

Dispelling Fears About Aging with a Disability: Lessons from the Disability Rights Community

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ABSTRACT. There have been revolutionary changes in the way that many people perceive and deal with the issue of disability. These changes effect both the nature of services and the expectations that people may have about disabilities acquired late in life. This raises issues about the fears and anxieties that non-disabled seniors have about acquiring a disability as they age. This article addresses the most important aspects of the reconceptualization of disability as it relates to the field of aging and proposes a model for addressing senior's fears about acquiring a disability and preparing for life with disabilities typically acquired as people age.

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Over the last quarter century there have been revolutionary changes in the way that many people think about disability. This has had major consequences for legislation and services for people with disabilities. The thesis of this paper is that these changes raise issues and suggest guidelines for addressing the fears and anxieties that non-disabled seniors have about acquiring a disability. This addresses the most important aspects of a reconceptualization of disability as it relates to the field of aging and proposes a model for (1) dealing with senior's fears about acquiring a disability and (2) preparing for life with disabilities similar to those often acquired as people age.

FUNDAMENTAL CHANGES IN OUR THINKING ABOUT DISABILITY

The *Americans with Disabilities Act of 1990* (ADA) was a sweeping piece of civil rights legislation. While many authors have struggled with the implications of the act, most have focused on mandated changes to physical structures, social policies and other legal ramifications.

What has received less attention is the symbolic value of the ADA. ADA marks a shift in consciousness that is only now beginning to be understood. Prior to ADA, a person with a disability was primarily characterized by their limitations. While Section 504 of the Rehabilitation Act and other laws such as PL 94-142 were important in protecting people with disabilities from discrimination—particularly in cases where federal money was being spent—these were laws that protected the rights of disabled people *only* under certain circumstances.

ADA reverses the logic of Section 504. Instead of mandating that rights are protected under certain specific circumstances, ADA declares that a disabled person's right to inclusion and self determination must be protected under virtually all circumstances, whether under public or private auspices. To be sure, ADA does not protect every disabled person from every form of discrimination. However, under previous laws, a disabled person's rights to non-discrimination and public accommodation were mostly unprotected, especially in the private sector. After ADA, their rights, even in the private sector, are protected in most circumstances with only a few notable exceptions.

In a way that Foucault would appreciate, this changes the nature of disability itself. In *The Birth of the Clinic*, Foucault (1975) suggests that with the advent of scientific medicine the very nature of illness shifted from a focus on something that was "wrong with the patient" to a focus on an objective disease which was seen as totally separate from the patient. In turn, ADA marks a shift by treating "disability" not as a functional and objective limitation located

within the disabled person, but as a socially constructed phenomenon. Although he was not the first to do so, Hahn (1984) articulately and persuasively suggested that being a person with a disability, is much more like being an ethnic minority, than like a person who is ill. Race was socially constructed in a similar manner in the Jim Crow South. It was not the color of African-American's skin that was limiting to them, but rather the discriminatory practices and attitudes of the dominant society that served to oppress and hold them back. Similarly, Hahn suggests that people with disabilities suffer more from barriers related to attitudes and policies that bar them from full participation than from the limitations imposed by their impairments. It is not the impairment itself, so much as society's restrictions that are disabling.

Disability as a Unifying Principle

Considering impairments as qualifications for membership in a minority group serves as an important unifying principle for people whose disabilities can be quite different. "Disabilities" form a disparate group of conditions—from blindness to cerebral palsy, to spinal cord injury. The newer notion of a "person with a disability" recasts this. Any person with *any* impairment is a person with a disability and has a right to the same protection from exclusion and discrimination as any other. *Exclusion* and *discrimination* are remarkably similar in their effect regardless of whether a person uses a wheelchair or a seeing-eye dog. This unifying principle allows people who may be very different from each other both physically and mentally to come together in an organized way to address their common needs.

