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There's No Place Like Home: The Right to Live in the Community for People with Disabilities, Under International Law and the Domestic Laws of the United States and Israel

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This article explores the developing 'right to live in the community' for people with disabilities under international law and the domestic laws of two countries: the United States and Israel. In 2006, the United Nations adopted the Convention on the Rights of People with Disabilities (CRPD). This Convention embraces a human rights approach to disability, based on the principles of equality, dignity, freedom and inclusion. Based on these principles, Article 19 of the CRPD includes a specific right of all people with disabilities 'to live in the community, with choices equal to others'. The author argues that the mandate of community living in Article 19 supports an explicit legal right of all people with disabilities not only to live in the community, but to choose where to live and with whom, and with supports, as needed. This new international legal right to live in one's home in the community also advances the goals and principles of the domestic laws of the US and Israel.

In the US, the Americans with Disabilities Act (ADA) protects the right of people with disabilities to receive services in 'the most integrated' setting. Relying on this 'integration mandate', the US Supreme Court, in 1999, upheld a limited right of people with disabilities to live in the community in Olmstead v LC and EW. *In Israel, the Parliament (Knesset) enacted a law similar to the ADA in 1998. This law, the Equal Rights of Persons with Disabilities Law ('Equal Rights Law') includes a general right of people with disabilities to equality and non-discrimination. Although the current version of the Equal Rights Law does not include a specific article*

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on the right to live in the community, the basis for such a right may be found in other articles of the law as well as other Israeli laws. In addition, in the recent case of Lior Levy et al.*, the Israeli High Court of Justice was asked to consider the right to live in the community under Israeli law. While the Court in this case recognised a limited right to live in the community, it failed to invalidate as discriminatory the Israeli government's policy of placing people with disabilities in large institution-like hostels rather than in homes in the community. The author concludes the article with a discussion of the scope and meaning of community living and the extent to which institutions, as well as community housing that functions just like institutions, should be prohibited under the CRPD as well as under US and Israeli law.*

Keywords: disability, Americans with Disabilities Act (ADA), Israeli Equal Rights of People with Disabilities Law, right to live in the community, *Olmstead*, Convention on the Rights of People with Disabilities (CRPD), international human rights law

1. INTRODUCTION

Five young people with disabilities, who need support for their daily living, wish to move out of their parents' homes and into their own apartments. The government denies their requests because, in the government's view, they are not sufficiently 'independent' to live in the community. Instead, the government requires them to move into an institution in order to receive the support they need for their daily living.[1]

In 2006, the United Nations (UN) adopted the Convention on the Rights of People with Disabilities (CRPD). Article 19 of the CRPD recognises the right of all people with disabilities, regardless of the type or severity of their disability, 'to live in the community with choices equal to others'. This right encompasses the view that living in the community is not just about being placed in a building zoned for residential use. Rather, it is about supporting people with disabilities to exercise their right to decide where and with whom to live, in the same way that people without disabilities are free to decide where and with whom they live.

In many countries today, including the United States (US) and Israel, the right of people with disabilities to live in the community is not the same as it is for people without disabilities. Often governments condition receipt of services for people with disabilities on their living in certain institutions or other congregate living facilities. Why is that, and to what extent do international and domestic laws and policies protect the right of the five young people mentioned above as well as countless other people with disabilities throughout the world who wish to live in their own homes in the community just like people without disabilities? What legal tools are available to protect the right of people with disabilities to live in the community, even if they need support in their daily living skills? This article will explore these and related questions in order to understand the meaning and scope of the 'right to live in the community' under international law as well as its application to the laws and policies of the US and Israel.

As we begin to explore these questions, we must bear in mind that people with disabilities are not a homogeneous group; they differ based on the type and severity of disability – not to mention age, nationality, race, gender and class. What this diverse group of people with disabilities

[1] Based on HCJ/07 *Lior Levy and Others v State of Israel and Others* IsrSC 2008(3) 4561 ('*Lior Levy*').

share, however, is a common history of exclusion, discrimination and mistreatment,[2] particularly with respect to their right to choose to live in the community rather than in institutions. People without disabilities can choose to live where they want and with whom, limited only by their personal preferences, housing stock availability and, of course, access to finances.[3] But once a person is labelled as 'disabled', especially as a person with a mental disability, he or she may lose the right to make many decisions about his or her own life, including the right to decide where to live and with whom. If the person requires services or support in daily living, it is more often the state (with or without family involvement) that will decide where the person will live and what services the person will receive.

According to Article 19 of the CRPD,[4] the right to live in the community is a human right that applies to all people with disabilities. This right has now been recognised in several countries and regions of the world. In Europe, for example, both the European Union (EU) and the Council of Europe (CoE) have developed policy objectives that seek to ensure the right of all people with disabilities to live in the community as equal citizens. The CoE's Commissioner for Human Rights recently highlighted the importance of Article 19's right to live in the community in a report that endorses recommendations for 'member states [to] establish timetables to stop new admissions to institutions and establish community alternatives'.[5] The Report goes on to recommend that states should:

> [d]evelop programs to enable persons with disabilities to live in the community. Cease new admissions to social care institutions and allocate sufficient resources to provide adequate health care, rehabilitation and social services in the community instead.[6]

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[2] Arlene S Kanter, 'The Globalization of Disability Rights Law' (2003) 30 Syracuse Journal of International Law and Commerce 241, 243.

[3] This article does not address such issues as affordable or accessible housing and the lack of it. See, for example, the BBC report on the question of whether people with low incomes have a right to stay in expensive neighbourhoods: Jon Kelly, 'Do the Poor Have the Right to Live in Expensive Areas?', 4 BBC News Magazine (2010), available at http://www.bbc.co.uk/news/magazine-11674864.

[4] UNGA Res 61/106, Convention on the Rights of Persons with Disabilities, UN Doc A/61/106, Annex I, 13 December 2006 (entered into force 3 May 2008) (CRPD).

[5] See Statement by Thomas Hammarberg, 'Protecting and Promoting the Rights of People with Disabilities in Europe: Towards Full Participation, Inclusion and Empowerment', Council of Europe, Commissioner for Human Rights, Strasbourg, 29 October 2008, available at https://wcd.coe.int/ViewDoc.jsp?id=1364885&Site=COE. See also Camilla Parker, 'Developing Mental Health Policy: A Human Rights Perspective' in Martin Knapp and others (eds), *Mental Health Policy and Practice across Europe: The Future Direction of Mental Health Care* (McGraw-Hill International 2007) 308–35; Jim Mansell and others, 'Deinstitutionalisation and Community Living – Outcomes and Costs: Report of a European Study', Vol 2: Main Report, Tizard Centre, University of Kent, 2007, 2, 25 ('the Mansell report'), available at http://www.kent.ac.uk/tizard/research/research_projects/DECLOC_Volume_1_Exec_Summary.pdf. This report found that of 25 countries in Europe alone it is estimated that there are at least 1.2 million disabled people living in institutions; most of the residents have mental health problems or intellectual disabilities.

[6] ibid; see also Mansell, ibid 1. The Mansell report is intended to bring together the available information on the number of disabled people living in residential institutions in 28 European countries, and to identify successful strategies for replacing institutions with community-based services, paying particular attention to economic issues in the transition. It is the most wide-ranging study of its kind ever undertaken.

