Editorial

Opening the community for persons with disabilities: How are we doing?

Significant barriers still exist that contribute to people with disabilities being forced to live in isolated situations. The most serious and pervasive barrier is related to public attitudes and misconceptions regarding disability issues. Foremost among these misconceptions is the belief that people with disabilities need to be raised in seclusion and live in protective environments, "for their own good". These negative attitudes or public misconceptions continue to be part of the general public's belief system. Evidence of this can be found in the structure of many of these new disability rights laws, although federal funds typically are tied to new specific public laws and/or projects when new regulations represent a major shift in policy. The Americans with Disabilities Act (ADA) is one such law where there was a major shift in public policy; however, it was structured in a manner that it did not include federal funding to promote and/or change old practices and to create critical new community practices. Therefore, it appears that while lawmakers and their constituents were supportive of the ADA, they still had sufficient lingering doubts that resulted in lack of federal funds to support this major shift in national policy.

Further evidence of the public's misconceptions that people with disabilities need to remain in seclusion and/or protective environments can be found in how the federal budget is divided. In the late 1990s, the bulk of federal funds to support persons with disabilities go directly to facility-based programs. These funds are not designed to flow down to the individual; rather, these funds continue to support the services of institution-based programs. The facility managers of these disability service programs make extremely strong arguments supporting the notion that facilities can efficiently care for the "disabled" in group settings such as residential facilities, sheltered workshops, and day treatment programs. Yet, these programs are not designed to meet the

individual needs of people with disabilities. Efficiency is achieved too often by meeting group demands and administrative convenience. Therefore, concepts such as people with disabilities exerting choice and/or control over the services that they receive does not occur in these environments.

The first time that these beliefs of segregation and protection underwent serious public questioning was in the 1960s. It was not surprising that these long-held beliefs would start being questioned during this time when so many other social changes were occurring in the country. Also, many movements were underway that were giving birth and life to the disability rights movement. Some of these were: the parent-motivated de-institutionalization movement, the Civil Rights movement, DeJong's non-medical model movement, and a variety of self-help movements. This atmosphere of changing social values and attitudes caused individuals with disabilities living in nursing homes to assert their right to an integrated community life [1]. By the 1970s, the outcry from this very large and diverse constituency group and their supporters was loud enough to cause the then President of the United States, President Jimmy Carter, to call for the first White House Conference on Disability.

Many of the recommendations that came out of the White House Conference on Disability formed the basis of the historic legislation which subsequently followed. More importantly, many of the people with disabilities attending this momentous conference became the leaders in the emerging disability rights movement. These leaders became the driving force that turned revolutionary recommendations into laws that have become more than words on paper. Many of these leaders not only played a key role in getting these historic laws passed but also served as role-models by encouraging the dis-

ability community to fight for the implementation of those laws.

Nevertheless, developing open and accessible communities remains a large and daunting task. Some communities are further along in this process than others. Here are four key strategies for people who care about these issues to consider.

Gaining knowledge of disability rights

A knowledge of disability rights is essential to accessing the community. It is empowering to know that federal laws require our communities to meet certain accessibility requirements. However, without specific knowledge about these laws and subsequent violations change cannot occur. The old adage of "knowledge is power" is particularly important when the goal is to create positive and effective change.

It is hard to believe, but the fact is that many people with disabilities have never heard of the Americans with Disabilities Act (ADA). The powerful titles of the ADA give people with disabilities the right to employment and the right to gain access to local government services, and in addition, give people with speech and hearing impairments the right to understand and be understood. These rights are all relatively new concepts to people living in institutional care facilities or in isolated situations with family members.

Putting the person with a disability in charge of services

Large residential care facilities and generic service agencies – not customer-controlled, community-based services – receive the majority of federal funds. For example, funding for personal assistance services is often relegated to home health agencies that give consumers little or no control over the very intimate services that a personal assistant provides. These agencies continue to thrive despite the growing body of evidence that documents lower operating cost and higher customer satisfaction ratings for community-based services [2]. As a result there is a struggle developing between small services organizations and the larger facilities. Although customers are voicing their desire for change, there appears to be to a strong interest in maintaining the current system.

Being determined

Getting access to the community takes more than having knowledge about disability rights and legislation or being able to obtain and direct services. It requires knowing which services are available in the community and having the tools and determination to obtain what is needed. People with disabilities and other community members must truly recognize that diversity builds a strong and effective community and nothing short of that goal is acceptable.

As was true with the civil rights movement in the 1950s and with the women's rights movement of the 1970s, it takes more than knowing one's rights to ensure equal access. People with disabilities must learn to exercise their right to self-determination as did African Americans and women. Only when a large majority of individuals with disabilities exercise their rights through self-determination and through the use of self-advocacy skills will the promises of laws like the ADA be fully realized and full access to the community be achieved.

Support and encouragement

People who have lived in isolated situations, in closed communities made up of family members or in a residential-care facility will need support to obtain important community access goals. Isolation has made many individuals fear the community, and, as a result may need support and encouragement to take the important first steps to community involvement. Sometimes fear of the unknown can be a barrier to an individual when attempting to gain access to new environments.

Progress comes slow. There have been gains made. More research is published every day. New ideas are created. New laws are passed. But, at the end of the day it is all local community implementation of grassroots services available to all in need and all who have unique challenges that require support. There can be no turning back. All efforts must move forward.

Paul Wehman
Editor

References

[1] G. McDonald and M. Oxford, *Independent Living Movement,* Research and Training Center on Independent Living, Houston, TX, 1996.
[2] M. Russell, A. Toy and B.L. Malone, A community divided, *New Mobility Magazine* **7**(38) (November 1996), 38–47.