Demedicalization

Another change in consciousness about disability that is symbolically marked by the passage of the ADA is its impact on people's thinking about how one becomes a person with a disability. Heretofore, only a qualified medical or educational professional could bestow the label "disabled." In part, this meant that the definition was out of the control of disabled people—and in the hands of professionals whom they often saw as controlling their lives. Disability could be and was measured functionally in terms of the performance of certain cognitive or physical tasks such as "activities of daily living" (ADLs), "instrumental activities of daily living" (IADLs), Mini Mental Status Exam scores, etc., (Cox 1993; Harper 1986; Nosek, Fuhrer and Potter 1995; Nosek and Fuhrer 1992).

ADA has changed this state of affairs in a fundamental manner. Under ADA a person can be considered "disabled" by having *any* physical or mental

condition that prevents or limits them from engaging in a major activity of daily life, OR by having had such a diagnosis in the past, OR by simply having a history of being considered disabled. This changes the focus from the limitations “imposed” by impairments to the *consequences of being considered disabled*. This new definition recognizes that people can indeed be discriminated against when others merely “think” they are disabled. Stated another way, the new definition recognizes that stereotypical attitudes and environmental barriers are ultimately disabling—regardless of whether people actually have an impairment or even if they are merely thought to have one. People with psychiatric disabilities are especially aware of such predicaments. For this reason, they include as members of their movement anyone who has ever received a “psychiatric diagnosis or label” (Wahl, 1997; <http://indiana.nami.org/research/970913201441.html>).

Focus on Consequences

The shift in the post ADA era to focusing on consequences rather than on specific impairments has some interesting ramifications. There is a growing recognition that not all of the consequences of calling attention to one’s disability are bad. Indeed, there are some advantages. Employers, merchants and others are becoming acutely aware that people with disabilities not only have rights, but are capable of exerting them.

As a politically empowered minority, people with disabilities have had some impressive successes in forwarding an agenda which includes greater autonomy, community integration and control of the services they receive. ADA is the most highly symbolic and prominent example of socio-political reform efforts by people with disabilities. Indeed, it was the only piece of *federal* legislation during the 12 years of a Republican White House that was devoted to civil rights. This is particularly impressive when one considers that legislation promoting the rights of women, ethnic minorities, immigrants, gays and lesbians did not fare as well during this same time period. These earlier successes, moreover, have been continued in the current administration. A prominent example has been the appointment of Judy Heumann, a leading disability activist and one of the founders of the disability rights movement, to head the Office of Special Education and Rehabilitation Services (OSERS).¹

People with disabilities have also had some notable successes in taking greater control of the services they receive. The Rehabilitation Act of 1973, and its subsequent Reauthorizations have required that people with disabilities have a greater voice in the use and distribution of federal funding for services designed to help them. For example, as of 1978, Title VII of the Rehabilitation Act has become the primary funding source for independent living centers.

The act also assures that a majority of the members on center governing boards be people with disabilities (Office of Special Education and Rehabilitation Services 1992).

LEADERSHIP IN SOCIAL SERVICE CONSUMER MOVEMENTS

These successes have increasingly caught the attention of other social service recipients, especially in areas where there are active consumer movements. An interesting side effect is that people with disabilities seem to be losing their stereotypical image as helpless and passive recipients of services. Rather, they are being seen as leaders in the push for consumer oriented and *directed* services. This trend is especially observable when reviewing the literature on aging, developmental disability and mental health (Ansello and Eustis 1992; Tower 1994; Wehmeyer 1997; Wilk 1994).

It is important to note that *consequences* can be *positive* as well as negative. For many, "person with a disability" has gone from meaning "person with severe limitations" to meaning "person with rights to accommodation and inclusion." In the literature about developmental disabilities, mental illness and even aging, there seems to be a burgeoning recognition that "disability" has a certain cache (Racino and Heumann 1992; Wehmeyer 1997; Wilk 1994). There is growing recognition that there are some advantages to the label of "disability." While for many "disability" still means "limitation" and "stigma," for a growing number it also is beginning to mean "political empowerment," "assertiveness" and, importantly, "person with rights" (Hahn 1984). Some authors have speculated that "disability" for some has become so important to their sense of personal identity that he or she would not want to be without it (Beaulaurier and Taylor 1999; Hahn 1984; Hahn 1988). Inside the disability rights movement, many people have begun to conceive of their disabilities as integral aspects of their identities, or as one consumer known to the authors put it "a badge of honor." A recent survey of an admittedly special population of persons who were disability advocates found, surprisingly, that 47% of their respondents indicated they would not take a "magic pill" that would cure their disability, even if such a pill existed (Hahn and Beaulaurier submitted manuscript).