The CoE Action Plan for 2006–15 also specifically outlines steps to achieve this goal:

> People with disabilities should be able to live as independently as possible, including being able to choose where and how to live. Opportunities for independent living and social inclusion are first and foremost created by living in the community.[7]

In addition, the CRPD Committee in Geneva is now taking individual countries to task in response to Country Reports that fail to indicate sufficient progress with respect to the development of community alternatives to institutionalisation.[8]

In addition to action by governmental bodies and the UN CRPD Committee, non-governmental organisations (NGOs) are also engaging in this issue. The International Movement for Global Mental Health has called for the implementation and enforcement of Article 19's right to live in the community for all people with disabilities throughout the world.[9] On 14 January 2011, the Mental Disability Action Center (MDAC) and other NGOs in Hungary issued a statement calling for changes in EU funding to facilitate the movement of 23,000 people with disabilities out of institutions throughout Europe and to develop services for them in the community.[10] Disability Rights International (DRI) in Washington, DC has also begun an international campaign to end the institutionalisation of children.[11] This campaign challenges the underlying policies that lead to the continued use of foreign assistance to build new institutions or rebuild old ones, instead of providing assistance and access to services for families who want to keep their children with disabilities at home.[12]

Legislatures and courts, too – in the US, Israel and elsewhere – have begun to enforce the right of community living on behalf of people with various types of disabilities.[13] In the

[7] Commission of the European Communities, Communication from the Commission to the Council, the European Parliament, the European Economic and Social Committee and the Committee of the Regions, 'Equal Opportunities for People with Disabilities: A European Action Plan' COM (2003) 650 final, 30 October 2003; Geert Freyhoff and others (eds), 'Included in Society: Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People, The European Commission 2003, available at http://www.community-living.info/contentpics/226/Included_in_Society.pdf.

[8] Committee on the Rights of Persons with Disabilities, Fifth session, 11–15 April 2011, Implementation of the Convention on the Rights of Persons with Disabilities: List of Issues to be Taken up in Connection with the Consideration of the Initial Report of Spain (CRPD/C/ESP/1), concerning arts 1 to 33 of the Convention on the Rights of Persons with Disabilities, UN Doc CRPD/C/ESP/Q/1, 20 June 2011; Committee on the Rights of Persons with Disabilities, Fourth session, 4–8 October 2010, Implementation of the Convention on the Rights of Persons with Disabilities: List of Issues to be Taken up in Connection with the Consideration of the Initial Report of Tunisia (CRPD/C/TUN/1), concerning arts 1 to 33 of the Convention on the Rights of Persons with Disabilities, UN Doc CRPD/C/TUN/Q/1, 10 November 2010.

[9] Movement for Global Mental Health, 'The Right to Live in the Community', available at http://www.globalmentalhealth.org/articles.php?id=57.

[10] MDAC, 'Advocating the Right to Live in the Community in Hungary', Budapest, 17 January 2011, available at http://www.mdac.info/content/advocating-right-live-community-hungary.

[11] DRI, 'The Worldwide Campaign to End the Institutionalization of Children', available at http://www.disabilityrightsintl.org/learn-about-the-worldwide-campaign-to-end-the-institutionalization-of-children.

[12] ibid.

[13] Many countries have begun to address the issue of the right to community living and services (and against institutionalisation) through litigation in domestic and regional human right tribunals and other forms of advocacy. For

United States, Congress enacted the Americans with Disabilities Act (ADA) which prohibits discrimination against people with disabilities, including the requirement that people with disabilities have the right to receive services in the 'most integrated' setting in the community as opposed to institutions.[14] But even this 'integration mandate' is not absolute. In *Olmstead v LC and EW* ('*Olmstead*'),[15] the US Supreme Court held that the 'integration mandate' of the ADA supports the right of people with disabilities to live in the community, but only to the extent that professionals agree that community placement is appropriate for the individual and that such placement does not constitute a fundamental alteration of the system that provides services to people with disabilities.

In Israel, the prohibition against discrimination against people with disabilities is enshrined in the Equal Rights of Persons with Disabilities Law.[16] The specific provision regarding the right to community living has not yet been adopted, even now, 13 years after the law was first introduced.[17] Nonetheless, other sections of the law as well as other laws and policies in Israel protect this right. The Israeli High Court of Justice also recently decided the case of *Lior Levy v State of Israel*, in which the court upheld a limited right of people with disabilities to live in the community. But, like the US Supreme Court's decision in *Olmstead*, the Israeli Court failed to declare an unqualified right to live in the community for all people with disabilities. The Court also defined a hostel for 24 people as community housing rather

example, MDAC filed two cases in the European Court of Human Rights (ECtHR) about the situation in Bulgaria, which were argued in November 2009: *Mitev v Bulgaria* App no 60922/00 (ECtHR, 7 January 2010) and *Stanev v Bulgaria*, App no 36760/06 (ECtHR, 9 February 2011). These cases were brought on behalf of Mr Mitev, who died in a social care institution. His case is being continued by his sister and Mr Stanev, who was the first person from a social care institution to bring a case before Europe's human rights court. Among other allegations, the plaintiffs allege that their confinement in the social care institution violates their rights under art 5 of the European Convention of Human Rights.

Similarly, DRI in Washington, DC recently filed a complaint with the UN regarding conditions in a private institution in Massachusetts that DRI documented in a report entitled 'Torture not Treatment: Electric Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center', available at http://www.disabilityrightsintl.org.

In Turkey, which has already ratified the CRPD, a NGO has developed a project on community living, which includes developing laws to promote community housing and services: Republic of Turkey Prime Ministry Administration for Disabled Persons, 'The Project: Deinstitutionalisation and Community Living – Outcomes and Costs', available at http://www.ozida.gov.tr/ENG/?menu=actual&sayfa=deinst_com; and a committee of psychiatrists: see Arlene S Kanter, 'The Right to Community Living Under International Law' (Uluslararası Hukuk Uyarınca Toplum İçinde Yaşama Hakkı) in Fatma Zengin Dagidir (ed), *The Right to Live in the Community: Community Based Services for People with Mental Disabilities* (*Toplum Içında Yaşama Hakkı: Zıhınsel ve Ruhsal Rahatsızlığı Olan Kısıler için Toplum Temellı Hızmetler*) (Karika 2010) (in Turkish).

[14] 28 CFR § 35.130(d) (2006): 'A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities'; see also Social Security Act, Title XIX, 42 USC § 1396–1396v (2008). This regulation implements Title II of the Americans with Disabilities Act, 42 USC § 12101 et seq (2006). See also Social Security Act, Title XIX, 42 USC § 1396–1396v (2008).

[15] *Olmstead v LC by Zimring* 527 US 581 (1999) ('*Olmstead*').

[16] Equal Rights of People with Disabilities Act, 1998 (Israel) ('Equal Rights Law'), s 5.

