

**Living Independently and in the Community:  
Implementation Lessons from the United States**

**National Council on Disability  
1331 F Street, NW, Suite 850  
Washington, DC 20004  
202-272-2004 Voice  
202-272-2074 TTY  
202-272-2022 Fax**

**Lex Frieden, Chairperson**

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**Foreword**

The National Council on Disability is an independent federal agency with 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities regardless of the nature or significance of the disability and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society. This topic paper is part of a series of topic papers designed to provide brief background information on United States disability policy for use by the delegates in their deliberations on the United Nations Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities.

**I. Introduction**

Living independently and in the community are preconditions for the enjoyment of human rights by people with disabilities and represent core values of the American disability community. Ensuring that people with disabilities have the opportunity and appropriate supports

to live how they choose, where they choose, and with whom they choose is a major focus of disability advocacy in the United States, as well as in other countries around the world.

Significantly, the convention on the human rights of people with disabilities, under negotiation at the United Nations, includes a draft article (Article 15), on living independently and in the community.

Many people with disabilities throughout the world are segregated in institutions, isolated in their homes, or in other ways disconnected from full and meaningful participation in their communities. Moreover, they often are unable to conduct their lives in ways that reflect their personal choices. Institutionalization is sometimes presented as the only option for receiving assistance with core activities of everyday living, yet people with disabilities can live in the community with appropriate long-term services and formal and informal supports. Recognition of the challenge to end institutional bias – and related forms of isolation and exclusion – and the creation of meaningful and affordable opportunities to receive community-based long-term services and supports will make living independently and in the community a reality for people with disabilities.

This paper seeks to:

- outline key concepts central to the understanding of living independently and in the community as expressed by the American disability community;
- identify the principal barriers that impede the enjoyment of living independently and in the community by people with disabilities;
- provide a summary overview of the existing international legal framework that promotes living independently and in the community;

- identify examples drawn from the American law and policy context that advance living independently and in the community; and
- provide a tool for assessing implementation of these rights in anticipation that they will be given full expression in the drafting of a convention on the rights of people with disabilities.

## **II. Understanding Living Independently and in the Community**

The concepts expressed by the phrase “living independently and in the community” are associated with the independent living movement begun in the 1970s in the United States, and also initiated in other countries around the world from that period onward.<sup>i</sup> These advocacy developments were in response to the practice of isolating individuals with disabilities in congregate institutions where they were distanced and utterly disconnected from their communities. First, the movement sought to overturn the traditional assumptions of the medical and charity models of disability so often used to justify exclusion from community life.<sup>ii</sup> It recognized “that the barriers that confront people with disabilities are less related to individual impairment than to societal attitudes, interpretations of disability, architectural barriers, legal barriers, and educational barriers.”<sup>iii</sup> Second, in keeping with a more functional approach to disability, people with disabilities based their advocacy on principles of autonomy and individual self-determination, participation in decision-making and consumer direction, choice, and community integration.<sup>iv</sup> In sum, living independently and in the community “means being in control of one’s life, choosing one’s own goals and activities, and ultimately defining one’s own goals and activities, including the tools, strategies, and people or animal supports necessary to accomplish any given task or objective.”<sup>v</sup>

The event that initiated the implementation of this vision was the establishment of the nation's first independent living center in Berkeley, California. The center, and the hundreds that developed thereafter, offered a range of services to facilitate living in the community, with appropriate "consumer driven" supports.<sup>vi</sup> These supports included, among others, peer counseling, advocacy services, accessible transportation, training in independent living skills, wheelchair repair, housing referrals, and personal assistant referrals.<sup>vii</sup>

While the American independent living movement emerged initially as a means of achieving the aims of people with physical disabilities, its basic premises influenced disability rights advocacy across the disability spectrum. During the 1990s, the self-advocacy movement by people with intellectual disabilities emerged and continues to develop, both in the United States and, increasingly, in many other countries.<sup>viii</sup> The drive for "self-determination" among people with psycho-social disabilities is another important manifestation of self-representation and independence among a historically marginalized sector of the disability community.<sup>ix</sup>

The primary aim of the independent living movement is for people with disabilities to achieve the capacity to live in their homes and communities in accordance with their own wishes, and therefore "independently."<sup>x</sup> This does not imply that individuals will perform daily tasks without the assistance of others. One can still retain control over decision-making, notwithstanding functional limitations that require the assistance of another person or an assistive device or other supports. Above all, living independently and in the community supports the right to live a life outside of institutions, where barriers for full social inclusion are removed and the necessary technical aids and personal assistance are provided."<sup>xi</sup> The goal is for people with disabilities to *live independently in community with others*; this does not preclude family living

or other communal arrangements. It is about choice, autonomy, and participation, *not* separation from families.