Community Services and Political Support for Independence: The Critical Synthesis

Laws such as the *Americans with Disabilities Act*, the *Air Carriers Act*, and Section 504 of the *Rehabilitation Act* have mandated changes in transportation

systems, employment settings, living settings, public buildings and spaces. Even the design and provision of social services have had to become more accommodating to those with physical and mental impairments. Although many social service reform efforts have met with mixed success, recent analyses suggest that laws such as the ADA have enjoyed a good measure of success (Blanck 1995).

Actually the notion of success is built upon a special collaboration among two types of organizations. Advocacy groups and organizations work toward assuring rights and entitlements for individuals and groups. Independent living centers and programs seek to assure that actual service options and assistance will be available when and if needed to support community based living.

Advocacy organizations that have emerged and matured as a part of the disability rights movement focus primarily on promoting people's access to and enjoyment of their new found rights (e.g., American Disabled for Assistance Programs Today [ADAPT], Disabled In Action [DIA], etc.). The major activities of such organizations are lobbying and launching social action efforts to assure that the policy and legislative mandates actually result in societal changes that translate into opportunities and protections for persons with disabilities. Independent living centers have also sprung from the disability rights movement in order to assist disabled people in their individual and collective efforts to maintain independent lives within mainstream communities. Independent living centers help individuals and groups with problems related to acquiring benefits, housing modifications, transportation, job-accommodations, legal problems, etc. These agencies tend to operate within a geographical region, although some have developed national and even international constituencies. Some examples of nationally known agencies are the Center for Independent Living in Berkeley, the Westside Center for Independent Living in Los Angeles, the Boston Center for Independent Living, Access Living in Chicago and the Arizona Bridge to Independent Living in Phoenix.

The objectives of both advocacy and independent living programs are quite similar: to maximize the ability of people with disabilities to live and work in mainstream communities and to have a maximum number of choices available when deciding how they will conduct their lives (Beaulaurier and Taylor 1999; Beedon 1992). In North America this has most often been termed "independent living," however, the German term "Selbstbestimptesleben"—literally "self-determined living" is somewhat more descriptive. Advocacy organizations work primarily to promote policy, regulatory and legislative changes that support rights and benefits needed by people with disabilities if they are to remain independent. Independent living centers are often active at the "systems advocacy" level as well, but their primary focus tends to be on helping clients and consumers to acquire and maintain the services and resources they need.

The Meaning of Independence

A common misconception is that “independent living,” as used by the disability rights community, is a state of being in which disabled people can live without the help of other people or assistive devices. Part of the confusion relates to the way the term “independent living” is used by medical and rehabilitation professionals. Zola (1983b) noted that the rehabilitation community tends to view independence as *first*, a minimal reliance on other people and *second* a minimal reliance on assistive devices to negotiate a world minimally accommodating to people with disabilities. The disability rights community uses the term to mean maximizing the choices and self-determination of disabled people and creating, whenever possible, environments which accommodate physical and mental impairments (Beaulaurier and Taylor 1999). These are very different orientations regarding rehabilitation processes and outcomes. Indeed, disability advocates from across the political spectrum stress *interdependence* and interconnectedness among people (Batavia 1997; Longmore 1995). “Independence” has more of a social connotation than a physical one. For disability rights advocates, “independence” is the ability to make one’s own decisions and “call one’s own shots” regarding how and where to live, work and associate without seeking *permission* or “clearance” or endorsement from service professionals (Beaulaurier and Taylor 1999).