[17] This law was adopted by the Israeli Parliament in 1998, in part, as a result of efforts by a coalition of disability groups to respond to widespread discrimination against people with disabilities in Israel: see Arie Rimmerman and Shirley Avrami, 'Israel's Equal Rights for Persons with Disabilities Law: Legal Base, Process and Impact' (2009) International Journal of Disability, Community and Rehabilitation 8.

than an institution.[18] Accordingly, the Israeli Court upheld the government's policy of placing people with disabilities in institution-like settings rather than in typical homes in the community. As a result, thousands of people with disabilities in Israel, as in the United States, remain institutionalised or living in community placements that are called 'homes', but function much like institutions.[19] Indeed, research reveals that many community-based alternatives function much like institutions by requiring people with disabilities to live only with other people with disabilities, by controlling where and with whom the residents live and what they do each day, as well as by placing people with disabilities in housing that is segregated from the rest of society. Furthermore, many children and adults with disabilities who live with their families also face exclusion from society because of the lack of the necessary supports which would enable them to live as independently as possible and to participate in the life of their communities. In short, people with disabilities, solely because of their disabilities, are forced to choose between living at home with their families, with friends or on their own, or moving into institutions or other congregate living facilities in order to obtain the services or support they need.

On the other hand, people without disabilities can remain in their own homes and arrange for services there or obtain the services they need in their local communities. The ostensible reason for the different treatment afforded to people with and without disabilities is the perception that people with disabilities need to be taken care of in institutions or institution-like settings, even though studies reveal that the majority of people with disabilities are not only capable of living independently or with supports, but also that their quality of life improves by living in the community. Another reason for the continued reliance on institutions and congregate living settings for people with disabilities relates to the perception that community living is too expensive.

In the following section of this article, Section 2, I discuss the development of the right of people with disabilities to live in the community under international law. This section also includes a discussion of the process within the UN that led up to the inclusion of 'the right to community living' language in Article 19 of the CRPD. In Section 3 I discuss the right to community living under United States law, and in Section 4 the same right under Israeli law. Section 5 contains discussion of the meaning and scope of the right to live in the community generally, and the extent to which a legal right to community living is being realised in the United States and in Israel. This Section also examines an example of a new housing project for people with disabilities in Israel, which contrasts with the 'supported housing' model in the US. I conclude this article with a view towards the CRPD. Although the US and Israel both

[18] *Lior Levy* (n 1).

[19] For a discussion of the meaning of home in various disciplines see, for example, Carole Després, 'The Meaning of Home: Literature Review and Directions for Future Research and Theoretical Development' (1991) 8 Journal of Architecture and Planning Research 96. The legal conception of home, however, has received surprisingly little attention: Lorna Fox, 'The Meaning of Home: A Chimerical Concept or a Legal Challenge?' (2002) 29 Journal of Law and Society 580. See also Carole A Robinson, R Colin Reid and Heather A Cooke, 'A Home Away From Home: The Meaning of Home According to Families of Residents with Dementia' (2010) 9 Dementia 490, 491.

have signed the CRPD, neither country has yet ratified it. If and when they do, I argue that the CRPD will provide a framework for the implementation of full equality rights for people with disabilities in Israel and the US, including the right of people with all types of disability to live in their own homes in the community, with choices equal to others.

2. THE RIGHT TO LIVE IN THE COMMUNITY FOR PEOPLE WITH DISABILITIES UNDER INTERNATIONAL LAW

2.1 THE RIGHT TO LIVE IN THE COMMUNITY PRIOR TO THE CONVENTION ON THE RIGHTS OF PEOPLE WITH DISABILITIES

People with disabilities are the largest minority in the world, totalling today over 1 billion people, or 15 per cent of the world's population.[20] Yet, when the United Nations was founded, and until recently, people with disabilities were not considered a distinct group worthy of human rights protection.[21] Instead, they were, and still are in many places, seen primarily as patients who need treatment or objects of charity, but not as human beings entitled to protection under international human rights law.

Prior to the CRPD, no binding international treaty existed to protect the rights of people with disabilities, generally, or their right to live in the community, in particular. However, in the years preceding the CRPD, a growing body of international interpretations and commentary, known as 'soft' laws, began to emerge to protect certain rights of individuals with disabilities, including the right to community living.[22]

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[20] World Health Organization (WHO) and World Bank, 'World Report on Disability' (2011), 29, available at http://www.gpdd-online.org/media/news/world_report_disability_2011.doc. This estimate is higher than previous World Health Organization estimates, which date from the 1970s and suggested around 10%: World Health Organization, 'Violence, Injuries and Disability: Biennial Report 2008–09', Geneva, 2010, available at http://whqlibdoc.who.int/publications/2010/9789241599474_eng.pdf.

[21] See Kanter (n 2) 241, 253; Arlene S Kanter, 'The Law: What's Disability Studies Got to Do with it or Introducing Disability Legal Studies' (2011) 43 Columbia Human Rights Law Review 403, 427–28, citing Colin Barnes, 'A Legacy of Oppression: A History of Disability in Western Culture' in Len Barton and Mike Oliver (eds), *Disability Studies: Past, Present and Future* (The Disability Press 1997) 3–24 (noting the systematic murder of disabled persons in Nazi death camps); Paul K Longmore and Lauri Umansky (eds), *The New Disability History: America Perspective* (New York University Press 2001) 1, 17 (noting the prevalence of abuse, discrimination and oppression of disabled persons throughout history); see also Jacqueline Vaughn Switzer, *Disabled Rights: American Disability Policy and the Fight for Equality* (Georgetown University Press 2003) 30–44 (highlighting the historic mistreatment of disabled persons, including movements toward forced sterilisation of disabled persons).

[22] Convention on the Rights of the Child (entered into force 2 September 1990) 1577 UNTS 3, art 23; UNGA Res 2856(XXVI), Declaration on the Rights of Mentally Retarded Persons, UN Doc A/RES/2856(XXVI), 20 December 1971; Standard Rules on the Equalization of Opportunities for Persons with Disabilities, annexed to UNGA Res 48/96, UN Doc A/RES/48/96, 20 December 1993; and the Charter of Fundamental Rights of the European Union (2000) OJ C364/01 all urge that a right to community integration be enforced under international human rights standards. See Eric Rosenthal and Arlene Kanter, 'The Right to Community Integration for People with Disabilities under United States and International Law' in Mary Lou Breslin and Silvia Yee (eds), *Disability Rights Law and Policy: International and National Perspectives* (Transnational 2002). Another more recent example of an international instrument recognising a right to community integration is the Inter-American

The first such 'soft law' relating to the rights of people with disabilities is the Declaration on the Rights of Mentally Retarded Persons, adopted in 1971 by the United Nations General Assembly.[23] The Declaration protects from discrimination people who were then referred to as 'mentally retarded'.[24] It established, for the first time, a formal recognition of the rights of people with mental disabilities, including a (limited) right to live in the community. As the Declaration states, '[w]henever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life'.[25] By including the opening words, 'whenever possible', the Declaration presents the possibility that, for some people some of the time, it will not be possible. Therefore, this Declaration cannot be read as conferring on people with disabilities an absolute right to live in the community.

Similarly, in 1975, the UN General Assembly adopted the Declaration on the Rights of Disabled Persons. This Declaration recognises 'the inherent right to respect for their human dignity' of all people with disabilities. It also recognises the 'fundamental right' of people with disabilities to 'enjoy a decent life, as normal and full as possible',[26] which necessarily includes the right to live in the community as opposed to segregated settings or institutions. The 1975 Declaration on the Rights of Disabled Persons also asserts a specific right to live with one's own family. However, it also states that differential treatment with respect to housing for people with disabilities may be permitted if 'required by his or her condition or by the improvement which he or she may derive therefrom'.[27] The Declaration further states that '[if] the stay of a disabled person in a specialized establishment is indispensable, the environment and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age'.[28] It not only says that people with disabilities have a right to live in settings that are not only as close as possible, but that, in fact, are like those of the normal life of a person of his or her age. Accordingly, the Declaration does not resolve the questions of who decides what constitutes indispensability and when such indispensability arises. In other words, the Declaration arguably created questions rather than resolved the issue of whether people with disabilities have the right to live in a home in the community, just like everyone else.

Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities (entered into force 14 September 2001) AG/RES 1608 (XXIX-O/99).

[23] Declaration on the Rights of Mentally Retarded Persons ibid, art 4.

[24] The term 'mentally retarded' is no longer used in the US. In response to demands by the self-advocacy community as well as professionals, the American Association on Mental Retardation changed its name to the American Association on Intellectual and Developmental Disabilities. The New York State Office of Mental Retardation changed its name to the NYS Office of People with Developmental Disabilities. See David Ferleger, 'The Constitutional Right to Community Services' (2011) 26 Georgia Law Review 763, 766 fn 15. 'Developmental disabilities' is a broader category than mental retardation and is statutorily (not clinically) defined. See Robert L Schalock and others, *Intellectual Disability: Definition, Classification, and Systems of Supports* (11th edn, American Association on Intellectual and Developmental Disabilities 2010). In Israel, the term 'mental retardation' is still commonly used.

[25] Declaration on the Rights of Mentally Retarded Persons (n 22) art 4.

[26] UNGA Res 3447(XXX), Declaration on the Rights of Disabled Persons, UN Doc A/10034 (1975), art 3.

[27] ibid art 9.

[28] ibid.

Following these declarations, the UN assigned two Disability Rapporteurs to investigate living conditions for people with disabilities.[29] In 1983, Special Rapporteur, Erica-Irene A Daes, reported on the inhumane conditions in which people with disabilities were forced to live, particularly psychiatric patients who are held against their will and used 'as guinea pigs for new scientific experiments'.[30] Nearly a decade later, in 1991, Special Rapporteur, Leandro Despouy, reported that people with disabilities were subjected to gross violations of their human rights in the form of institutionalisation and abuse in institutions.[31] According to the Despouy Report, institutionalisation, institutional abuse (including the misuse of medication), and forced sterilisation of persons with disabilities were among a litany of practices identified as serious violations of international human rights law.[32]

In response to these reports, the United Nations directed international attention to the plight of people with disabilities, particularly those living in institutions rather than in the community.[33] In 1991, for example, the UN General Assembly adopted the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care, known as the 'MI Principles'.[34] Although the MI Principles are non-binding, they can be, and have been, used as a guide to interpret related provisions of international human rights conventions.[35] In fact, the MI Principles have become known to 'represent the minimum United Nations standards for the protection of fundamental freedoms and human and legal rights of persons with mental illness'.[36] In particular, the MI Principles provide the minimum standard of practice for the delivery of mental health services, including standards for treatment and living conditions within

[29] Leandro Despouy, Human Rights and Disabled Persons, UN Doc E/CN.4/Sub 2/1991/31 1 (UN Center for Human Rights 1993) ('Despouy Report'); Erica-Irene A Daes, Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill Health or Suffering from Mental Disorder, UN Doc E/CN.4/Sub.2/1983/17/Rev.1 (United Nations Publications 1986) UN ESCOR, Sub-Commission on Prevention of Discrimination and Protection of Minorities ('Daes Report').

[30] Daes Report (ibid) para 225.

[31] Despouy Report (n 29) paras 195–99.

[32] ibid.

[33] Leslie Bennetts, 'The Disabled Seek Public Awareness', New York Times, 1 November 1981, 65. The year 1981 was the International Year of Disabled Persons, the primary purpose of which was to change public attitudes and create awareness.

[34] UNGA Res 46/119, The Protection of Persons with Mental Illness and the Improvement of Mental Health Care, UN Doc A/RES/46/119, Annex, 17 December 1991 ('MI Principles').

[35] Kanter (n 2) 261; Eric Rosenthal and Leonard S Rubenstein, 'International Human Rights Advocacy under the "Principles for the Protection of Persons with Mental Illness"' (1993) 16 International Journal of Law and Psychiatry 257, describing the use of the MI Principles as a guide to the interpretation of related provisions of human rights conventions.

[36] Henry Steel, Report of the Working Group on the Principles for the Protection of Persons with Mental Health Care, UN Doc E/CN. 4/1991/39 (Economic and Social Council, Commission on Human Rights, Human Rights and Scientific and Technological Developments, 1991), Annex II; Leandro Despouy, Special Rapporteur on Human Rights and Disability, reaffirmed this viewpoint in his report to the UN Human Rights Commission: Leandro Despouy, Human Rights and Disability, UN Doc E/CN.4/Sub.2/1991/31 (Economic and Social Council, Commission on Human Rights, Sub-Commission on Prevention of Discrimination and Protection of Minorities, 1991); see also Eric Rosenthal and Clarence J Sundram, 'The Role of International Human Rights in National Mental Health Legislation', World Health Organization, Department of Mental Health and Substance Dependence, 2004, available at http://www.who.int/mental_health/policy/international_hr_in_national_mhlegislation.pdf.

psychiatric institutions and protection against arbitrary detention in such facilities.[37] The MI Principles also have been found to apply to persons with mental disabilities regardless of whether or not they are in psychiatric facilities, and to all persons admitted to mental health facilities regardless of whether or not they are diagnosed as mentally ill. In fact, prior to the CRPD, the MI Principles were recognised as 'the most complete standards for the protection of the rights of persons with mental disabilities at the international level'.[38]

Although the MI Principles do not ban institutionalisation outright, Principle 3 of the MI Principles states that people with mental disabilities 'shall have the right to live and work, *to the extent possible*, in the community'. Principle 7 also recognises that '[e]very patient shall have the right to be treated and cared for, *as far as possible*, in the community in which he or she lives'. Because the phrase 'as far as possible' is not defined, it obviously leaves open the possibility that at times such rights will be limited as being 'not possible'.[39]

The UN took another step towards acknowledging the right of people with disabilities to live in the community when the World Conference on Human Rights met in Vienna in 1993.[40] In what has become known as the 'Vienna Declaration,' the World Conference declared that 'all human rights and fundamental freedoms are universal and thus unreservedly include persons with disabilities'.[41] Immediately following this conference, the UN General Assembly adopted a resolution entitled 'the Standard Rules on the Equalization of Opportunities for Persons with Disabilities' ('Standard Rules').[42] These Rules, which formed the primary text guiding international disability rights until the adoption of the CRPD, affirm the principle that people with disabilities 'should be enabled to live with their families'.[43]

The Standard Rules, together with the MI Principles, provide detailed guidance to governments regarding the applicability of international human rights law to people with disabilities, generally, and regarding their right to live in the community, in particular. Few governments, however, took steps to ensure the enforcement of these rights prior to the CRPD.[44] As a result, it was not until the formal adoption of the CPRD that people with disabilities were granted the full panoply of human rights protections under international law, including the 'right to live in the community, with choices equal to others'.

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[37] MI Principles (n 34) 15–18.

