THE ISSUE IS

The Olmstead Decision: Landmark Opportunity or Platform for Rhetoric? Our Collective Responsibility for Full Community Participation

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Occupational therapy's core values and founding beliefs reflect a commitment to the attainment of a self-directed life that enables full community participation. The reality that this desired outcome remains unattainable for millions of persons with disabilities due to the institutional bias of current public policies cannot be ignored. The Supreme Court's landmark Olmstead decision provides a judicial mechanism to right this fundamental injustice. The executive branch's response to the Olmstead decision, the New Freedom Initiative (NFI), offers the potential to finally end the societal segregation of persons with disabilities. Occupational therapy practitioners share a moral collective responsibility to advocate for the major systemic changes that will be needed to fully implement the NFI and achieve the promise of the Olmstead decision. By joining with the disability rights movement, occupational therapy practitioners can become effective activists to help persons with disabilities attain full participation in life.


Recent initiatives within occupational therapy have reaffirmed the practitioner's primary role as the facilitator of the person's self-directed “engagement in occupations to support participation in life” (American Occupational Therapy Association [AOTA], 2002, p. 609). However, the right to self-determination and full community participation is denied to millions of persons with disabilities who are forcibly segregated from society due to public policy (National Council on Disability [NCD], 2000). The entrenched institutional bias of funding for long-term care in the United States presents major barriers to social integration (Department of Health and Human Services [DHHS], 2002). This paper explores these pervasive impediments and provides key information about the landmark Supreme Court Olmstead decision, which effectively challenged this segregation. The executive decisions made and the legislative initiatives proposed in response to the Olmstead decision and their potential for attaining full community participation for persons with disabilities are examined. Finally, this paper discusses implications for occupational therapy. The purpose of the paper is to increase occupational therapists’ awareness of the significant sociopolitical constraints that limit the fulfillment of our profession's espoused desired outcomes. The collective responsibility of practitioners to develop a consciousness about these issues and a commitment to advocating for community participation is emphasized.

Occupational therapists must first recognize the reality that the vast majority of disability results from environmental deficiencies, not individual impairments. The ideological view that impairment is synonymous with disability has been strongly confronted by disability studies scholars, who argue that factors external to the individual precipitate and perpetuate disabling and handicapping conditions (Charlton, 1998; Shapiro, 1994). Disability studies scholars have emphasized the critical role that physical, social, economic, and political barriers play in disenfranchising persons with disabilities (Kielhofner, 2005). They have effectively argued that persons with disabilities form an oppressed minority group that experiences discrimination on a daily basis with respect to education, housing, employment, transportation, and social participation (Charlton; Shapiro). As other minor-
ity groups have done before them, disability rights activists have sought to create societal change through the judicial system and legislative processes. Although these efforts have culminated in some achievements (e.g., passage of the Americans with Disabilities Act of 1990 [ADA]), progress toward full integration of persons with disabilities into society has been slow. Major sociopolitical change is needed to alter the continued marginalization, oppression, and segregation of persons with disabilities (NCD, 2000).

Current Realities
In 1990, the ADA was heralded as landmark legislation that would enable individuals with disabilities to fully integrate into society (Wells, 2000). Although the promise of ADA has been realized for many American citizens with disabilities, its full implementation has not yet been achieved (NCD, 2000). The most blatant failure of the ADA is society’s inadequate response to the ADA declaration that persons with disabilities should not be isolated or segregated. Despite it, over 1.8 million Americans reside in institutions; the vast majority of these live involuntarily in skilled nursing facilities. Millions more are isolated in their homes due to the lack of essential community services. Of these, over 2 million are considered to be at risk for entering an institution (DHHS, 2002; State of the Union, 2003).

Society’s failure to enforce legislation that supports community participation is also evident in the implementation, or lack thereof, of the Individuals with Disabilities Education Act of 1997 (IDEA). IDEA requires transitional planning for students with disabilities to address their goals related to employment, postsecondary education, independent living, recreation and leisure, and community participation. However, few schools effectively meet this mandate (Orentlicher & Michaels, 2000). Such planning is considered an integral part of IDEA and is to begin at 14 years of age, with implementation at 16 years of age. In addition, transitional planning and implementation at younger ages are indicated if the student has significant needs. The reality is that few school districts provide this planning during the middle- or high-school years. As a result, even the most self-determined youth are “thwarted in their efforts . . . by people and institutions that present barriers or fail to provide needed supports” (Bremer, Kachal, & Schoeller, 2003, para. 2).

