Special Focus Series: Health Promotion and Fitness

Health Promotion for People With Disabilities: The Emerging Paradigm Shift From Disability Prevention to Prevention of Secondary Conditions

The premise of this article is that, until recently, health promotion for people with disabilities has been a neglected area of interest on the part of the general health community. Today, researchers, funding agencies, and health care providers and consumers are leading an effort to establish higher-quality health care for the millions of Americans with disabilities. The aims of a health promotion program for people with disabilities are to reduce secondary conditions (eg, obesity, hypertension, pressure sores), to maintain functional independence, to provide an opportunity for leisure and enjoyment, and to enhance the overall quality of life by reducing environmental barriers to good health. A greater emphasis must be placed on community-based health promotion initiatives for people with disabilities in order to achieve these objectives. [Rimmer JH. Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions. *Phys Ther.* 1999;79:495–502.]

Key Words: *Disability, Disease prevention, Health promotion.*

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Health promotion for people with disabilities must become a major focus for the new millennium.

Among some people with disabilities, there is a belief that the emphasis in health care has been directed at the primary prevention of disability rather than at prevention or reduction of secondary health conditions in people who have a disability.[1–4] Many health care professionals would agree that terms such as "wellness" and "health promotion" are often not associated with people with disabilities.[2] Teague et al wrote:

> Federal efforts in health promotion and disease prevention, as described in the 1990 Health Objectives for the Nation Report, focus on primary prevention for the general, nondisabled population and strategies that promote and maintain health among people already healthy. Unfortunately, specific attention to prevention strategies for people with disabilities has not received sufficient attention. Health maintenance objectives have been largely ignored since many health providers fail to distinguish between primary and secondary disabilities.[5(p54)]

The focus of this article is to describe the field of health promotion as it relates to people with disabilities and to offer a conceptual model of health promotion that addresses the growing needs of people with disabilities.

Shift From Disability Prevention to Health Promotion

Studies on health promotion for people with disabilities are almost nonexistent.[1] Although the federal government has made an effort in the last two decades to improve the health of Americans, there has been little emphasis on addressing the needs of people with disabilities. The *Healthy People 2000* report that was developed over the course of several years and became the nation's road map to improving the health of supposedly all its citizens, exposed the glaring absence of baseline data on people with disabilities.[6] In the lengthy report released by the federal government, *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*, an expert panel wrote:

> As with minority populations, the elements of this report that explicitly call for [health] improvements of *people with disabilities* are limited by the availability of data with which to set targets. One of the major challenges of the coming years is to improve our understanding of the needs of the full range of *people with disabilities* by improving the effectiveness of data systems.[6(p40)]

The panel also wrote:

> A clear opportunity exists for health promotion and disease prevention efforts to improve the health prospects and functional independence of *people with disabilities*. Gaps, overlaps, inconsistencies, and inequities in existing programs require the effective coordination of existing services if the health of *people with disabilities* is to be promoted.[6(p41)]

The emphasis on prevention of disease and disability that has been entrenched in the American health care system for many years may be the underlying reason why it has taken so long for the health promotion movement to address the needs of people with disabilities.[2,5,7] The absence of information on health promotion for people with disabilities has, in my view, kept this subgroup out of the limelight and in the background of research agendas across the country. Only recently has health promotion been given a greater amount of attention concerning the lives of people with disabilities.[8,9]

In the emerging paradigm shift from disease and disability prevention to prevention of secondary conditions in people with disabilities,[9] physical therapists and other rehabilitation professionals can play an important role in the integration of health promotion into the fabric of a community.[5,7,10] As noted by Renwick and co-workers, "Rehabilitation has strong potential as a collaborator in the process of making health promotion people-centered in that it has collective expertise in client centeredness at the individual level of analysis and application."[11(p366)] According to Teague et al, "In restructuring health promotion services for people with disabilities, rehabilitation professionals are challenged to assume the roles of collaborator, educator, researcher, and program provider."[5(p56)]

The Changing World of Health Care Delivery and the Emerging Role of Health Promotion

Changes in health care financing have been having an impact in recent years on the traditional ways of doing

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things.[12] The old fee-for-service delivery system has largely been replaced by new managed care initiatives.[13] Many hospitals and rehabilitation centers are trying to find ways to reduce costs while still trying to maintain quality.