[38] See *Victor Rosario Congo v Ecuador*, Case 11.427, Report No 12/97, InterAmCHR, OEA/Ser.L/V/II.95, Doc 7 rev, 257 (1997); Report No 63/99, Inter Am CHR, OEA/Ser L/V/II 95 (1998) para 54. The Inter-American Commission went on to say that '[t]hese Principles serve as a guide to states in the design and or reform of mental health systems and are of utmost utility in evaluating the practice of existing systems'. See Mental Health Principle 23.

[39] See MI Principles (n 34) 3 and 7 (emphasis added).

[40] Vienna Declaration and Program of Action, UN Doc A/CONF/157/23, 14–16 June 1993.

[41] ibid, para 63.

[42] UNGA Res 48/96, Standard Rules on the Equalization of Opportunities for Persons with Disabilities, UN Doc A/RES/48/96, 4 March 1994.

[43] ibid, Rule 9.

[44] Kanter (n 2) 263–64.

2.2 The Adoption of the Convention on the Rights of People with Disabilities

The first proposal for a disability-specific convention was introduced at the United Nations by Italy in 1987, and again by Sweden in 1989.[45] It was not until 28 November 2001 when the UN General Assembly adopted Mexico's resolution creating an Ad Hoc Committee 'to consider proposals for a comprehensive and integral international convention to protect and promote the rights of persons with disabilities'.[46]

The idea of a disability-specific convention gained broad support during the five years (2001–06) during which the Ad Hoc Committee met at the UN.[47] Never before in the history of the UN were the people affected by a treaty present in such great numbers and as actual participants in the drafting process.[48] While the CRPD focuses on the rights and needs of people with disabilities, it also speaks about the need to change societies to enable every person to contribute to society to the best of his or her abilities and without discrimination.[49] The CRPD was eventually adopted by consensus on 13 December 2006. When it opened for signature on 30 March 2007, 82 countries signed the Convention, and 44 countries signed the Optional Protocol,[50] which amounted to more countries signing this treaty on opening day than any other treaty on any other opening day in the history of the UN.[51]

The purpose of the CRPD is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.[52] As such, the CRPD reflects a major shift in global understanding and responses towards disability by adopting a human rights approach. By 1 May 2012, 153 countries had signed the CRPD, of which 112 had also ratified it.[53]

The human rights approach is distinguished from the medical model of disability which views a person with a disability as someone in need of treatment, a cure, or charity. The human rights model incorporates a social model of disability by focusing less on the functional impairments or

[45] UN Doc A/C.3/42/SR 16, 19 October 1987, para 7; UN Doc A/C.3/44/SR 16, 24 October 1989, para 8.
[46] Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities, UNGA Res 56/119b, UN Doc A/C.3/56/L67/Rev.1 (2001).
[47] Arlene S Kanter, 'The Promise and Challenge of the Disability Convention' (2007) 34 Syracuse Journal of International Law and Commerce 287, 288; National Council on Disability, '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', 12 June 2002, 35–61 (available from the author).
[48] ibid.
[49] ibid 290.
[50] Optional Protocol to the Convention on the Rights of Persons with Disabilities (entered into force 3 May 2008) UN Doc A/RES/61/106, Annex II. The Optional Protocol has been signed by 90 countries of which 63 have ratified it, ibid. 'The 18-article Optional Protocol on Communications allows petitioning by individuals and groups to the Ad Hoc Committee, once all national recourse procedures had been exhausted' in order to seek redress for violations of rights under the Convention directly with the international monitoring body, as well as to allow the monitoring body to undertake inquiries in relevant countries: Press Release, General Assembly, 'General Assembly Adopts Groundbreaking Convention, Optional Protocol on Rights of Persons with Disabilities', UN Doc GA/10554, 13 December 2006.
[51] Kanter (n 47) 288–89.
[52] CRPD (n 4) art 1.
[53] See http://www.un.org/disabilities/countries.asp?navid=12&pid=166.

diagnosis of the individual with a disability, and more on the limitations of a society that categorises who is normal and who is not.[54] This human rights approach recognises the inherent equality of *all* people and not only accepts but also values people with disabilities for their differences and abilities. In order to accommodate human differences, it is the society, as opposed to the individual, that must change.[55] By rejecting the view that disability is solely a medical problem, the human rights approach transforms the needs of people with disabilities into rights they can claim and for which they can advocate.[56]

One such right that is central to the human rights approach to disability is the right to be free from discrimination.[57] Of course, discrimination can take many forms. For people with disabilities, discrimination can be overt and intentional. People with disabilities are all too often denied access to jobs, custody of their children, or access to education or services on that basis. But more often than not, discrimination against people with disabilities is less obvious, when it takes the form of fear, pity and patronisation. It is no less discrimination against a person with a disability when he or she is denied a job that an employer (incorrectly) thinks would be too difficult for that person as when an employer refuses to hire a person with a disability outright on that basis. It is also no less discrimination when the state condones inaccessible buildings and services. In such cases, simply banning discrimination on the grounds of disability is insufficient to achieve equality for people with disabilities. In order to fully protect people with disabilities from discrimination, affirmative steps are required. Changes in the physical environment, how services are delivered, how information is communicated, as well as changes in attitudes are necessary in order to protect the right of people with disabilities to be free from discrimination in all aspects of life. As such, the human rights approach to disability makes clear that people with disabilities are rights holders and entitled to the full range of civil and political, social, economic and cultural rights. Moreover, the limitations placed on people with disabilities by their social and physical environments are considered violations of their human rights.[58]

The CRPD is the first disability-specific international treaty and the first treaty to adopt the human rights approach to disability. Accordingly, it protects the right of people with disabilities to make their own decisions, including the right to decide where to live, what services to receive and where. The next section will address Article 19 of the CRPD, which includes a specific provision 'recognizing the equal right of all persons with disabilities to live in the community with choices equal to others'.

2.3 Article 19 and the Right to Live in the Community

Prior to the final adoption of the CRPD, the UN Ad Hoc Committee considered two official drafts of the Convention. The first draft, known as the Working Group Draft, included a proposed

[54] Kanter (n 2) 247.
[55] ibid.
[56] Kanter (n 2) 248.
[57] Kanter (n 47) 290.
[58] Kanter (n 2) 247; Kanter (n 47) 291.

Article 15 on the right of people with disabilities to live independently and to be included in the community. This draft article read:

> States Parties to this Convention shall take effective and appropriate measures to enable persons with disabilities to live independently and be fully included in the community, including by ensuring that:
>
> (a) persons with disabilities have the equal opportunity to choose their place of residence and living arrangements;
> (b) persons with disabilities are not obliged to live in an institution or in a particular living arrangement;
> (c) persons with disabilities have access to a range of … community support services …; and that community services for the general population are available on an equal basis to persons with disabilities and are responsive to their needs;
> (d) persons with disabilities have access to information about available support services.

This draft version of the article on community living appeared to protect the various rights relating to the right to live in the community – from the right to choose one's place of residence, to the prohibition on forcing a person to live in an institution or a particular living arrangement, to ensuring access to support services in the community. Noticeably absent from this list of rights, however, is the basic right of all persons with disabilities to live in the community.

The 'right to live in the community' is not the same as 'the right to choose one's place of residence'. Indeed, the right to live in the community generally is a negative (civil and political) right since, as a matter of law, the government is charged with prohibiting discrimination in housing. But the right to live in the community is also a positive (social, economic and cultural) right since the right to live in housing in the community requires the government to act and expend funds to effectuate the right for individual people.