### **III. Persistent Barriers to Living Independently and in the Community**

Researchers have documented the medicalization of disability and the building of custodial residential institutions during the early industrial age and period of urbanization in the West.<sup>xii</sup> People with disabilities were separated from their families and communities and, more generally, from full participation in society. This segregation manifested itself in the building of mental institutions for people with psycho-social and intellectual disabilities, rehabilitation centers and special education schools. The egregious abuses that so often accompany congregate custodial arrangements have been well-documented, as has the near impossibility of providing for the full enjoyment of civil, political, economic, social and cultural rights within institutions, irrespective of the conditions.<sup>xiii</sup> Isolation and abuse within institutions is certainly not the only form of community exclusion facing people with disabilities. People with disabilities around the world too often are isolated within their homes, even locked away in back closets or basements, and are unable to participate in the life of their communities or make even the most basic decisions about their everyday lives. Persistent barriers to living independently and in the community remain, and form the basis for disability rights advocacy both in the United States and in countries around the world.

In 2003, the National Council on Disability released an extensive report that identifies the many barriers confronting Americans with disabilities in their efforts to live independently and in the community.<sup>xiv</sup> The report is based on extensive consultation with representatives from all disability groups who identified the following principal obstacles to living independently and achieving community integration for people with disabilities:

- Lack of affordable or physically accessible housing
- Qualified support staff
- Parent/guardian opposition
- Lack of affordable and accessible transportation
- Lack of adequate medical or dental care
- Neighborhood opposition
- Lack of jobs, job training and supported employment
- Lack of residential services
- Lack of day services

#### **IV. International Human Rights Law and Living Independently and in the Community**

In many respects, the international human rights system is geared towards ensuring that all people have the opportunity to live their lives in dignity and in a way that ensures the development of their full potential. In this sense, human rights law is an important source for addressing the barriers that people with disabilities face in living self-determined lives. For example, principles of non-discrimination and equality are among the most well-established human rights obligations and certainly apply without exception to people with disabilities.<sup>xv</sup> Similarly well-grounded are principles of participation and autonomy.<sup>xvi</sup>

Non-discrimination principles under international law go well beyond prohibiting laws that explicitly or purposefully exclude or deny opportunities to people with disabilities. The UN Committee on Economic, Social and Cultural Rights, the body that monitors implementation of the International Covenant on Economic, Social and Cultural Rights,<sup>xvii</sup> has emphasized that States are under an obligation to protect against discrimination and, to that end, must adopt

policies to “enable persons with disabilities to live an integrated, self-determined and independent life.”<sup>xviii</sup> According to the Committee,

Both de jure and de facto discrimination against persons with disabilities have a long history and take various forms. They range from invidious discrimination, such as the denial of educational opportunities, to more “subtle” forms of discrimination, such as segregation and isolation achieved through the imposition of physical and social barriers. ...the effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing, transport, cultural life, and access to public places and services.<sup>xix</sup>

Other international documents relating to disability have stressed that services for people with disabilities should be provided within *existing* social, education, health, rehabilitation and labor structures – underscoring aims of integration and inclusion – and that procedures should be established to facilitate the meaningful participation of people with disabilities in decision-making processes.<sup>xx</sup>

Direct support for these aims may be found elsewhere in human rights law. For example, Article 12(1) of the International Covenant on Civil and Political Rights specifies the right of an individual “to liberty of movement and freedom to choose his [/her] residence.”<sup>xxi</sup> As applied to the specific situation of people with disabilities, this right has been interpreted to mean that people with disabilities have choices equal to others to move around and live where they choose in a community setting.<sup>xxii</sup> Other human rights reinforce important aspects of living independently and in the community including, for example, freedom of expression, freedom of association and the right to privacy.<sup>xxiii</sup>