With the introduction of managed care, research has shown that rehabilitation services have declined dramatically.[14] Shorter hospital stays usually translate into less rehabilitation. Where it was once common practice to keep a patient in the hospital for as long as necessary to achieve what health care professionals considered adequate recovery, the incentive in health care today is cost reduction by truncating or eliminating services.[15] Patients no longer have the luxury of leaving the hospital when they are close to resuming a normal daily routine. Today, they are told that they must continue their recovery in another setting, often without the ancillary services that are needed to achieve good progress.[16]

One of the major reasons for this transformation in health care is the perception among members of the business community that it is much too expensive.[17] As corporations began downsizing in the 1980s and early 1990s, searching for ways to reduce overhead became a national obsession. Health care became a topic of great discussion and debate, and managed care, or managed competition as some people would call it, became the code words for reducing costs.[18]

Many health care professionals, including physical therapists, have known for years that what is needed is not a larger-based hospital system, but rather a health promotion/disease prevention agenda that strikes at the core of the problem.[19] Unfortunately, under the traditional system of health care in the United States, most of the financial resources are spent on diagnosing and treating disease, which leaves little or no remaining funds for health promotion.[20] Only after all is said and done with the nondisabled community, do people with disabilities get any attention.[12] Fortunately, this is slowly starting to change, and funding agencies have begun to support health promotion initiatives for people with disabilities.[21]

Promoting Health in People With Disabilities

For years, the most widely accepted definition of health was the absence of disease.[22] This antiquated definition may be one of the strongest reasons for the lack of attention given to people with disabilities in health promotion. If a person had a congenital disability such as spina bifida or cerebral palsy, developed multiple sclerosis, or had severe asthma, the individual was not considered a good candidate for a health promotion program because the aim of health promotion was not to take care of the "sick" and "disabled," but rather to prevent disease and disability in the "healthy."

Health for all of us shifts back and forth on a continuum from low (poor) to high (excellent) and high to low. Take, for example, the person who exercises regularly and has good dietary habits. He or she may be at the high end of the health continuum at the age of 40 years, but, after being diagnosed with cancer and going through several chemotherapy treatments, there would be a shift in health to the lower end of the continuum. Once treatment is completed and the person resumes a healthy lifestyle, there could presumably be a shift back to the higher end of the continuum.

Variations in health during the course of a person's lifetime are no different for people with disabilities. Someone who has sustained a spinal cord injury but practices good health habits by eating properly, exercising, getting regular medical checkups, preventing pressure sores, and maintaining adequate body weight and could be considered on the high end of the health continuum. Alternatively, a person with spina bifida who gets frequent pressure sores, has a poor diet, does no exercise, and is overweight would most likely be in poor health and at the low end of the continuum because these behaviors will often have unwanted consequences. With the right treatment plan, however, this person could improve his or her health.

Once members of health care industry accepts the reality that health is not a static entity but rather a dynamic one that is multifactorial in nature and shifts back and forth on a continuum during the course of a person's lifetime, they will find it easier to understand how a person with a disability can improve or worsen his or her health in the same manner as anyone else. The only difference, however, is that people with disabilities often start at the lower end of the health continuum due to secondary conditions that overlap with their primary disability.[23] In some respects, it could be argued that this is even a greater reason for shifting some of the focus in health promotion to people with disabilities, because a minor illness could compromise their functional mobility and potentially lead to an earlier decline in health and a dependency on other individuals for care.[7,21,24]

People with disabilities are highly susceptible to secondary health conditions.[25] In a report entitled *Preventing Secondary Conditions Associated With Spina Bifida and Cerebral Palsy*,[23] it was noted that secondary conditions affecting people with disabilities include osteoporosis; osteoarthritis; decreased balance, strength, endurance, fitness, and flexibility; increased spasticity; weight problems; depression; and other conditions.