Many people with disabilities throughout the world are given no choice about where they will live and with whom or, more fundamentally, whether they have the basic right to decide to live in the community and receive services there, as opposed to in institutions. Accordingly, this early version of Article 15 which guaranteed that 'persons with disabilities have the equal opportunity to choose their place of residence and living arrangements' was considered by disability activists and advocates, in the first instance, to be insufficient to protect the fundamental right to live in the community.

Representatives to the UN Ad Hoc Committee from Bizchut, the Israel Human Rights Center for People with Disabilities, the Israel Commission on the Equal Rights of People with Disabilities, the International Disability Caucus (IDC),[59] Inclusion International[60] and others took the lead in organising a lobby for the inclusion of the 'right to live in the community' in the CRPD. Following interventions by this coalition of groups, the final report of the Sixth

[59] The IDC consists of 35 international, regional and national organisations representing persons with disabilities from all regions of the world and from all groups of persons with disabilities: see http://www.disabilityworld.org/09-11_04/news/caucus.shtml.

[60] Inclusion International represents over 115 member federations in 200 countries on the issue of the rights and inclusion of people with developmental disabilities. It is one of the largest of the international disability NGOs and is one of the five disability-related organisations officially recognised by the UN: see http://www.cacl.ca/about-us/international.

Session of the Chair of the Ad Hoc Committee opened its summary of the article on living in the community with the following statement: 'The key to this draft article is the right of every person with a disability to live in the community'.[61] However, the 'right to live in the community' language still did not appear in the Convention itself. As a result, 'efforts to incorporate the exact language of the "right to live in the community" within the CRPD continued up to and during the final negotiation session, from which the final official draft emerged'.[62]

During the break between the Sixth and the Seventh Sessions of the Ad Hoc Committee meetings at the UN, the Chair of the Ad Hoc Committee, Ambassador Donald MacKay, returned to his home in New Zealand. At the suggestion of representatives from Bizchut and Inclusion International, Ambassador MacKay arranged to meet there with several people with disabilities and high support needs who were living in regular apartments in the community. The Ambassador had an opportunity to hear from them directly about their experiences and the importance, to them, of being able to choose where to live and with whom.[63]

At the Seventh Ad Hoc Session on 19–20 January 2006, the article on living in the community came up for its final reading before the Ad Hoc Committee. More than 25 different state delegations supported the right to live in the community, as proposed by the Israeli delegation.[64] These member states agreed that, given the high number of persons with disabilities who still live in institutions, it was not sufficient for the right to live in the community to remain implicit; rather, this right must be explicitly stated within an article of the CRPD.[65] The Chair of the Ad Hoc Committee referred the matter to informal meetings to resolve the final language of what became Article 19. He summarised the previous discussion on the 'right to live in the community' as follows:

- There was strong support for the text, although several important issues had been raised.
- An approach must be found that protects the freedom of choice of PWD [people with disabilities] while ensuring that existing cultural/religious practices and, in some cases, national laws are acknowledged and not undermined, as long as they are not discriminatory against PWD.
- Despite the support for Israel's proposal, which resolves some issues in the chapeau, retaining the concept of 'living independently' was important to many delegations. This phrase has been extensively discussed in the past and its presence in the text has been

[61] Report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, UN Doc A/60/266, 17 August 2005.
[62] Correspondence with Tirza Liebowitz, chief negotiator for Bizchut, 26 April 2010 (by email).
[63] ibid.
[64] Discussion at the Seventh Ad Hoc Session, pending issuing of new and last draft of the CRPD: 'Daily Summary of Discussion at the Seventh Session: UN Convention on the Human Rights of People with Disabilities Ad Hoc Committee – Daily Summaries', 20 January 2006, available at http://www.un.org/esa/socdev/enable/rights/ahc7sum20jan.htm.
[65] For the complete summary of the discussion of the community living article that took place during the Seventh Ad Hoc Meeting on 19–20 January 2006: 'UN Convention on the Rights of People with Disabilities Seventh Session on the Ad Hoc Committee', 19–20 January 2006, available at http://www.un.org/esa/socdev/enable/rights/ahc7summary.htm.

supported. Thus language should be found to retain this concept without allowing for its misuse such that PWD who cannot live independently are prevented from living in the community.

- There was a wide variety of views regarding the articulation of a specific 'right', with a strong view in favour of doing so, and there should be informal meetings to discuss this issue.[66]

Following this discussion, the revised draft article on community living emerged from the negotiations. It included the explicit right to live in the community for all people with disabilities. As such, the final version of Article 19, as adopted, reads as follows:

> Article 19
> *Living independently and being included in the community*
> States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:
> (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
> (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
> (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

With the adoption of Article 19 of the CRPD, the right of all people with disabilities to live in the community is now firmly enshrined in international law. This right extends to people throughout the world, regardless of their country of origin or the severity of their impairment. Yet, despite this accomplishment, the right to live in the community remains elusive for millions of people with disabilities throughout the world today.

One reason why the right to live in the community has not been realised for so many years is that, prior to the CRPD, the domestic disability laws (in those countries that had such laws) did not include a specific right to live in the community (as opposed to institutions).[67] Therefore, even with the CRPD, there is no infrastructure in many countries for the delivery of services in the community. Further, in those countries that have enacted domestic disability laws, some do not include a specific right to live in the community. On the other hand, in those countries that do have domestic disability laws which do include the right to live in the community, this right has not been adequately enforced. This situation may change, of course, as more countries draft new laws or amend their current laws to conform with the CRPD, and to

[66] ibid.
[67] Kanter (n 2).

Article 19 in particular.[68] Recent cases filed in regional human rights tribunals that are challenging institutionalisation may also result in greater enforcement of the right to live in the community in those countries subject to the jurisdiction of regional human rights courts.[69] As for the United States and Israel, both have comprehensive domestic disability laws. Indeed, Israel's law is based on the Americans with Disabilities Act, which was enacted in 1990 and had enormous effect worldwide in spurring the development of disability laws in other countries.[70] Both the US and Israel also have signed the CRPD, although as of the date of this writing, neither country has ratified it. Yet, despite the existence of domestic disability laws in the US and Israel as well as their commitment to the CRPD (evidenced by their signatures to the treaty), in both countries thousands of people with disabilities continue to live in institutions, deprived daily of the opportunity to live in their own homes in the community. In the following sections

[68] For example, Turkey has ratified the CRPD and the Optional Protocol and is working actively with non-governmental organisations and disabled peoples' organisations to implement the community living provision of the CRPD as well as other articles: Fatma Zengin Dagidir (n 13). Further, art 9 of Turkey's new Disability Law provides that 'care services can be presented in home care or institution care models. First of all it is essential that the service is provided without separating the person from his/her social and physical environment': Turkish Law on Disabled People and on Making Amendments in Some Laws and Decree Laws, Law No 5378. This law became effective on 7 July 2005, available at http://www.law.syr.edu/media/documents /2009/9/Turkish_Disability_Law.pdf.