Finally, in some cases, international instruments do give explicit expression to living independently and in the community.<sup>xxiv</sup> The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities<sup>xxv</sup> expresses the right to participation in all forms of

community life. The Standard Rules further identify both preconditions to equalization of opportunities (e.g., awareness-raising, medical care, rehabilitation services, support services) and key target areas for equalization of opportunities (e.g., accessibility to physical and communications environments, employment, education, recreation). Article 23 of the Convention on the Rights of the Child <sup>xxvi</sup> acknowledges the need for States to take positive action to equalize opportunities for children with disabilities to facilitate “active participation in the community”<sup>xxvii</sup> and the “fullest possible social integration.”<sup>xxviii</sup> Article 15 of the European Social Charter similarly supports the right of persons with disabilities to the effective enjoyment of “independence, social integration and participation in the life of the community.”<sup>xxix</sup> The drafting of an international convention has the potential to give full expression to living independently and in the community for people with disabilities.

## **V. Living Independently and in the Community: Experience from the United States**

On February 1, 2001, President Bush launched the “New Freedom Initiative (NFI),” a comprehensive national plan to remove existing barriers to community living for Americans with disabilities.<sup>xxx</sup> The proposals of NFI aim to increase access to assistive technology, expand educational opportunities, increase the ability of people with disabilities to integrate into the employment sphere, and promote increased access to daily community living. NFI reinforces the overriding objective of federal disability law, which is to facilitate independent living and full participation in communities for people with disabilities. What follows are highlights from the U.S. federal law and policy framework that prioritize living independently and in the community for Americans with disabilities. While these examples are by no means exhaustive, they provide



a general understanding of law and policy developments with particular application to independent living and community integration.

### **The Americans with Disabilities Act**

The Americans with Disabilities Act (ADA), enacted in 1990, prohibits discrimination on the basis of disability in employment, in access to and benefit of public services, and in access to public accommodations, transportation and support services, and communications. It is the springboard for a number of recent developments that continue to refine, and in some cases extend, laws and policies directly aimed at achieving independent living and community integration for all people with disabilities. Section 202 of the ADA provides that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs or activities of a public entity, or be subject to discrimination by such entity.”<sup>xxxix</sup> Significantly, as noted by Senator Harkin (D. Iowa), the sponsor of the ADA in the United States Senate, the purpose of Congress in passing this legislation was to “ensure once and for all that no Federal agency or judge will ever misconstrue the congressional mandate to integrate people with disabilities into the mainstream.”<sup>xxxix</sup>

### **U.S. Supreme Court *Olmstead* Decision**

In 1999, the U.S. Supreme Court had occasion to review the scope of disability-discrimination protection under the ADA and its particular relationship to institutionalization and community integration. In *Olmstead v. L.C.*<sup>xxxix</sup> the U.S. Supreme Court held (interpreting the ADA<sup>xxxix</sup> and its implementing regulation 28 C.F.R. § 41.51(d))<sup>xxxv</sup> that “[u]njustified isolation ... is properly regarded as discrimination based on disability.”<sup>xxxvi</sup> In so holding, the court concluded that, in appropriate circumstances, the prohibition against discrimination “may require placement of persons with mental disabilities in community settings rather than institutions.”<sup>xxxvii</sup>

The Court therefore acknowledged in *Olmstead* that discrimination entails practices that perpetuate the isolation of people with disabilities. In so doing, the Court signaled a strong preference, though not an unqualified right, for community integration for people with disabilities, consistent with principles of living independently. U.S. Supreme Court Justice Ruth Bader Ginsberg provided two bases for this conclusion in her interpretation of the principle of non-discrimination in the ADA: “First, institutional 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.”<sup>xxxviii</sup> And, second, “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, education advancement, and cultural enrichment.”<sup>xxxix</sup> The *Olmstead* decision represents a significant step forward in advancing community integration and independent living and has provided the impetus for a number of both federal and state initiatives to realize its aims.

