July 1 to June 30), they provided 4,000 health trainings to over 35,000 people. This modality of creating a special unit to provide training is not a unique concept, although most of such entities do not address health needs for people with disabilities. The strength of the HCQU approach is that they provide health information and education not only for consumers but also for their caregivers. From the standpoint of nutrition and eating habits, people that do not cook eat what is cooked for them. If their meals contain a high fat content and lots of calories, then they will more likely have difficulty with weight. The way to change that behavior is to increase the knowledge of the people cooking the meals so that they can provide more healthy foods. In addition to providing health information, HCQUs conduct a health survey to collect health indicators representative of the population of people living in licensed residential settings within the commonwealth. This serves as a way to follow health indicators related to topics of training in order to identify whether or not there has been a significant impact related to the increased exposure to health information. The instrument used is the health risk profile (HRP) (2001), and it gathers information related to weight, height, and physical activity among other health conditions.

Analysis of the HRP data from 2000 to 2001 showed that about 60% of the population of people in the random sample had a body mass index (BMI) in the overweight or obese range (CDC, 2004). This is not different from that found in the general population (CDC, 2007a). Over the time that the HCQUs have been providing training to the stakeholders of the ODP service system, nutrition was the most commonly presented topic. Subtopics within nutrition included healthy food choices, appropriate portions, and reading food labels. Included with this were trainings about physical activity and how to increase participation in physical activity. Individual service providers worked on developing physical activity opportunities or using existing programs, like that from UIC, in which people could participate. This provides specific guidance for implementing a program or information that was developed specifically for people with intellectual disabilities. In this manner, neither family members nor paid staff have to take information developed for the general public and modify it for this population. Because this approach is more individualized either to an individual or a small group of consumers, it may not reach as many people as the approaches used with the general public. However, with a population of people that are less able to access the tools provided to the general public,

this may afford them the same impact. In fact, the data from fiscal year 2006 to 2007 shows that significantly more people had a BMI in the normal range than in the sample from 5 years prior in fiscal year 2001 to 2002 (ODP, 2007). In addition, there were significantly less people that participated in no leisure-time physical activity in the later sample. Without any other significant initiatives related to controlling weight and increasing participation in physical activity targeting this group in the state, the training provided by the HCQUs likely contributed to these positive changes in the population.

Review Questions

1. Who is the audience for health education for people with intellectual disabilities?
2. Would health education have more or less of an impact on this population as compared to the general population?
3. What modifications might need to be made to deliver this type of health education to a population of people with intellectual disabilities with limited or no reading abilities?

CONCLUDING REMARKS

Traditional public health methods of gathering health indicators in the general population may not access information about particular sub-populations, especially that of people with disabilities. As well, given the diversity between the groups of people with disabilities makes using a single category of people with disabilities a less useful activity. This is especially true because reaching different populations of people with disabilities depends on how they can both access and understand that information to increase their knowledge and to change their behavior. The population of elderly people with disabilities related to chronic diseases may not have the same needs or respond to the same strategies as the population of people with intellectual disabilities. Thus, not only do surveying techniques need to accommodate different groups of people with disabilities but so do the methods used to convey the information to each population.

As the population of the country grows older and people with and without disabilities are living longer, there will be an additional need to access the health status and issues for these populations. As well, reaching populations with disabilities through government and community partnerships, including the program offices where they receive services, may prove to be an effective strategy for public health officials to pursue. Using existing surveys and modifying them to address public health goals not only can gather information that can be compared to the general population but also can be used to improve the health of these populations.

Examples of public health interventions adopted by program services for people with disabilities include mechanisms to increase awareness for health issues; health education provision that is accessible to the population and their caregivers; adaptation of existing strategies to meet the particular needs such as those related to physical activity for people with disabilities; and judicious use of regulation or legislation. All can have an impact on the lives and health of people with disabilities. As particular groups of people within the general population occupy a larger and larger proportion of the population, public health focus on health promotion for these groups will become important to continue to make progress toward the health promotion goals for the country.

DISCUSSION QUESTIONS

1. What factors must be considered when developing a survey to assess health issues for people with disabilities?
2. How are groups of people with different disabilities the same? How are they different?
3. Where might you find information about health issues for people with disabilities?
4. How do you approach health promotion activities such as physical activity for people with disabilities?
5. Is legislation or regulation an effective way to promote health for people with disabilities? Why or why not?

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