Can Disability, Chronic Conditions, Health and Wellness Coexist?

Can disability, chronic conditions, health and wellness coexist? This question has broad and significant implications on the quality of life for people with chronic conditions and disabilities.

Depending on personal beliefs, values and current experience, people often emphasize one aspect over another in their own definitions of health. Traditional definitions describe health and disability at opposite ends of a single health continuum. Such definitions lead far too many people to view health and disability as mutually exclusive of each other, an either/or proposition.

This view must be examined as it has damaging and lasting effects on people who live with disability and chronic conditions. As Bob Williams, Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy, Department of Health and Human Services puts it, "Learned helplessness truly is the greatest crippler anyone can experience. And, many people with disabilities have unfortunately learned to be passive, if not completely disengaged, where questions of their own health and well being are concerned." Many see health as just one more thing beyond their control, something they cannot change or influence. (Williams, p.5).

The ability to practice healthy behaviors, even in the presence of disability, has led to newer models of health. These newer definitions view health as multi-dimensional and see optimal health as defined within a given person's unique circumstances. Health is viewed as the maximizing of one's potential along various dimensions. Health include a dynamic balance of physical, social, emotional, spiritual and intellectual factors. When this definition is used, disability poses no obstacle to maximizing health and one's potential (Lanig, p.13). When health is viewed not as the absence of disability or chronic conditions, but as the ability to function effectively in given environments, to fulfill needs and to adapt to major stresses, then, by definition, most people with disabilities are healthy.

Elements of health include a dynamic balance of physical, social, emotional, spiritual and intellectual factors.

Peg Nosek, Director, Center for Research on Women with Disabilities and Professor Department of Physical Medicine and Rehabilitation at Baylor College of Medicine, writes, that the stereotype of infirmity, sick people in wheelchairs covered with blankets, haunts people with disabilities. Curious new acquaintances or health providers will ask, "when did you first get sick?" Instead of, "how are you doing?" people with disabilities often get asked, "how are you feeling?" (Nosek, p. 2) Even in those situations where people are experiencing poor health, chronic fatigue or pain, they don't want to be asked how they feel all the time.

Health care providers, like many others, are not free of the common disability stereotypes which cause discrimination and environmental and attitudinal barriers that people with disabilities encounter daily. Health providers, like society at large, have the same, if not stronger, misunderstandings about the health of people with disabilities. People working in medical settings constantly have these stereotypes reinforced, often because they are only exposed to people with disabilities and chronic conditions who are indeed sick. In addition, medical students report there is very little, if anything, taught about disability, living with disability, or health, wellness and disability in medical school.

When the medical system does not understand the health needs of people with disabilities, this translates into practices and mistakes that affect people in the most important aspect of their lives, their health (Nosek, p. 6). A provider who equates disability and difference with dysfunction and illness, invalidates people with disabilities.

While disability and long-term conditions can involve pain

or poor health, disability and health can and do coexist. Most people with disabilities are not sick. They are indeed healthy, when health is defined as the absence of illness and disease beyond disability. The assumption that health, wellness and disability cannot coexist is a myth.

Providers who understand that people with disabilities can be healthy, active, and assertive participants and co-managers of their health and health care, can be of tremendous assistance in helping people select and practice tailored health promotion behaviors and activities directed at increasing a person's level of well-being.

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Physical exercise, good nutrition, stress-management and social support are important for every one, but they are actually more critical for people with disabilities who sometimes have been described as having "thinner margin of health" (Becker, p. 236).

This does not imply that people with disabilities are sick. It means that people with disabilities are more vulnerable and more susceptible to certain health and secondary conditions depending on their disability. For example, some people with spinal cord injuries are more likely to have to deal with pressure sores, urinary tract infections and kidney conditions. People with respiratory conditions can be more vulnerable to upper respiratory infections and pneumonia.