PREPARING FOR THE ACQUISITION OF A NEW DISABILITY

Most seniors will acquire some disabilities during their lives. It is therefore not a question of “whether,” but “how” they will live with their disabilities (Cox and Parsons 1993, chap. 1). All too often, seniors do no anticipatory preparation. An accident or a disabling illness occurs, which may or may not have been preventable. When such events happen seniors often find themselves in physically and mentally stressful recovery or rehabilitative situations. Their resources and energies focus on obtaining needed services from medical and rehabilitation professionals. At the same time they may also be required to make adaptations to their housing and locate special assistance in order to maintain themselves and adapt to their new physical condition. They are suddenly enmeshed in two related, but very different scenarios, one oriented toward their recovery from the accident and the other involving hiring service, craft and professional people to help them make changes in managing their physical environment. This can be stressful and overwhelming at points, even for the most resourceful of people.

If an accident or illness also impairs their ability to meet their own transportation needs, they may also need assistive devices in order to drive their car, or attempt to utilize public transportation. This constitutes a third system of major changes all precipitated by the same event. It is at such times when not only the patient, but also family members and friends often feel stressed and overwhelmed by the amount of time-consuming effort, physical assistance and help the “newly disabled” person requires. Even with the best of intentions, this is the point in time when loved ones begin talking about the need for residential care because they do not have the requisite time, energy and resources to mobilize and manage activities in all of these sectors simultaneously (Wacker, Roberto and Piper 1998).

In many cases there will be no *single* “event” that results in an older person suddenly becoming a person with a disability (Lewis 1989). The term *frailty* is often used to describe disability in older people, especially in the “older old.” Frailty is commonly characterized by functional limitations and measured in the same ways that other disabilities are measured (Cox 1993, chap. 2). However, frailty often manifests somewhat differently in the elderly than other disabilities do in younger populations. In younger populations (and sometimes among the elderly as well) the onset of disability is often characterized by a catastrophic incident or condition leading to impairment. By contrast, frailty is generally associated with multiple, gradual losses of functioning and energy. Since the acquisition of disability in the elderly is often quite gradual, and can affect multiple systems, the transition from “non-disabled” to “frail” may be the sum of incremental losses in functioning over time rather than a sudden, clear cut change. Moreover, frailty can affect different areas of the body, reducing both mobility and sensory ability simultaneously (Lewis 1989). This can make the acquisition of a disability quite frightening especially when the individual considers it to be a harbinger of increased incapacity and dependency to come. This is often the case in spite of studies that have indicated that the acquisition of a disability by older persons does not necessarily correlate with continued decline (Brody and Morrison 1992, p. 24).

In most situations preparatory, adaptive steps and changes in the physical and social environment can and should be made before disabling conditions occur. This would greatly ease the burden these transitions pose for older people. If one or more of the stress-producing arenas could be eliminated or mitigated, the transition that an accident or disabling event (such as a stroke, etc.) causes might be far more manageable. For example some modifications such as ramps, non-slip floors, lowered kitchen counters (reachable by a seated person), easy-grip utensils and doors and toilet, shower and bathtub railings can be installed when older persons move to new housing or have renovations done. Such modifications can allow non-disabled seniors to begin to take

charge of their transitions with fewer risks of accidental injuries (such as from falls) while also helping them to increase the likelihood of their aging-in-place.

The benefits derived from environmental designs that accommodate both disabled and non-disabled people is a major thrust behind the universal design movement in architecture. Universal designs stress maximization and ease of use of the physical and spatial environment in order to make it as “user-friendly” as possible (Dobkin and Peterson 1999, chap. 1; Lifchez 1987). Moreover, the universal design movement challenges the notion that disability accommodations must be unattractive and appear like a retrofit. A key principle of universal design is that buildings and housing can be architecturally constructed in ways that will be appealing to people with a wide range of abilities by subscribing to the four “A’s” of universal design: accessibility, adaptability, affordability and attractiveness (Dobkin and Peterson 1999, p. 167). In order to meet such goals they stress access and ease of use in addition to aesthetics (Beaulaurier and Taylor 1999; Dobkin and Peterson 1999).