[69] See e.g., *Purohit and Moore v The Gambia*, Communication no 241/2001, Sixteenth Activity report 2002–03, Annex VII (African Commission on Human and Peoples' Rights (ACHPR)). Here, the ACHPR found conditions in a Gambian mental hospital so inhumane as to violate the residents' rights under the African Charter. Although the ACHPR did not recognise a right to live in the community per se, it did state that exposing the mental hospital residents to 'personal suffering and indignity' violates the right to human dignity. The ACHPR also observed that 'mentally disabled persons would like to share the same hopes, dreams and goals and have the same rights to pursue those hopes, dreams and goals just like any other human beings. Like any other human being, mentally disabled persons or persons suffering from mental illnesses have a right to enjoy a decent life, as normal and full as possible, a right which lies at the heart of the right to human dignity. This right should be zealously guarded and forcefully protected by all states party to the African Charter in accordance with the well established principle that all human beings are born free and equal in dignity and rights': ibid, para 61.

See also *Malacu and Others v Romania* App No 55093/09, filed with the ECtHR on 11 December 2009. This case involves an institution in which, from 2002–03, 155 patients died, 28 of such deaths occurring during the first five months of 2004. The applicants are four women and a man who suffered from various mental health problems and spent long periods, in some cases their whole lives, in social care institutions, being subjected to poor care, inadequate treatment, as well as extremely substandard living conditions, including insufficient food and heating. According to the lawyers who filed the case, '[t]he case raises issues of access to justice for people with disabilities as well as shedding light on the failure of authorities to prevent the numerous abuses perpetrated against people with disabilities inside social care institutions and psychiatric hospitals. The [attorneys] hope that a positive decision from the Court will strengthen further the case against long-stay residential institutions and in favour of community living for people with disabilities'.

See also *Câmpeanu v Romania*, App no 47848/08, filed with the ECtHR on 23 April 2009, available at http://www.interights.org/campeanu. This case alleges negligence by a system that moved a young man with HIV and intellectual disabilities to an institution where he died seven days later, and which highlights the difficulties associated with the transitioning process from a social care home for children to, ideally, life in the community, as well as the widespread stigma attached to positive HIV status. See also *Varbanov v Bulgaria* ECHR 2000-X; *Aerts v Belgium* ECHR 1998-V; *Victor Rosario Congo v Ecuador* Case 11 427, Report no 63/99 Inter Am CHR OEA/Ser L/V/II 95 (1998). Although these are examples of negligence, or even abuse in institutions, they reflect the dangers inherent in institutionalising populations who are admitted ostensibly for treatment rather than allowing them to receive treatment in the community.

[70] See Kanter (n 2) 248–50.

of this article, I will discuss the right to live in the community under the laws of the US and Israel, respectively, and the challenges that lie ahead in implementing the CRPD's 'right to live in the community' in these countries and elsewhere.

3. THE RIGHT TO LIVE IN THE COMMUNITY UNDER UNITED STATES LAW

3.1 HISTORY OF THE RIGHT TO LIVE IN THE COMMUNITY IN THE UNITED STATES

The United States, like many countries, shares a despicable history of segregating people with disabilities, particularly those with mental disabilities, in large, remote institutions. In the US, the forced institutionalisation of persons with disabilities reached its peak in the first half of the twentieth century, when most, if not all, states passed laws that singled out people with disabilities for institutionalisation as part of the eugenics movement.[71] Such laws encouraged the institutionalisation of those who were considered 'a menace to society'.[72] Institutionalisation was seen as necessary to relieve society of the 'heavy economic and moral losses arising from the existence at large of these unfortunate persons'.[73] Some state legislation even authorised the removal of children with disabilities from their homes against their parents' wishes. The State of Washington, for example, made it a crime for a parent to refuse state-ordered institutionalisation.[74] Further, parents were also required to waive all custody rights once they placed their children in institutions.[75]

Following the horrors of the Second World War, US policy makers and advocates sought alternatives to institutionalisation and began to expand services for people with disabilities in

[71] For a comprehensive history of the treatment of people with mental disabilities in the US, see Justice Marshall's dissenting opinion in *Cleburne v Cleburne Living Center, Inc* 473 US 432 (1985) ('*Cleburne*'). See also Kanter (n 2) 243; Rosenthal and Kanter (n 22); Arlene S Kanter, 'A Home of One's Own: The Fair Housing Amendments Act of 1988 and Housing Discrimination Against People with Mental Disabilities' (1994) 43 American University Law Review 925; See also Samantha A DiPolito, '*Olmstead v LC* – Deinstitutionalization and Community Integration: An Awakening of the Nations' Conscience?' (2007) 58 Mercer Law Review 1381, 1382–88; Jefferson DE Smith and Steve P Callandrillo, 'Forward to Fundamental Alteration: Addressing ADA Title II Integration Lawsuits after *Olmstead v LC*' (2001) 24 Harvard Journal of Law & Public Policy 695, 703–05 (the harms of institutionalisation and benefits of community services); Mark C Weber, 'Home and Community-Based Services, *Olmstead*, and Positive Rights: A Preliminary Discussion' (2004) 39 Wake Forest Law Review 269, 273–77 (the history and nature of institutionalisation); Ferleger (n 24) 766–67, citing Jacobus tenBroek, 'The Right to Live in the World: The Disabled in the Law of Torts' (1966) 54 California Law Review 841 (perhaps the first article by a legal scholar to explore the question of living in the community for people with disabilities, but as a matter of tort law).

[72] *Cleburne* ibid, Marshall J dissent, fn 9, citing Anne Moore, *The Feeble-Minded in New York: A Report Prepared for the Public Education Association of New York* (United Charities Building 1911) 3. See also Peter L Tyor and Leland Bell, *Caring for the Retarded in America: A History* (Greenwood Press 1984) 71–104. The segregationist purpose of these laws was clear: see, for example, Act of 22 March 1915, Ch 90, 1915 Texas Gen Laws 143 (repealed 1955) (Act designed to relieve society of 'the heavy economic and moral losses arising from the existence at large of these unfortunate persons').

[73] ibid.

[74] *Cleburne* (n 71) Marshall J dissent.

[75] ibid.

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the community. Consequently, in 1954, the US Congress passed the country's first broad-based rehabilitation legislation, the Vocational Rehabilitation Amendments, which expanded community-based rehabilitation programmes for people with a range of disabilities.[76] Two decades later, in the midst of the Civil Rights Movement, Congress passed the Rehabilitation Act of 1973, which prohibits discrimination against people with disabilities in federal programmes (including state institutions and schemes that receive federal funding), as part of the larger movement to achieve community integration and inclusion of people with disabilities in society.[77] Moreover, in 1984, Congress passed the Developmental Disabilities Assistance and Bill of Rights Act, which requires states to guarantee to individuals with developmental disabilities the right to receive treatment in the setting least restrictive to the individual's personal liberty.[78] The Federal Fair Housing Law, which was amended in 1988, includes a prohibition on discrimination against people with disabilities in housing. But this law is limited to private housing and provides as its only enforcement mechanism the right of the complainant and/or the government to pursue legal action in court.[79]

The Social Security Act also supports community living by requiring states to develop written case plans to ensure the provision of services in appropriate settings that are the least restrictive to personal liberty.[80] Various state laws also have started to mandate that children and young persons with disabilities receive services in the 'least restrictive' environment. More recently, the new national initiative, 'Healthy People 2010,' although not legally binding, establishes specific goals and objectives regarding access to health care in the US, including as a national goal the reduction of 'the number of people with disabilities in congregate care facilities, consistent with permanency planning principles'.[81] With respect to children with disabilities, the goal is to