Aday has characterized the health care needs of people with disabilities as extensive:

> ...(1) their needs are serious, in many cases, debilitating or life-threatening ones; (2) they require an extensive set of medical and nonmedical services; (3) the growth in their number and the seriousness of their needs are placing greater demands on the medical care, public health, and related service delivery sectors; (4) their complex and multifaceted needs are, however, not adequately met through existing financing or service delivery arrangements; and (5) federal, state, and local policy makers are increasingly concerned about how to deal with the demands they place on the existing systems of care, as well as about how to aid the growing number of Americans at risk for serious physical, psychological, and/or social health problems.[26]

These concerns are driving the need for health promotion strategies that reduce or eliminate secondary conditions in people with disabilities.

A collaborative effort on the part of federal funding agencies, health care providers, researchers, consumers, and advocates aimed at raising the level of awareness concerning the health promotion needs of people with disabilities is finally emerging.[19,21,27–30] One of the major themes behind the independent living movement is inclusion and participation in all aspects of society, including the right to maintain good health.[4] Health promotion for people with disabilities is now being addressed by several major agencies, including the Institute of Medicine, the Centers for Disease Control and Prevention, the National Center for Medical Rehabilitation Research, the National Institutes of Health, and the National Institute on Disability and Rehabilitation Research.[21]

In a recent working document, *Healthy People With Disabilities 2010*, the definition of health promotion for people with disabilities consists of 4 parts: (1) the promotion of healthy lifestyles and a healthy environment, (2) the prevention of health complications (medical secondary conditions) and further disabling conditions, (3) the preparation of the person with a disability to understand and monitor his or her own health and health care needs, and (4) the promotion of opportunities for participation in commonly held life activities.[9]

This definition clearly views the magnitude of a disability in relation to the person's interaction with the environment. In many instances, the environment can be considered the *barrier* to good health practices and not the disability.[29] For example, by making a fitness center accessible to a person in a wheelchair or having labels on medicine bottles in different forms of print for people who are blind or visually impaired, the disability is no longer the primary barrier to improving health. By eliminating certain environmental obstacles, the process of promoting health in individuals with disabilities is greatly enhanced. The emphasis in the independent living movement is on consumer control and direction of their own health, with professionals assisting in altering the environment so that the individual has access to health promotion activities aimed at the general population.[4,29]

Moving Toward a Community-Based Health Promotion Model: The Future Role of Fitness Centers

Given the proper guidance and direction from rehabilitation professionals, fitness centers are poised to become the future centers of health promotion for people with disabilities. I believe that the potential for a new market is quickly emerging.

Before this transformation can occur, however, there is an urgent need for fitness professionals to become more knowledgeable about disability. Based on my own experiences, most fitness professionals get very little training, if any, in exercise prescription for people with disabilities in their undergraduate and graduate programs.[31] The fact that there is such a lack of knowledge concerning how to work with people with physical, intellectual, and sensory disabilities is very troubling because it serves as a major barrier to participating in community-based fitness programs.[32,33]

The Figure illustrates a conceptual model of health promotion for people with disabilities. This model takes into account the strong need to establish linkages between rehabilitation facilities and community-based fitness centers in order to extend the recovery process into the community. Fitness centers, with their ambiance and health-oriented focus, have the potential to become a logical extension of the rehabilitation continuum by offering a location in the person's natural environment to continue the recovery process, as well as serve as a bridge to other health promotion activities that often take place at these centers such as nutrition seminars, relaxation classes, and health fairs.