SENIOR’S FEARS ABOUT ACQUIRING A DISABILITY

Disability and Fears About Mortality

For many seniors even the prospect of the onset of a disability can have seriously unsettling and anxiety-provoking connotations. This is a generation whose formative years included the polio epidemic, images of poster-children and iron lungs. This generation’s attitudes about “the handicapped” formed the basis for many of the examples in Goffman’s (1963) classic work on stigma and “spoiled identity.” As the elderly enter another stigmatized area of American life, *old age*, they may be understandably reluctant to consider adding another “layer” of stigma by embracing the label of “person with a disability.”

The notion that a disability may have some positive consequences and that the negative ones can often be managed, has not been completely accepted in the field of aging, let alone by the general population. The point in life at which a disability manifests itself is often perceived as that point at which older individuals believe they are beginning to die (Brody and Morrison 1992, p. 24). The failure or impairment of a bodily system, process or mental function is all too often seen as “just the beginning,” to be followed by more systems failing and eventually death. This attitude about the *meaning* of disability can make any loss or limitation of physical or mental functioning a terrifying symbol of what is perceived to be a descending spiral with little hope for improvement (Marino 1996, pp. 67-70; Weinberg 1972).

A possible linkage has been suggested between death anxiety or *depletion* anxiety and a person's acquisition of actual disabilities (Shamoian 1991, p. 4). This can make just the *prospect* of acquiring a single disability terrifying. Anxieties can be so extreme that people suddenly become unable to think ahead or plan for them—even though some disabling conditions are an inevitable aspect of most people's later years (Cox and Parsons 1993, chap. 1). Moreover, persons who do not realistically acknowledge the likelihood of their becoming disabled, may even exhibit denial of symptoms and avoid contact with other people who already have disabling conditions. Just the sight of disabled people may serve as a conscious or unconscious reminder of their own mortality (Weinberg 1972).

DISABILITY AND FEARS ABOUT THE LOSS OF INDEPENDENCE

Another important fear among seniors is that they will acquire an impairment that will limit their independence (Atchley 1991, 218-219; Marino 1996, p. 67; Waters and Goodman 1990, pp. 138-139). One likely reason for this fear appears to be an association between the loss of physical or mental functioning and increased dependence. In fact, it is probable that at some point in their lives most people will develop sensory and/or mobility related impairments that can significantly limit their range of activities (Buttler, Lewis and Sunderland 1991, chap. 7; Cox and Parsons 1993, pp. 21-23; Safford 1997). In fact, many seniors do become dependent on family members and others in their later years. However, whether the onset of disability automatically leads to a corresponding increase in dependence is more complex. In recent years the relationship between a loss of functioning and a corresponding loss of independence has become much more of a question and an issue particularly with regard to its inevitability (Beedon 1992; Brody and Morrison 1992; Racino and Heumann 1992; Sabatino and Litvak 1992).

Barriers to Obtaining Services

Most metropolitan areas, and many rural regions now have a range of independent living services (many funded by Title VII of the Rehabilitation Act) available to help people with disabilities continue to live active, self-determined lives (<http://www.ilru.org/Jump1.html>). Such services can assist them to remain as independent as possible during health crises or when they acquire frailties and impairments. Fears about disability may block many seniors from acquiring or using pertinent information, resulting in several related difficulties. They may be less receptive to hearing about or becoming aware of infor-

mation that would acquaint them with services already available within the disability rights community.

One of the complicating factors in acquiring and using information and services is that both disability and senior services tend to be organized and function within separate service and agency networks. One can assume that in most communities, staff are simply not aware of potential resources in different networks, or if they are, they may not have established inter-agency linkages or referral procedures to facilitate making this knowledge available to seniors. A first step might be purposeful efforts to establish avenues of communication and interaction.