#### **Executive Order on Community-Based Alternatives for Individuals with Disabilities**

In response to the Supreme Court’s decision in *Olmstead*, the President issued an Executive Order on Community-Based Alternatives for Individuals with Disabilities, Executive Order No. 13217,<sup>xl</sup> thereby undertaking to implement the integration requirement of the Americans with Disabilities Act as interpreted in the decision.<sup>xli</sup> Section 1 of the Executive Order outlines the following findings and principles which underpin the fundamental goals of living independently and in the community:

1. The United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interests of Americans.<sup>xlii</sup>

2. The United States seeks to ensure that America's community-based programs effectively foster independence and participation in the community for Americans with disabilities.<sup>xliii</sup>
3. Unjustified isolation or segregation of qualified individuals with disabilities through institutionalization is a form of disability-based discrimination prohibited by Title II of the Americans with Disabilities Act of 1990...States must avoid disability-based discrimination unless doing so would fundamentally alter the nature of the service, program or activity provided by the State...<sup>xliv</sup>
4. The Federal Government must assist states and localities to implement swiftly the *Olmstead* decision, so as to help ensure that all Americans have the opportunity to live close to families and friends, to live more independently, to engage in productive employment, and to participate in community life.<sup>xlv</sup>

The Executive Order requires federal agencies to promote community living for people with disabilities through the following means: (i) providing coordinated technical assistance to states; (ii) identifying specific barriers in federal law, regulations, policies and practices that inhibit community integration; and (iii) enforcing the rights of people with disabilities.

**DHHS Principles for the Development by States of Community-Based Alternatives for People with Disabilities**

The U.S. Department of Health and Human Services (DHHS), in response to directives set forth in the Executive Order, issued principles for the development by states of plans for placing qualified people in less restrictive settings and establishing a waiting list that moves at a

reasonable pace to place people in appropriate community settings.<sup>xlvi</sup> DHHS recommended that states:

- Develop a comprehensive, effectively working plan (or plans) to strengthen community service systems and serve people with disabilities in the most integrated setting appropriate to their needs;
- Actively involve people with disabilities, and where appropriate, their family members or representatives, in design, development and implementation;
- Use ... technical assistance material [provided by DHHS] as one of the guides in the planning process; and
- Inform [DHHS] of questions that need resolution and of ideas regarding technical assistance that would be helpful.<sup>xlvii</sup>

### **DHHS Federal Grants**

In 2001, in furtherance of the *Olmstead* objectives, the Department of Health and Human Services made available some \$64 million in federal grants to provide assistance to states, in full partnership with people with disabilities, to design and implement programs to support community living.<sup>xlviii</sup> The grants target four major areas for community living: (i) Nursing Facility Transition Grants, to enable States to transition eligible people from nursing facilities into the community; (ii) Community-integrated Personal Assistance Services and Supports Grants, to support State efforts to improve personal assistance services that are consumer-driven or offer individual choice and control; (iii) Real Choice Systems Change Grants, to help states design and implement improvements in community long term support systems to enable children and adults of any age who have a disability or long-term illness to live in and participate in their communities; and (iv) National Technical Assistance Exchange for Community Living Grants, to provide technical assistance, information, and training to States, families, consumers and other eligible organizations and agencies.<sup>xlix</sup> Additional grants have been awarded in subsequent years.

### **The Ticket to Work and Work Incentives Improvement Act**

The Ticket to Work and Work Incentives Improvement Act of 1999<sup>1</sup> was enacted to address a specific barrier to community integration for people with disabilities, namely, the loss of public health benefits and supports for people with disabilities who wish to return to work. The legislation allows individuals with disabilities to retain their Medicare benefits longer than had been previously allowed, and removes limits on the Medicaid buy-in option for workers with disabilities. The law also modernizes the employment services system for people with disabilities, and extends tax provisions for working families, education, the environment, and scientific research. The legislation is therefore designed to allow people to continue receiving much-needed benefits and support services to facilitate their participation in the employment sphere.

### **VI. Conclusion and Implementation Guidelines**

The decision by the U.S. Supreme Court in the *Olmstead* case is recognized as a landmark decision in the disability rights community in the United States. It has served as a powerful tool for expanding national and state-level initiatives to end (and over time, one hopes, eliminate altogether) institutional placements. More broadly, it has generated policies, programs and resources to advance living independently and in the community for all people with disabilities.