The Olmstead Decision
Although society trumpets the visible advances of the ADA (e.g., curb cuts, captioning, and universal design), persons with significant disabilities are denied social participation because they have no real living choice other than institutional settings (Cottrell, 2003; DHHS, 2002; NCD, 2000). This reality has been a source of unrelenting frustration for disability rights activists (Charlton, 1998; State of the Union, 2003). In 1999, it was taken to the courts. Two Georgia women with mental illness and mental retardation were forced to live in a state-run psychiatric hospital because there were no community-based alternatives despite their treatment team’s determination that they were appropriate candidates for community-based care. The ensuing lawsuit asserted that forced continued institutionalization was in violation of these plaintiffs’ rights under the ADA. The Supreme Court ultimately ruled in favor of the plaintiffs (DHHS, 2001; Rosenbaum, Teitelbaum, & Stewart, 2001).

This decision, termed Olmstead, was based upon the Supreme Court’s determination that Georgia had violated the ADA’s integration regulation that a “public entity shall administer services, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (DHHS, 2001, p. 42). The Court defined the most integrated setting as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible” (DHHS, 2001, p. 42). The Supreme Court decision required states to place qualified individuals with mental disabilities in community settings, rather than institutions because

[I]nstitutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. (DHHS, 2001, p. 42)

Although this Supreme Court ruling resolved a case concerning individuals with developmental and mental disabilities in a psychiatric hospital, it has subsequently been legally interpreted to include all disabilities, all institutional settings including skilled nursing facilities, and persons at risk for institutionalization due to a lack of appropriate community services (Cottrell, 2003). This includes, for example, students with disabilities with inadequate transition plans.

After the Olmstead decision was decreed in 1999, the Clinton administration responded to guide states in its implementation by instituting programs to facilitate states’ transition from institutional care to community-based care (Centers for Medicaid & Medicare Services [CMS], 2000; Rosenbaum et al., 2001). However, since Clinton’s term ended in 2000, the full implementation of Olmstead will rely on subsequent administrations.

The New Freedom Initiative
In 2001, President Bush responded to the Olmstead decision with the declaration of the New Freedom Initiative (NFI) and the formation of the Interagency Council on Community Living (ICCL) (DHHS, 2002). The ICCL, composed of six federal agencies, was charged to conduct comprehensive self-evaluations of barriers to community integration and to identify resources and potential solutions to these impediments. Over 250 consumer and professional organizations participated in and contributed to this exhaustive review, culminating in the completion and submission of the “Delivering on the Promise Report” to the President in 2002 (DHHS, 2002). The ICCL report examined impediments to full integration into society for individuals with disabilities. The following significant barriers were identified:

• Health Care Structure and Financing
many housing options unaffordable (Social Security Administration, 2004). As a result, persons with disabilities are disproportionately reliant on subsidized housing programs. These programs often have multiyear waiting lists and are frequently subject to spending freezes or budget cuts (LaFleur, 2004). In addition, most public housing was built prior to the implementation of universal design. As a result, many affordable rental units are completely inaccessible (DHHS, 2002). This existing housing crisis will be exacerbated as individuals with disabilities seek homes outside of institutional settings (GAO, 2001).

Personnel Shortages
For many persons with disabilities, independent living requires a personal care assistant. Poor salaries, long hours, little to no employee benefits, and limited training has contributed to a critical lack of personal care assistants (PCAs) (DHHS, 2002). This shortage is especially critical in community-based services. In Texas alone, more than 100,000 persons with disabilities are on the wait list for home-based services, while there is no wait to enter a skilled nursing facility (LaFleur, 2004). The demand for PCAs is expected to increase drastically as the baby boomers age and develop age-related disorders that require direct care (GAO, 2001). Advances in medical technology that improve the survival rates of persons with disabilities will also amplify the need for PCAs (LaFleur).