As the continuum of rehabilitation moves further into the community, physical therapists will have a growing number of opportunities to serve as itinerant consultants to local fitness centers. Although some physical therapists are beginning to rent space in more affluent fitness facilities,[34] there is also a need to increase their involvement in the full range of public and private facilities, including senior centers, park districts, and local YMCAs. When the need arises to develop an exercise program for a new client with a disability, the physical therapist would assist in developing the program and would serve

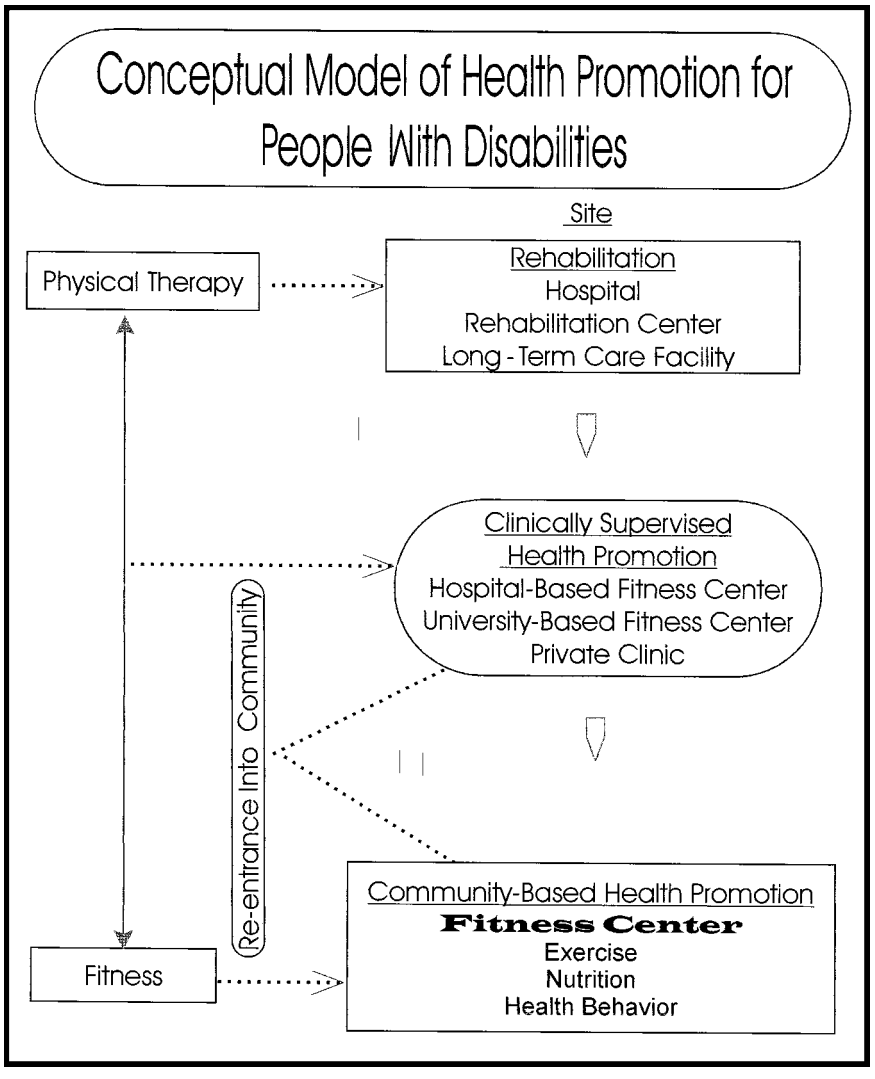

Figure.
Health promotion model for people with disabilities.

as the liaison between the primary care provider and the fitness instructor. The therapist would also be available to provide direct care if an individual needed specialized physical therapy services.