The following implementation guidelines are intended to serve as an overall assessment tool to be applied in the analysis of law, policy and practice concerning the furthering of living independently and in the community for all people with disabilities. While these guidelines are derived from the American experience, they are non-exhaustive and are intended to be used as

the basis for the development of more detailed and context-specific checklists for use at the national and local levels. In sum, they are intended to serve as a basic framework for the collection of information that will yield a full analysis and commentary on the implementation of obligations concerning living independently and in the community for all people with disabilities, based upon principles of choice, independence, autonomy, and community integration.<sup>li</sup>

*General Principles Guiding Laws and Policies to Promote Living Independently and in the Community*

- Do programs/legislative initiatives foster the empowerment of persons with disabilities, real and informed choice, and active participation in decision processes at the individual and systemic levels?
- In particular, do programs/legislative initiatives foster the real and informed choice of individuals with disabilities in key target areas for equalization of opportunities, including education, employment, transportation, housing, health care and rehabilitation/habilitation support services?

*Specific Issues of Implementation*

**Living Independently**

- Do programs/legislative initiatives foster the capacity of individuals with disabilities to live independently through support for living skills development in the following target areas:
  - Training in individual and systemic advocacy
  - Service relating to securing food, clothing and shelter
  - Training in managing personal assistants

- Training in using assistive devices

Is there specialized planning for making the transition to living independently and in the community?

- Are there programs/legislative initiatives in place to enable people with disabilities to live independently through the provision of long-term services and formal and informal supports in the community, such as assistive devices?
- Are there programs/legislative initiatives in place to enable people with disabilities to live independently and in the community, including through the provision of financial support where appropriate?

### **Social & Community Integration**

- Is there in place a comprehensive plan to create community-based services for people with disabilities?
  - Are people with psycho-social disabilities and intellectual disabilities included in such plans?
  - Does the plan include the provision of support services for people detained in institutions who can live in the community?
  - Does the plan create independent community supports for individuals without families or individuals in abusive family situations?
  - Does the plan introduce awareness-raising measures to address community/guardian/parental opposition?
- What opportunities are available for people with disabilities to live in the community, with their choice of affordable, accessible, quality housing?

- What opportunities exist in the community for people with disabilities to access affordable, accessible transportation?
- Do people with disabilities have access to appropriately trained personal assistants?
- Are appropriate and quality health care services available for people with disabilities in their communities?
- Are appropriate and quality rehabilitation/habilitation services available for people with disabilities in their communities?
- What opportunities are available for people with disabilities to be employed in their communities? Are there opportunities for supported employment?
- What support is available to people with disabilities living in rural areas to improve their access to services so that they may remain in their communities?

## Acknowledgements

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<sup>i</sup> For a comprehensive overview of the founding of the independent living movement in the United States, see Kathy Martinez (with Barbara Duncan), "The Road to Independent Living in the USA: An Historical Perspective and Contemporary Challenge" 20 *Disability World* (Sept./Oct. 2003). Available at: [http://www.disabilityworld.org/09-10\\_03/il/ilhistory.shtml](http://www.disabilityworld.org/09-10_03/il/ilhistory.shtml); G. DeJong, *The Movement for Independent Living: Origins, Ideology, and Implications for Disability Research* (East Lansing, MI: Michigan State University, 1979). See also Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* 184 – 210 (1993).

<sup>ii</sup> For more on traditional models of disability see "A White Paper – Understanding the Role of an International Convention on the Human Rights of People with Disabilities: An analysis of the legal, social and practical implications for policy makers and disability and human rights advocates in the United States," pp. 27-28 (National Council on Disability, May 23, 2002), available at: <http://www.ncd.gov/newsroom/publications/2002/publications.htm>.

<sup>iii</sup> David L. Braddock and Susan L. Parish, "An Institutional History of Disability," in *Handbook of Disability Studies*, (Gary Albrecht, Katherine D. Seelman, & Michael Bury, eds., Sage Publications, 2001), p. 48. Ed Roberts, a founder of the independent living movement in the United States, identified four core components of the movement, namely, (i) individual self-determination; (ii) self-image and public education; (iii) advocacy; and (iv) service to all. See Ed Roberts, "A History of the Independent Living Movement: A Founder's Perspective," in



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Psychological Interventions with Physically Disabled Persons 231-34 (Heller et al, New Brunswick, NJ: Rutgers University Press, (1989)).

<sup>iv</sup> For more on the social model of disability, see especially Simi Linton, *Claiming Disability: Knowledge and Identity* 11 (New York University Press, 1998).