Caregiver and Family Support Service Gaps
The vast majority of direct care for individuals with disabilities is provided by their family members, friends, and neighbors. These caregivers take on tremendous physical, emotional, and financial burdens with no formal supports, direct assistance, or respite (GAO, 2001). The resulting caregiver strain often becomes unbearable, especially when caregivers age and incur health problems or disabilities of their own. Unrelieved caregiver burden is a major precipitant to the institutionalization of persons with disabilities, regardless of age (DHHS, 2002).

Inaccessible Transportation
Accessible transportation is a fundamental prerequisite for community participation, yet 40% of the counties in the United States have no public transportation systems (DHHS, 2002). In counties with public transportation, accessible transportation ranges from nonexistent to extremely limited. Persons with disabilities who do not live in the few cities that offer accessible transportation options have no means to travel to work, school, or community resources and events (DHHS, 2002).

Employment Disadvantages and Disincentives
The Ticket to Work and Work Incentives Improvement Act (TWIIA) has removed some disincentives to employment for persons with disabilities but many obstacles remain. The existing work incentives are complex whereas employment services are fragmented and difficult to access. A further impediment is employers’ attitudinal barriers regarding the employability of persons with disabilities and these attitudes are often resistant to change (DHHS, 2002).

Noncompliant Education Systems
The high school graduation rate for students with disabilities is only 57% for a standard diploma, with an additional 11% receiving alternative credentials, such as certificates of attendance. Furthermore, only one third of students with disabilities receive job training and employment assistance (DHHS, 2002). The lack of adequate transition planning and transition services needed to prepare students for work and life after high school is widespread.

Limited Access to Technology
Assistive technology can decrease the need for personal care assistance and provide access to education, employment, and social opportunities. However, due to personal income limits and significant funding deficits, basic computer use and access to the Internet for persons with disabilities is at half the rate of persons without disabilities, even though this technology has tremendous equalizing potential (DHHS, 2002).
Summary

This section discussed the eight major systemic problems identified in the Delivering on the Promise report. This report also proposed over 400 actions to remove barriers and improve community and home-based services in order to achieve full integration for persons with disabilities (DHHS, 2002). The next section discusses key aspects of these recommended initiatives.

Delivering on the Promise Proposals

Many of the recommendations put forth by the ICCL focused on overhauling the Medicaid system through the revision of eligibility standards and payment guidelines to fund community-based services for a level of care equivalent to a skilled nursing facility. Programs to facilitate the transition from institutional settings to community-based living were also strongly recommended. Recognizing that systemic change takes time, the report endorsed the development of demonstration projects. Finally, the report called for grant programs to improve housing accessibility and affordability and for the expansion of the subsidized housing programs to increase affordable housing stock and allow these funds to be used for the purchase of private homes (DHHS, 2002).

However, the ICCL recognized that moving a person from an institution into a home was not sufficient to attain the Olmstead goal of participation in society. PCAs must be available to help with daily life tasks. Substantial improvements in education, employment, transportation, and technology are required to enable persons with disabilities to fully participate in the life of their communities. Therefore, many proposals were put forth to address these needs. Improvements in the recruitment, hiring, training, and supervision of PCAs were recommended. An emphasis was placed on the development of consumer-directed personal care programs (DHHS, 2002).

A high priority was given to the expansion of transition planning and transition services for students with disabilities to prepare them for adult life (DHHS, 2002). The development of programs to adequately address the training and employment needs of individuals with disabilities who are transitioning from institutions to the community and for individuals at risk of institutionalization was also emphasized. Multiple initiatives to promote, attain, and retain employment for persons with disabilities were put forth. Recognizing the importance of technology in school and work environments and the tremendous participation opportunities that technology holds for persons with disabilities, many recommendations were made related to technology. The expansion of high-tech options for persons with significant disabilities and the implementation of new programs and innovative policies to improve access to assistive technology for all persons with disabilities were proposed (DHHS, 2002).