Health promotion activities are critical for people with disabilities who are prone to have a more sedentary lifestyle and have a tendency for under, over, or misuse of various muscle groups. Although we cannot yet replace the cells we lose as we age, " . . . research is showing us that we can improve the efficiency of the remaining cells by staying as flexible as possible and by challenging our heart, lungs, and muscles to maximize in strength and endurance through exercise (Ontario Federation, p. 9)."

People with disabilities have many questions about strategies pertaining to weight control, diet, fitness and exercise. Some of these key questions include:

- Where do people with disabilities go for fitness information that has a disability filter? How should we exercise? How much?
- What is the effect of exercise on preventing increasing disability for specific types of disability groups?
- How important is conditioning, flexibility and endurance for people with disabilities? Is it more important that conditioning and flexibility be maintained because many people with disabilities work harder to physically function?
- Does active and consistent participation in various physical activities (i.e., sports, fitness) for people with disabilities accelerate musculoskeletal injury or pain or does it slow or prevent pain or injury?"
- How do people with disabilities maintain cardio pulmonary conditioning, physical strength, bone density, coordination, and joint mobility?
- Should aerobic conditioning come before specific muscle strengthening or the reverse?
- What type of strengthening program is best for people with significant spasticity?
- Where do people with disabilities find affordable personal trainers with disability expertise?
- What exercise books should people with disabilities read?
- What exercise videos should people with disabilities use?
- Which strengthening and aerobic equipment should people with disabilities use?
- Is a weight-lifting program going to strengthen

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muscles or will it cause or exacerbate pain and stiffness and lead to arthritis?

- Will osteoporosis become a major problem for people with mobility disabilities? Should screening be conducted earlier for people with disabilities than for people without disabilities? What interventions are effective? When should they be started?

- Since living with disability often means continual body strain and stress, should specialized diets be tailored to people with specific types of disabilities? For example, do wheelchair users need a greater intake of calcium than the recommended daily allowance to prevent bone loss? Are peak performance diets more relevant for people with disabilities?

- What are the implications for people with disabilities, of the fact that people without disabilities who have been athletic all their lives, and who have continued to eat and exercise properly, seem to age less rapidly and are healthier than their non-athletic counterparts?

When health care providers take the time to explore and understand negative misconceptions and stereotypes surrounding disability, many will be discarded. Providers who invest time in understanding issues related the health, wellness, and health care needs of people with disabilities can be strong supporters and advocates. Providers need to encourage people with disabilities to be healthy and active, as well as assertive participants and co-managers of their health and health care.

Unfortunately health promotion and preventative health care has received little attention, in part due to the strong perception that health and disability is are mutually exclusive. As a friend, Kathleen Lankasky put it, "The lack of knowledge and understanding on the part of health care professionals concerning my disability and how it is affecting me as I age is extremely frightening to me....We are tired of reacting to pain and stiffness rather than preventing them."

The inability of people with disabilities to get helpful information regarding what types of exercises is best suited to their specific limitations is exasperating. This information gap is extremely troubling given the vast amount of existing evidence that indicates that many physical difficulties which accompany aging in people without disabilities can be prevented or lessened by exercise. Although good health habits, including exercise, do not guarantee a long life, they do greatly increase chances for a good quality of life.

People with disabilities need:

- *Exercise guidelines* that are age and functional limitation-sensitive, to help assess how "fit" we are using appropriate standards and measures, fitness facilities we can get to, enter and use, integrated and convenient, not special or separate,

- *Exercise facilities* (YMCA's and other community-based fitness centers and programs) that are aware of and comply with their legal obligations under the Americans Disability Act,

- *Exercise equipment* that incorporates universally designed features so the equipment can then be used by people with a broad spectrum of strength and abilities without reducing the equipment's usability or attractiveness for all exercisers.

Everyone agrees that exercise and good nutrition is important, but helpful and specific information for people with disabilities in difficult to find. Although scarce, scientific and practical information does exist, it is poorly organized and spread over a wide range of disciplines (National Center on Physical Activity and Disability). Answers that will help people with disabilities deal with these issues are needed. Its up to you to help fill these research, service and information gaps!

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