<sup>v</sup> Simi Litvak and Alexandra Enders, "The Interface between Individuals and Environments," in *Handbook of Disability Studies*, (Gary Albrecht, Katherine D. Seelman, & Michael Bury, eds. Sage Publications, 2001), p. 725

<sup>vi</sup> For a comprehensive listing of independent living centers throughout the United States, see [http://www.ncd.gov/living\\_centers.htm](http://www.ncd.gov/living_centers.htm)

<sup>vii</sup> David L. Braddock and Susan L. Parish, "An Institutional History of Disability," in *Handbook of Disability Studies*, (Gary Albrecht, Katherine D. Seelman, & Michael Bury, eds., Sage Publications, 2001), p. 48.

<sup>viii</sup> Within the United States there are now more than 1,200 self-advocacy chapters addressing a range of issues, such as institutional closures and quality community supports and services. For an excellent study on the rise of the self-advocacy movement by people with disabilities, see Mary Hayden, *The Self Advocacy Movement: The Unacknowledged Civil Rights Movement* (Mary E. Switzer Fellowship, US Department of Education, 2004). See also Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* 184 – 210 (1993). For a worldwide directory of self-advocacy organizations of people with intellectual disabilities, see <http://www.peoplefirst.org.uk/pflinks.html>.

<sup>ix</sup> While the psychiatric survivor community has embraced (and significantly added content to) the principles underlying the independent living movement, it has also noted the failure of the mainstream disability rights and independent living movements to fully embrace the rights claims of people with psychiatric disabilities. See National Council on Disability, *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak For Themselves* (Washington, DC, January 20, 2002), p. 10, available at: <http://www.ncd.gov/newsroom/publications/2000/privileges.htm#1>.

<sup>x</sup> Andrew I. Batavia, "The Growing Prominence of Independent Living and Consumer Direction as Principles in Long-Term Care: A Content Analysis and Implications for Elderly People with Disabilities," 10 Elder L.J. 263, 266 (2002).

<sup>xi</sup> "Discussion Paper on Founding Principles of a Convention on Rights of Persons with Disabilities," Danish Institute for Human Rights, A/AC.265/2003/CRP/9, available at: [http://www.un.org/esa/socdev/enable/rights/a\\_ac265\\_2003\\_crp9.htm](http://www.un.org/esa/socdev/enable/rights/a_ac265_2003_crp9.htm).

<sup>xii</sup> David L. Braddock and Susan L. Parish, "An Institutional History of Disability," in *Handbook of Disability Studies*, (Gary Albrecht, Katherine D. Seelman, & Michael Bury, eds., Sage Publications, 2001), p. 48.

<sup>xiii</sup> See generally Mental Disability Rights International, *Not on the Agenda: Human Rights of People with Disabilities in Kosovo* (2002); *Human Rights & Mental Health: Mexico* (2000); *Children in Russia's Institutions: Human Rights and Opportunities for Reform* (1999); *Human Rights & Mental Health: Hungary* (1997); *Human Rights & Mental Health: Uruguay* (1995). These reports are available at <<http://www.MDRI.org>>. For a detailed report outlining specific abuses against people labeled with psychiatric disorders, see National Council on Disability, *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves* (Washington, DC, January 20, 2002) available at: <http://www.ncd.gov/newsroom/publications/2000/privileges.htm#1>.

<sup>xiv</sup> National Council on Disability, *Olmstead: Reclaiming Institutionalized Lives* (Washington, DC, September 29, 2003), available at: <http://www.ncd.gov/newsroom/publications/2003/pdf/reclaimabridged.htm>.

<sup>xv</sup> While the principal international human rights conventions do not explicitly prohibit disability discrimination, their non-discrimination clauses are well understood to apply to people with disabilities. See Gerard Quinn and Theresia Degener, et al. "Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability" (Office of the High Commissioner for Human Rights, 2002), p. 37. It is clear, for example, that the non-discrimination clauses of the International Covenant on Civil and Political Rights (Article 2 & 26) do cover disability discrimination under the umbrella of the term "other status." See International Covenant on Civil and Political Rights, G.A. res. 2200A (XXI), U.N. GAOR 21<sup>st</sup> Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1966), entered into force Mar. 23, 1976. The drafting of a new convention on the rights of people with disabilities will introduce a disability-specific non-discrimination provision into the human rights framework.