The ICCL consistently recognized the role of the family in providing care and support throughout the lifespan. The Delivering on the Promise Report is forthright in acknowledging that even with the implementation of many of its recommendations, family caregivers, especially for children with significant disabilities, will often assume long-term care responsibilities. In addition, many persons with disabilities will choose to live with their family of origin and/or start their own families. Therefore, the ICCL strongly supported the development of flexible service options to help family caregivers and prevent caregiver burnout (DHHS, 2002).

Finally and most significant, the ICCL emphasized that its report would be rendered meaningless, if there was no accountability for programs initiated or compliance with existing laws. Therefore, permeating all discussions about recommended program initiatives and systemic change was a solid recognition that research would be needed to identify and support best practices. In addition, the ICCL advocated for increased enforcement of all federal statutes regarding the civil rights and full participation of individuals with disabilities (DHHS, 2002).

The New Freedom Commission on Mental Health

Subsequent to the Delivering on the Promise report, the President formed the New Freedom Commission on Mental Health (NFCMH), which was charged to examine the mental health care system in the United States and “recommend improvements to enable adults with serious mental illnesses and children with serious emotional disturbances to live, work, learn, and participate fully in their communities” (New Freedom Commission on Mental Health [NFCMH], 2003, p. 1). The Commission’s Final Report, “Achieving the Promise: Transforming Mental Health Care in America” documented the inadequate, fragmented, disconnected care that has consistently resulted in the institutionalization and/or community segregation of, and lack of, societal participation for persons with mental illnesses in the United States. As a result, the Commission called for a complete transformation of our mental health service delivery system (NFCMH, 2003).

Limitations and Concerns

The ICCL proposals to promote full community participation and the call for the transformation of the mental health care delivery system seemed to be encouraging steps towards achieving the promise of the ADA and the aims of the Olmstead decision. However, disability rights advocates doubted whether these suggestions would result in real changes in the lives of individuals with disabilities (“Steps,” 2002; Van Tosh, 2002). Their caution has proven valid since only limited action has been taken to implement the Olmstead decision (LaFleur, 2004).

Although demonstration projects have been funded to provide community-based services as alternatives to institutional care, these “Promising Practices” (the moniker given to these programs by DHHS) are limited to small discrete programs in just a few states (CMS, 2003). Activists’ concerns that no major systemic change would result from the Olmstead decision and the NFI are based upon:

- Restrictions to the Olmstead Decision
- Funding Inadequacies and Constraints
- Absence of Mandates

Restrictions to the Olmstead Decision

Although the Olmstead decision requires that states pursue community-based alternatives to institutional placements, there are several existing ADA regulations cited in
Funding Inadequacies and Constraints

The executive and legislative branches of government have supported the principle of full community participation for persons with disabilities, but have never provided adequate funding to support these aspirations. IDEA funding deficiencies is one example. Although IDEA legislation established federal funding at 40% of the total monies needed, local schools have received only 7% to 15% of their mandated costs from the federal government (DHHS, 2002).

Furthermore, advocates who review federal and state budget proposals question the likelihood that future budgets will include adequate resources for the implementation of Olmstead. The following are some examples of why this concern exists. The proposed 2006 federal budget for non-Homeland Security domestic programs is $14 billion below requested 2005 levels and $22 billion below actual 2004 levels when adjusted for inflation (Weisman, 2004). In 2004, the Mississippi state legislature reduced the maximum Medicaid income allowance from $12,569 per year to $6,768 per year, effectively eliminating access to essential Medicaid services for over 65,000 seniors and persons with disabilities (Herbert, 2004). The 2004–2005 California Governor’s budget proposed reducing the salaries of PCAs from $9.50/hour to $6.75/hour and eliminating health care benefits (Veslet, 2004). As these examples attest, funding is likely to move in directions that further restrict rather than support community participation.