As shown in the conceptual model of health promotion presented in the Figure, the physical therapist and the fitness professional would work closely in providing the safest and most effective programs for people with disabilities along the entire health promotion continuum. The person would move from *rehabilitation* in an inpatient setting to *clinically supervised health promotion* after discharge, ultimately ending up in a local fitness center in close proximity to his or her home. Notice that the arrows pointing to *physical therapy* and *fitness* in the Figure are bidirectional. This illustrates that therapy and fitness may occur in any of the 3 settings. For example, some private physical therapy clinics hire exercise physiologists to implement fitness programs after an extensive evaluation is completed by the therapist. Several rehabilitation centers have fitness and sports facilities that are directed by physical therapists, exercise physiologists, or therapeutic recreation specialists. Many hospital-based and university-based fitness centers also employ physical therapists and exercise physiologists to direct cardiac rehabilitation programs.

In some instances, the person with a disability may not necessarily require physical therapy services, whereas on other occasions, a health club member without a disability may be referred for physical therapy by a fitness instructor. The major strength of this conceptual model is that the individual—with or without a disability—is offered the best care by qualified professionals. The arrows in the model also indicate that as a person's health shifts in either direction during his or her lifetime, the opportunity to receive inpatient acute care or community-based rehabilitation or fitness is always available.

For this model to be successful, however, 3 things must occur. First, fitness professionals must strengthen their skills in health promotion and disability. A lack of knowledge in these areas will make it difficult to communicate with physical therapists and other rehabilitation professionals when providing services to individuals with disabilities. Steadward wrote that "expanding fitness professionals' knowledge about appraisal and exercise prescription will facilitate encouraging and increasing physical activity participation among people of all abilities."[33(p165)]

Second, the rehabilitation profession must embrace the concept of extending its services into community-based fitness centers. A stronger relationship must be established between fitness professionals and physical therapists. Without the guidance and support of physical therapists, it will be difficult for fitness instructors to provide high-quality programs to people with disabilities. Physical therapists can enhance their visibility in community-based fitness centers by offering lectures at these settings so that fitness instructors become familiar with the local therapists and how they can be of assistance when developing programs for people with disabil-

ities. Another way to bridge the relationship between therapy and fitness is to develop media-related materials that describe the role of physical therapists and how they can be of assistance to clientele who have a disability. This material can be disseminated to the managers of local fitness centers.

Third, because very few people with disabilities have the financial resources to join a fitness center,[32] Medicaid and Medicare, insurance companies, and managed care organizations must be willing to pay for the membership and the consultative services of physical therapists who would work alongside fitness professionals in delivering health promotion programs to people with disabilities. Although in an era of downsizing this may sound improbable, the independent living movement and the freedom of choice over a person's health may lend support to the concept of receiving services in the community. Because space has become a premium in many hospitals, we may also begin to see more and more therapists providing rehabilitation in community-based fitness centers.[34]

The Future of Health Promotion for People With Disabilities

As a result of the growing interest among federal funding agencies to improve the health of people with disabilities, the Centers for Disease Control and Prevention (CDC) recently funded several new projects to examine the health promotion needs of people with disabilities. The aim of these projects is to reduce secondary conditions in people with disabilities by reducing or eliminating barriers that prevent them from participating in health-promoting activities.[6]

In a recent study assessing the barriers to health promotion in women with physical disabilities, Rimmer found that the 4 major barriers to participation were transportation, cost of the program, lack of energy, and lack of knowledge concerning where to obtain a program.[32] In one of the CDC-funded projects, these barriers were eliminated by providing free transportation, not charging a fee for the program, reducing the fatigue level that often occurs getting to a site by providing door-to-door transportation, and developing an accessible and individually designed exercise program in a newly constructed fitness center.[35] In the first iteration of stroke survivors, attendance for the 12-week program was over 85%, and none of the participants dropped out. These findings could largely be attributed to the elimination of these barriers.

As shown in the conceptual model of health promotion presented in the Figure, when an individual is discharged from an inpatient facility, the names of 1 or 2 clinically supervised facilities, preferably in close proximity to the person's home, would be provided. Hospital-based fitness centers, university-based fitness centers, and private physical therapy clinics are excellent sites for continuing the recovery process before joining a local health club. These sites offer greater monitoring of the individual's progress and place a strong emphasis on education. For certain individuals who have not had any exposure to a health promotion program, a clinically supervised setting is an excellent intermediary step before joining a local health club.