<sup>xvi</sup> Rights to participate in decision-making under human rights law traditionally centered around participation in political life, principally through voting rights and the right to hold public office. See, e.g., International Covenant on Civil and Political Rights, G.A. res. 2200A (XXI), U.N. GAOR 21<sup>st</sup> Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1966), entered into force Mar. 23, 1976, Article 25. Human rights law has broadened the scope of participation

rights and many specialized conventions specifically address the application of these rights in a variety of contexts. For further examples and discussion, see “A Reference Tool – Understanding the Potential Content and Structure of an International Convention on the Human Rights of People with Disabilities: Sample treaty provisions drawn from existing international instruments,” (National Council on Disability, 2002), available at:

<http://www.ncd.gov/newsroom/publications/2002/publications.htm>.

<sup>xvii</sup> G.A. res. 2200A (XXI), 21 U.N. GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316 (1966), entered into force Jan. 3, 1976.

<sup>xviii</sup> General Comment No. 5 (1994) on Persons with Disabilities, report on the Tenth and Eleventh Sessions, U.N. ESCOR 1995, Supp. No. 2 [according to U.N. Doc. E/1995/22/Corr.1-E/C.12/1994/20/Corr.1], at 102, para. 15, U.N. Doc. E/1995/22-E/C.12/1994/20 (1995). For the sake of completeness, it should be noted that the MI Principles express a preference for community living arrangements for people with mental disabilities, though it is more qualified than other documents in providing that “[e]very person with mental illness shall have the right to live and work, as far as possible, in the community.” Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles), G.A. Res. 46/119, U.N. GAOR 46<sup>th</sup> Session., Supp. No. 49, Annex at 188-92, U.N. Doc. A/46/49 (1991). Gerard Quinn and Theresia Degener have also noted in the seminal study that the MI Principles “give valuable guidance for the interpretation of Article 7 [of the International Covenant on Civil and Political Rights] in the context of institutionalized disabled persons.” See Gerard Quinn and Theresia Degener, et al. “Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability” (Office of the High Commissioner for Human Rights, 2002), p. 38. The MI Principles are highly disfavored by many in the psychiatric survivor community and are clearly outmoded, something that a new convention offers the potential to correct. For a critique of the MI Principles, see World Users and Survivors of Psychiatry, Position Paper on the Principles for the Protection of Persons with Mental Illness (July 2001), available at: <http://www.wnusp.org/wnusp%20evas/Dokumenter/positionpaper.html>.

<sup>xix</sup> General Comment No. 5 (1994) on Persons with Disabilities, report on the Tenth and Eleventh Sessions, U.N. ESCOR 1995, Supp. No. 2 [according to U.N. Doc. E/1995/22/Corr.1-E/C.12/1994/20/Corr.1], at 102, para. 15, U.N. Doc. E/1995/22-E/C.12/1994/20 (1995).

<sup>xx</sup> Leandro Despouy, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, *Human Rights and Disabled Persons*, p. 29, U.N. Doc. E/92/XIV.4 (1992).

<sup>xxi</sup> International Covenant on Civil and Political Rights, G.A. res. 2200A (XXI), U.N. GAOR 21<sup>st</sup> Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1966), entered into force Mar. 23, 1976, Article 25.

<sup>xxii</sup> See Gerard Quinn and Theresia Degener, et al. “Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability” (Office of the High Commissioner for Human Rights, 2002), p. 39.

<sup>xxiii</sup> International Covenant on Civil and Political Rights, G.A. res. 2200A (XXI), U.N. GAOR 21<sup>st</sup> Sess., Supp. No. 16, at 52, U.N. Doc. A/6316 (1966), entered into force Mar. 23, 1976, Article 19 (freedom of expression); Article 22 (freedom of association); Article 17 (right to privacy).

<sup>xxiv</sup> For a detailed overview of sources for a right to community integration in international law, see Eric Rosenthal and Arlene Kanter, “People with Disabilities in Institutions and the Emerging Right to Community Integration for People with Disabilities under United States and International Law,” paper presented for the Disability Rights and Education Defense Fund (DREDF) Conference (Washington, DC, 2000).