Our Collective Responsibility for Advocacy

In the 6 years that have passed since the Olmstead decision was rendered, little systemic change has been made to end the segregation of persons with disabilities (Rosenbaum & Teitelbaum, 2004). The following two examples illustrate the personal consequences of the current situation and their potential repercussions for persons with disabilities. A Medicaid waiver program in Utah funds the transition from skilled nursing facilities to community homes for individuals with traumatic brain injury and pays for consumer-directed PCAs. Although this program works, its funding allows only two persons per year to be served. Given a wait list of 30 persons, the last person on this list will need to wait 15 years until he or she is able to leave institutional living (CMS, 2003). Two other individuals forced to live in institutions, because of their disabilities, sought the right to end their lives rather than continue their current existence. One won her case and died. The other also won, but because he was able to leave the institution to reside in his own home in his community of choice, he chose to live (Polatajko, 1994). The Olmstead decision has provided a constitutional foundation for the development of community-based services that can enable persons with disabilities to live in environments of choice, facilitating the attainment of a self-directed life.

However, the implementation of the Olmstead decision will require persistent vigilance and tenacity from disability rights advocates and others. Occupational therapy has historically professed a strong commitment to full participation by persons with disabilities.
disabilities. The field’s core values affirm the person’s freedom of choice to pursue personal goals, demonstrate independence, be self-directed and autonomous, and attain societal membership (AOTA, 1993).

Although asserting such values is important, I contend that occupational therapists have historically shown limited response to entrenched societal constraints and discriminatory policies (Abberley, 1995; Friedland, 1998; Linton, 1998; Townsend, 1993). As Rogers (1983) noted, “our ‘clinic-bound’ view of the person may lead us to ignore or underestimate impediments to occupational performance residing in the environment” (p. 615). Moreover, occupational therapists cannot just focus on impairments or immediately evident environmental barriers; they must also address sociopolitical contexts that become barriers for persons with disabilities. As Triendenberg (2000) noted, engaging in ethical practice only on an individual level is inadequate; there is a collective responsibility for health professionals to join the moral dialogue about social policies that perpetuate inequity and sustain disability. Further, Grady (1995) argued occupational therapists must take concrete steps to become informed about the social, economic, and political constraints that impede people’s abilities to fully participate in their communities. There are two concrete steps that therapists can take.

First, we can join with external groups to advocate for disability rights. Several disability rights groups are actively working for full community participation and the implementation of the Olmstead decision. A description of two leading organizations and their contact information is provided in this paper’s appendix. Joining the American Association of Persons With Disabilities (AAPD) and American Disabled for Attendant Programs Today (ADAPT) can provide the occupational therapy practitioner with a wealth of information about federal and state executive orders, legislative actions, and judicial decisions related to community participation and social equity. In addition, The Justice for All Network provides timely releases about advocacy actions that occupational therapy practitioners can participate in to promote participation. A quick scan of the Web sites provided in the appendix will demonstrate the need to bridge these organizations’ goals and the purported aims of occupational therapy. Forming partnerships with the disability rights movement, both individually and collectively, can contribute to the development of a critical mass to explicitly effectuate change (Triendenberg, 2000; Williams, 2004).

Second, many of the desegregation and community integration proposals resulting from the NFI can benefit from the knowledge and skills of occupational therapy practitioners. Table 1 identifies just a few of the practice, research, education, and advocacy actions that occupational therapy practitioners can take to help achieve the participation aims of the Olmstead decision and the NFI. Most importantly, occupational therapists must become more assertive about transforming our profession’s stated values into action. What is the worth of collaborating with an individual to develop the knowledge, skills, and attitudes needed to live a self-directed life, if there is no societal change to allow the person to live in an environment of choice?