Fears may block seniors from becoming knowledgeable about their rights as disabled citizens, or about employer's responsibilities to provide reasonable work-related accommodations. This may lead some older people to leave the workforce prematurely, which can have negative consequences for their lifetime earnings and income, as well as their ability to receive employer-provided health and job-benefits. Many authors have noted that employment itself may have substantial psychological, social, health and other benefits for seniors (Cox and Parsons 1993, pp. 155-158; Mor-Barak and Tynan 1993; Waters and Goodman 1990, chap 6). Increasing one's awareness regarding how to continue working even after one begins to develop disabling conditions may actually have many *direct* and indirect health benefits. This issue is especially significant in light of recent passage of the *Freedom to Work Act of 2000* which removes the social security tax penalty on the wages of people over 65 (Kristof 2000; U.S. House of Representatives 2000).

Education About the Local Community

Many non-disabled elders remain quite unaware of disability-oriented accommodations present in metropolitan transit systems or the relatively new access requirements for public and retail facilities. Such accommodations can and should help to make community based living more feasible for elderly disabled people than at any time in the past. Seniors are likely to have formulated their attitudes about the *meaning* and consequences of being a disabled person at a time when rights to access were not yet a matter of law. As noted earlier, such legislation is relatively recent, the first being the *Rehabilitation Act of 1973*.

A simple awareness about disability rights and independent living organizations and groups could have significant beneficial consequences. For example, involvement with such interest groups may reduce the isolation that both disabled people and seniors frequently experience (Albrecht and Levy 1981, p. 23; LaVeist et al. 1997; Waters and Goodman 1990, pp. 22, 41, 163; Zola

1983a, pp. 50-51). Awareness of, and interactions with, disability groups and organizations may serve to connect older persons with intergenerational networks of people with similar problems, as well as introduce them to useful strategies for accommodating or overcoming the worst aspects of their disabilities. Moreover, contact with disability rights organizations, independent living centers and other consumer oriented programs can provide seniors with established avenues of redress for any lacks of responsiveness or restrictive accommodations that they may encounter. Such groups also serve as vehicles for social action to bring about environmental changes or the establishment of new services and benefits that improve the lives of all senior and disabled people (Racino and Heumann 1992).

Although there have been no reported studies to date with regard to senior's awareness of their potential rights should they become disabled, it stands to reason that in general their knowledge about disability rights and services is limited (Racino and Heumann 1992). This is especially likely for seniors who are, either consciously or unconsciously, reluctant to investigate their potential options *as a disabled person*. Moreover, the attitudes of many seniors regarding disability, its consequences and sequelae, are likely to have been formed long before there were services to promote independence and community living and laws to protect their rights. In fact, most people outside of legislative and advocacy circles were not even aware of the disability rights movement until the passage of the *Americans with Disabilities Act* of 1990 (Renz-Beaulaurier 1998). Senior centers, AARP publications and social workers who work with the aging population might be instrumental in informing and linking seniors to resources in the disability rights community.

EDUCATION ABOUT INDEPENDENCE

Organizations within the disability rights movements have focused on helping disabled people maintain an independent life-style so that they are able to reside and function in mainstream community settings (Crewe and Zola 1983; Kailes 1988; Lachat 1988; Renz-Beaulaurier 1998). At times this means energetic engagements in legislative and class advocacy efforts as well as client advocacy on behalf of individuals. For over three decades campaigns and related efforts to educate newly disabled people, the general public, legislators and others about the need for and benefits derived from independent living have been a fundamental activity for members of the disability rights movement.

Some of the principal purposes and anticipated outcomes of these educational efforts are:

- Dispelling prevailing myths and stereotypes about the limitations of having a disability.
- Education about how to optimize “real-world” functioning despite having a disability.
- Identifying the unique consequences and needs of particular disabilities such as orthopedic, vision, hearing, etc.
- Education about the rights of disabled people to accommodation in settings such as housing, shopping, restaurants, public means of transportation, etc.
- Information about other agencies and community resources that can offer aid in order to facilitate community living by people with disabilities.
- Building awareness about the types of physical and structural barriers to community integration and participation that can be removed by simple structural modifications (such as ramp installations, etc.).
- Building awareness about the types of barriers that can be removed or surmounted only by well organized and persistent consciousness raising social action and client advocacy.