<sup>xxv</sup> 85<sup>th</sup> Plenary meeting, 20 Dec. 1993, para. 1, Part IV, A/Res/48/96.

<sup>xxvi</sup> Convention on the Rights of the Child, G.A. res. 44/25, annex, 44 U.N. GAOR Supp. (No. 49) at 167, U.N. Doc. A/44/49 (1989), entered into force Sept. 2, 1990.

<sup>xxvii</sup> Id. Article 23(1).

<sup>xxviii</sup> Id. Article 23(3).

<sup>xxix</sup> Article 15 states:

With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration and participation in the life of the community, the Parties undertake, in particular:

1. to take the necessary measures to provide persons with disabilities with guidance, education and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialised bodies, public or private;
2. to promote their access to employment through all measures tending to encourage employers to hire and keep in employment persons with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability. In certain cases, such measures may require recourse to specialised placement and support services;
3. to promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure.

(Revised) European Social Charter, European Treaty Series, n. 163, Strasbourg 1996, Council of Europe, available at: <http://conventions.coe.int/treaty/en/treaties/html/163.htm>.

<sup>xxx</sup> Available at: <http://www.whitehouse.gov/news/freedominitiative.html>.

<sup>xxxi</sup> 42 U.S.C. § 12132.

<sup>xxxii</sup> 135 Cong. Rec. S4986 (daily ed. May 9, 1989) (Statement of Senator Harkin).

<sup>xxxiii</sup> 527 U.S. 581 (1999). *Olmstead v. L.C.* was brought by a woman with disabilities who was institutionalized in a state mental hospital in Georgia. The plaintiff, Lois Curtis, challenged her continued confinement in the institution on the basis that, according to physicians treating her, she no longer required inpatient treatment but instead would benefit from community residential and habilitation services. Ms. Curtis claimed violations of the Due Process clause of the U.S. Constitution as well as violations of the Americans with Disabilities Act.

<sup>xxxiv</sup> 42 U.S.C. § 12132.

<sup>xxxv</sup> 28 C.F.R. § 35.130(d).

<sup>xxxvi</sup> 527 U.S. at 597.

<sup>xxxvii</sup> 527 U.S. at 587.

<sup>xxxviii</sup> *Id.* at 600

<sup>xxxix</sup> *Id.* at 601.

<sup>xl</sup> Exec. Order No. 13,217, 66 Fed. Reg. at 33,155 (2001). An Executive Order is a rule or order having the force of law issued by the U.S. President.

<sup>xli</sup> For an overview of the implementation of *Olmstead* in federal and state policies and programs, see Mary C. Cerreto, “*Olmstead: The Brown v. Board of Education for Disability Rights - Promises, Limits and Issues*,” 3 Loy. J. Pub. Int. L. 47 (2001).

<sup>xlii</sup> *Id.*

<sup>xliii</sup> *Id.*

<sup>xliv</sup> *Id.*

<sup>xlv</sup> *Id.*

<sup>xlvi</sup> *Id.*

<sup>xlvi</sup> Letter to State Medicaid Directors, January 14, 2000, available at:

<http://www.cms.hhs.gov/states/letters/smd1140a.asp>

<sup>xlvi</sup> For detailed information on the Systems Change Grants, see

<http://www.cms.hhs.gov/systemschange/backgrnd.asp>.

<sup>xlvi</sup> *Id.*

<sup>l</sup> Public Law 106-70.

<sup>li</sup> A number of these implementation guidelines are derived from recommendations and plans to promote living independently and in the community both in the United States, as well as elsewhere. See, e.g., “*Olmstead: Reclaiming Institutionalized Lives*” (National Council on Disability, Washington, DC, September 29, 2003), pp. 176-190, available at: <http://www.ncd.gov/newsroom/publications/2003/pdf/reclaimabridged.htm>; MDRI, “Not on the Agenda: Human Rights of People with Mental Disabilities in Kosovo,” (Washington, DC: 2002), pp. 25-30, available at: [www.mdri.org](http://www.mdri.org); Minister of Disability Issues, New Zealand, “the New Zealand Disability Strategy: Making a World of Difference,” (Wellington, NZ: April 2001), pp. 22-23, available at: <http://www.odi.govt.nz.htm>.