### Table 1. Occupational Therapy Actions to Achieve the Participation Aims of the New Freedom Initiative

<table>
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<th>Practice</th>
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<tr>
<td>1. Develop and implement educational, vocational, and transitional services for youths and adults with disabilities to attain meaningful employment and community living</td>
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<td>2. Conduct home assessments and make modification recommendations to public housing authorities, private landlords, tenants, and homeowners</td>
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<tr>
<td>3. Train consumers and caregivers in the recruitment, hiring, training, and supervision of personal care assistants and direct care providers</td>
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<tr>
<td>4. Evaluate, prescribe, and train persons in assistive technology, durable medical equipment, orthotic, and adaptive equipment</td>
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<tr>
<td>5. Train family caregivers and direct care workers in physical, cognitive, and psychosocial rehabilitation principles and methods</td>
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<tr>
<td>6. Consult with One-Stop Centers, corporations, and small businesses regarding work place accommodations</td>
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<th>Research</th>
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<tr>
<td>1. Direct or participate in home and community-based demonstration projects</td>
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<td>2. Critically examine home and community-based services to determine best practices</td>
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<tr>
<td>3. Conduct qualitative research to explore the subjective experiences of persons with disabilities who live in environments of choice versus those who do not</td>
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<th>Education</th>
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<tr>
<td>1. Incorporate disability studies and disability civil rights issues throughout occupational therapy curricula and clinical fieldwork</td>
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<tr>
<td>2. Develop students’ ability to critically assess and consciously respond to social, economic, and political inequities</td>
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<tr>
<td>3. Integrate justice issues and advocacy actions in course assignments and student projects</td>
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<th>Advocacy</th>
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<tr>
<td>1. Serve as a member on state and local Olmstead implementation planning boards</td>
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<tr>
<td>2. Present disability awareness and outreach programs to community forums</td>
</tr>
<tr>
<td>3. Promote occupational therapy as an essential service for community-based programming for full inclusion in living, educational, work, and social environment</td>
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### Conclusion

The need to transform our profession’s core values into sociopolitical action was immediately evident to the founders of occupational therapy. Because our profession was born during World War I, its development was strongly influenced by public policy. As a result, our founders actively led efforts for societal change (Johnson, 1981). One stellar example of this activism is described by Bing (1981), who recounted the efforts of Beatrice D. Wade to amend the 1920 Vocational Rehabilitation Act because it excluded persons with mental illnesses. Wade allied herself with veteran groups to right this fundamental wrong. Their efforts were finally successful over a decade later when President Franklin D. Roosevelt signed the amendment to Public Law 113 extending vocational rehabilitation benefits to veterans with mental illness (Bing). In subsequent years, Wade, as director of the occupational therapy program at the University of Illinois at Chicago, was a leader in withstanding external pressures on occupational therapy educational programs.
to adopt the medical model and its impairment view of persons with disabilities as the sole guiding philosophy for professional curricula (Abberley, 1995; Colman, 1992; Friedland, 1998). Although Wade stands as a classic example of an occupational therapist dedicated to our profession’s holistic roots and involved in social change, few in the profession have followed in her footsteps. For occupational therapy to be perceived as a profession truly committed to the attainment of participation for all, we, individually and collectively, will need to be more active in advocating for the rights of persons with disabilities. We must expand our roles to serve as advocates, social critics, lobbyists, and program planners to help remove environmental impediments to participation (Grady, 1995; Lohman, 2003; Polatajko, 1994), if occupational therapy is to achieve its professed purpose, that is, “to support participation in life” (AOTA, 2002, p. 609).

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Dedication

This paper is dedicated to my brother, Kevin Michael Fleming (1954–1989). Although Kevin lost his battle with Friedrich’s Ataxia, his tenacious fight to live a self-directed life remains my inspiration.

References


Appendix: Advocacy and Informational Resources

*American Disabled for Attendant Programs Today (ADAPT)* focuses on promoting services in the community instead of institutions and nursing homes by organizing the disability community and using civil disobedience and similar nonviolent direct action tactics to achieve its goals. www.adapt.org

*American Association of Persons With Disabilities (AAPD)*, the largest national nonprofit cross-disability member organization in the United States, is dedicated to ensuring economic self-sufficiency and political empowerment for Americans with disabilities. www.aapd-dc.org

*Centers for Medicare & Medicaid Services (CMS)* is the primary source for federal and state government actions toward implementing the Olmstead decision and the New Freedom Initiative. A New Freedom link provides access to all official documents and “Promising Practices” program descriptions. www.cms.gov

*The Justice for All Network (JFA)* works with individual advocates and organizations of people with disabilities to share information and call people to defend and advance disability rights. It disseminates extensive information about national disability policy issues and the broader domestic policy and political debates that shape disability-specific priorities. AAPD serves as the host site for this network. To subscribe, go to www.aapd-dc.org/JFA/JFAsubscribing.htm

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