The emphasis in all of these educational efforts includes developing educational, resource and advocacy training that enhances participant’s independent living skills (Roberts 1989). Some centers, such as Access Living in Chicago, have developed extensive educational and training curricula which can be more sharply focused to address the need to help seniors overcome many of their fears and anxieties about acquiring disabilities (Shreve and Access Living 1993).

Community Action and Advocacy

It is important, to begin to survey the environment to identify essential independent living services *before* they are needed. Social workers and others who work with seniors need to review and analyze community resources and services to determine whether there are sufficient adult day care options, personal care attendant services, attendant registries, in-home therapeutic services, etc. Moreover, professionals in the field of aging need to begin looking for resources outside the normal channels for aging services. Relatively unfamiliar networks may include independent living centers, vocational rehabilitation programs and even mental health and developmental disability networks. Although the systems do not necessarily overlap, each system has been independently developing resources that allow its constituents to live and work in mainstream communities and to help them be more self-directed about the care

they receive (Ansello 1992; Genskow 1988; Racino and Heumann 1992; Sabatino and Litvak 1992).

If the services do not exist, it is important to know the reason. Are there policies, customs or regulations that block the formation of such services? Is there sufficient funding? Have needs been articulated? Are consumers *outside* the field of aging faring any better in getting independent living services? All of these problems are surmountable, but not instantaneously. If regulations are the problem, campaigns and political actions may need to be initiated to get the regulations changed. The question then becomes "Is anyone else already working on such an initiative?" If there is insufficient funding, then channels for funding need to be located or created. Questions need to arise as to where revenues are currently going and whether there are options for funding which are available but not well known by the general public.

Where regulations do permit independent living services and funding is available, sometimes there is simply not enough demand to attract service providers. It becomes important to know why demand is low. Are consumers well informed? Are providers concerned about startup costs, or "softness" of demand for a new service? Are there providers in the area with vested interests who are attempting to control the market by keeping potential competitors out?

The answers to these questions will help determine whether and what kinds of actions at the community, state or even federal levels are most likely to be necessary as well as productive (Austin 1991). This also suggests that effective consumers and their advocates need advocacy and organizing skills (Hyduk and Moxley 1997). Many universities offer such educational programs in their schools of social work and public administration and, either in formal coursework or in continuing education and internet based extension courses that people can access at home with their computers (Schwartz 1996).

CONCLUSION

As social workers adopt service modalities and approaches that have been pioneered by the disability rights movement, they need to bear in mind the central philosophical tenants that have driven the movement. These have always included consumer control and self-determination (Roberts 1989). Independence, as construed by the disability rights movement, is impossible to achieve without self-determination. Although there is much that remains to be done in order to insure that all people with disabilities are able to exercise control and self-determination in their daily lives, very substantial progress has been made in recent years. This has the potential to help make the acquisition of a disabil-

ity less terrifying for those who still hold stereotypical attitudes about the *inevitability* of lost independence with the onset of a disability.

A third and important concept in the disability rights movement, as in most empowerment-oriented consumer movements, is raising the level of people's consciousness about disability. As people age, it becomes increasingly important that they become aware of how rewarding and fulfilling life is, or can be, for many people with disabilities. This is consciousness raising at group as well as at personal levels. At the interpersonal level it is important that the aging and their families begin to learn about and develop clearer understandings of what changes are required in their communities in order to support independent and fulfilling lives for people with a disability. When individuals and families gain such understandings *before* the onset of a disability, limits to independence resulting from diminishing physical capabilities can be reduced or eliminated. In a sense this is merely enlightened self-interest, since the minority group of people with disabilities belong to is one that most of us will join at some point in our lives.

At another level, publications that reach aging populations such as *Modern Maturity*, as well as the centers and practitioners who serve seniors need to make a more concentrated effort to educate them and their families about independent living. Part and parcel of this process is dispelling the myths and stereotypes about disabilities that have kept disability and aging professionals, consumers and families from working together to address their common interests and concerns.

NOTE

1. OSERS oversees the Rehabilitation Services Administration, the main federal agency financing disability programs and the National Institute for Disability and Rehabilitation Research (NIDRR), the major federal funding source for research in the area of disability.

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