Fitness

The major components of a fitness program for people with disabilities are the same as for the general population: cardiovascular endurance, strength, and flexibility. What may vary, however, are the types of activities that would be used to improve fitness (eg, use of an upper-extremity ergometer to improve cardiovascular endurance in a person with a lower-extremity disability, use of a recumbent bicycle in place of a stand-up bicycle for a person with poor upper-body control) and the intensity, frequency, and duration of the activities. With some individuals who are lacking in balance and pulmonary function, additional exercises may have to be added to the exercise prescription.[36] When developing an exercise program for a person with a disability in a community-based setting such as a YMCA, the fitness instructor should be in close communication with the physical therapist to ensure that the program is safe and effective for the client. Closely supervised programs are often not available in many fitness facilities unless the person is able to pay for a personal trainer.

Nutrition

The role of diet in preventing chronic disease is well-established. The typical American diet is too high in saturated fat, cholesterol, salt, and sugar and too low in fiber and life-enhancing nutrients such as antioxidants.[37] Some experts believe that as much as one third of coronary heart disease and cancer can be attributed to dietary factors.[37] Obviously, people with disabilities have needs similar to those of the general population in terms of reducing unwanted fats, cholesterol, salt, and sugar in the diet. There is too high a consumption of unhealthy foods and too low a consumption of healthy foods.

A major emphasis in a nutrition program for people with disabilities should be relatively consistent with the general population. Proper eating habits and weight reduction strategies should be emphasized. Because overweight appears to be a greater problem among people with disabilities because of poor nutrition and a sedentary lifestyle,[6,38] instruction in weight management strategies is essential.

It is also important to develop a nutrition program around the person's environment. Cultural and socioeconomic differences must be addressed if a nutrition program is to be successful. Suggesting to someone on a fixed income that he or she should eat more fish may be impractical, because fish is often more expensive than meat. Instruction in proper nutrition should be linked to the person's lifestyle, culture, and eating behavior.

Health Behavior

I believe that one of the fastest growing areas in health promotion is health behavior. Researchers are searching for answers as to what motivates some people to engage in a healthy lifestyle while other people continue to lead an unhealthy lifestyle. In a recent editorial in the *American Journal of Health Behavior*, health behavior was defined as the core of why people behave as they do and ultimately attempts to explain the multifaceted phenomena of human behavior.[39]

A general health behavior curriculum should include topics related to stress management, smoking cessation, and coping strategies. Other areas could include substance abuse reduction, proper medication usage, spirituality, proper sleep habits, and good hygiene. These components should focus on disability-related issues. For example, many stroke survivors continue to smoke and, therefore, need a strong unit on smoking cessation strategies. People with Down syndrome have a very low incidence of smoking but may have other pressing needs such as proper dental hygiene. People with spina bifida and spinal cord injury may need instruction in the prevention of pressure sores. Many people with disabilities need a better understanding of medication management.

Teaching coping strategies is an important area of health behavior. Many survivors of stroke, for example, struggle with depression, which is often related to the loss of their job, spouse, or mobility.[35] Rimmer and Hedman[35] have noted that many survivors of stroke are overly sensitive about their paralysis and slow gait, which they often perceive as an annoyance to their friends, family, and society. Moving slowly through a mall or supermarket appears in their minds to be a burden to the people around them. A health behavior unit should address these issues because a poor mental health status could undermine the success of a health promotion program.

Conclusion

Health promotion for people with disabilities must become a major focus for the new millennium. In the long run, preventing secondary health conditions by empowering people with disabilities to take control of their own health will be more cost-effective, and certainly more humane, than watching people with disabilities decline in function from a lack of good health maintenance. Health care professionals should join in this collective effort to enrich the lives of people with disabilities. It could truly be an exciting era if rehabilitation professionals extend their services into community-based fitness centers and facilitate the promotion of good health practices for the more than 50 million Americans with disabilities.

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