

U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation Office of Disability, Aging and Long-Term Care Policy

LAST THOUGHTS:

BELIEFS SHAPE EXPECTATIONS

Office of the Assistant Secretary for Planning and Evaluation

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The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This article appeared in the *Window on Wellness* (Spring 1999, page 19). For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Bob Williams.

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Bob Williams

U.S. Department of Health and Human Services
Office of the Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

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Good health and disability. To many, if not most Americans, these two concepts are contradictory. Even many people with disabilities and their families view good health and disability as opposite. We have accepted and internalized the idea that as individuals with disabilities, good health can never fully be ours. Illness, onset of secondary disabilities, and decline in quality of life are our destinies.

1. Challenge The Assumption Directly

First, we must challenge this type of thinking directly. It is the same kind of myth and stereotype that leads to discrimination against people with disabilities and that necessitated passage of the Americans with Disabilities Act.

We must challenge it in others because it hurts the well-being of our nation, our economy, and our healthcare system. Most importantly, we must challenge it in our own hearts and minds, where it has its most damaging and lasting effects.

Our persistent attention will enable us to benefit from these important lessons:

- Prejudice and low expectations undercut the health status and economic well being of Americans with disabilities of all ages.
- We have allowed similar misperceptions about our health to creep into and guide our lives and expectations. Learned helplessness is the greatest crippler of all.
 The one effective antidote is to put people in charge of their own lives.

Many people with disabilities have learned that in some ways it is easier to accommodate themselves to the perceptions of others than it is to demand either more from themselves or what is fair and right from others. They have learned to be passive--to view themselves as being helpless, especially where questions of their own health and well-being are concerned.

No individual with a disability is completely immune from such feelings. Why? Because, whether we were born with our disability or acquired it, most of us have come to view our health as something immutable: just one more thing that is beyond our control.

I grew up with cerebral palsy. Looking back, I see now that a central message I and most others with my disability received was that cerebral palsy was a static condition. That is, it did not get worse. However, implicit in the same message was the idea that if cerebral palsy did not get any worse, it certainly did not get any better, either.

Another central message was that our health and disabilities went hand-in-hand. Society, our doctors, parents, and others all told us the same thing: Our health and disabilities were inextricably linked, beyond our power and influence.

2. Take A Second Look At Our Meaning Of "Good Health"

The second step in challenging the assumption that health, wellness, and disability do not go together is to take a second look at what "good health" means. This must be done not only in the interest of Americans with disabilities but also for our nation's health and well-being as a whole.

For far too long, most have taken it for granted that good health means the absence of disability, illness, and injury. We must rethink and revamp our collective definition of true health. We Americans with disabilities, our families and our allies know, better than most people, that good health is much more than absence of sickness, injury or disability.

True health is really about having the ability, assistance, and support to achieve greater choice and control in life.

Excerpted with permission from "Lifelong Wellness and Disability," a speech delivered at Harvard University, Boston, MA, Nov., 1998. Bob Williams is Deputy Assistant Secretary for Disability, Aging and Longterm Policy at U.S. Health and Human Services, Washington, DC.

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