[76] The current Vocational Rehabilitation Act is codified at 29 USC §§ 701–796 (2001). The history of the Vocational Rehabilitation Act is detailed in S Rep No 318, 93rd Cong, 1st sess, reprinted in 1973 USCCAN 2076.
[77] 29 USC § 794 (1976 edn).
[78] On 30 October 2000, President Clinton signed into law the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (Public Law No 106-402), which reauthorises the law and created the Developmental Disabilities Councils (renamed the Councils on Developmental Disabilities), the Protection and Advocacy Systems, the University Affiliated Programs (renamed University Centers for Excellence in Developmental Disabilities Education, Research, and Service), and programmes of national significance. In addition, the legislation authorises separate grants for family support and a programme of direct support for workers who assist individuals with developmental disabilities: Bobby Silverstein, 'Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000', Maryland Developmental Disabilities Council, available at http://www.md-council.org/about/dd_act.html.
[79] See the Fair Housing Amendments Act, 42 USC § 3601 et seq; See also Kanter (n 71) 925, 943.
[80] 42 USC § 675(5)(A) (2007) ('Title Five'). The phrase the right to treatment 'in the least restrictive setting' originated from Dr Morton Birnbaum, who termed it a 'necessary and overdue development of our present concept of due process of law': Morton Birnbaum, 'The Right to Treatment' (1960) 46 American Bar Association Journal 499, 503. For the development of this right, see *Rouse v Cameron* 373 F2d 451, 455 (DC Cir 1966); 'Developments in the Law: Civil Commitment of the Mentally Ill' (1974) 87 Harvard Law Review 1190; Jack Drake, 'Enforcing the Right to Treatment: *Wyatt v Stickney*' (1972) 10 American Criminal Law Review 587; Stanley Herr, 'Civil Rights, Uncivil Asylums and the Retarded' (1974) 43 University of Cincinnati Law Review 679, cited in Ferleger (n 24) 766.
[81] Objective 6.7 in Healthy People 2010, Vol I, Ch 6, 'Disability and Secondary Conditions', Center for Disease Control and Prevention, available at http://healthypeople.gov/2020/default.aspx; discussed and cited in SA Larson and others, 'Children and Youth with Intellectual or Developmental Disabilities Living in Congregate Care

'[r]educe to zero the number of children aged 17 years and younger living in congregate care facilities'.[82]

The most significant US legislation regarding the rights of people with disabilities is the Americans with Disabilities Act (ADA), enacted in 1990 and amended in 2000 and 2008.[83] The ADA seeks to eradicate discrimination against people with disabilities in most aspects of life, including the segregation of people in institutions. By enacting the ADA, the US Congress explicitly found that 'individuals with disabilities continually encounter various forms of discrimination, including . . . segregation'.[84] The Congress also acknowledged that 'historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem'.[85] Upon introducing the ADA, Senator Harkin, for example, listed as one of the intended purposes of the legislation, getting people out of institutions.[86] As he stated:

> For too long, individuals with disabilities have been excluded, segregated, and otherwise denied equal, effective, and meaningful opportunity to participate in the economic and social mainstream of American life. It is time we eliminate these injustices.[87]

Unnecessary and unjustifiable institutionalisation was also specifically identified in congressional testimony by a number of other sponsors and supporters of the ADA, including then-Senator Lowell Weicker:

> For years, this country has maintained a public policy of protectionism toward people with disabilities. We have created monoliths of isolated care in institutions and in segregated educational settings. It is that isolation and segregation that has become the basis of the discrimination faced by many disabled people today. Separate is not equal. It was not for blacks; it is not for the disabled.[88]

Settings (1977–2009): Healthy People 2010 Objective 6.7b Outcomes' (2011) 49 Intellectual and Development Disabilities 209–13. Congregate care facilities are defined as settings in which four or more children or adults with disabilities live in order to receive needed support and services, regardless of whether they reside in the community, such as a school, group home, nursing facility or institution: ibid.

[82] ibid, Objective 6.7b.

[83] See Americans with Disabilities Act, 42 USC § 12132 (2006) and Americans with Disabilities Amendments Act of 2008, S3406, 110th Cong (2008) (as signed by the President on 25 September 2008).

[84] 42 USC § 12101(a)(5) and (1)(2).

[85] 42 USC § 12101(a)(2).

[86] Statement accompanying his introduction of the ADA Bill in the Senate, 135 Cong Rec 8505, 8508 (1989).

[87] 135 Cong Rec 19801 (1989) (Comments by Senator Harkin, D-Iowa).

[88] ADA: Hearing Before the Senate Committee on Labor and Human Resources and the Subcommittee on the Handicapped, 101st Cong, 1st Sess 215 (1989) (Comments by Senator Lowell Weiker, R-CT), as cited in Memorandum 01-05690 for *Williams v Wasserman*, 164 F Supp 2d 591 (2000), 11, available at http://www.justice.gov/crt/foia/readingroom/frequent_requests/ada_settlements/md/md3.txt; and ibid 12, citing also 135 Cong Record S4993 (daily edn 9 May 1989). Senator Kennedy also testified that the ADA 'will roll back the unthinking and unacceptable practices by which disabled Americans today are segregated, excluded, and fenced off from fair participation in our society by mindless biased attitudes and senseless physical barriers': 136 Cong Record H2447 (daily edn 17 May 1990) (Comments by Senator Kennedy, D-MA). Similarly, Republican George

Despite extensive reference to the continued segregation of people with disabilities in institutions during the drafting and negotiation process of the ADA, the Act itself does not prohibit institutionalisation per se, nor does it mandate community living for all people with disabilities. The closest the ADA comes to prohibiting institutionalisation is in Title II, which prohibits discrimination by state and local governments in the services they provide.[89] But neither Title II nor its implementing regulations require community living in all cases. As a result, even with the ADA, thousands of people with disabilities in the US continue to live in institutions or in community homes that function more like institutions than 'homes'.[90]

The regulations implementing Title II of the ADA, which were promulgated by the US Department of Justice (DoJ), require all public entities to 'administer services, programs, and

Miller stated, during a Congressional debate on the Bill, that American society made disabled people 'invisible by shutting them away in segregated facilities': ibid.

[89] Title II of the ADA states 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 subjected to discrimination by any such entity': 42 USC § 12132 (2001).

[90] Data on the number of people with disabilities in institutions varies between states and is difficult to ascertain on a nationwide basis. The most comprehensive research (on people with intellectual disabilities) is undertaken on an annual basis at the University of Minnesota's Research and Training Center: Charlie Lakin, Sheryl A Larson and Shannon Kim, 'Behavioral Outcomes of Deinstitutionalization for People with Intellectual and/or Developmental Disabilities: Third Decennial Review of US Studies, 1977–2010', April 2011, available at http://ici.umn.edu/products/prb/212/default.html.

In another study, carried out in 2002, the US Census found 69,136 nursing facilities and 28,448 mental retardation, mental health and substance abuse facilities in the US: 'Nursing and Residential Care Facilities: 2002', August 2004; available at http://www.census.gov/prod/ec02/ec0262i03.pdf. As of 30 June 2008, 42 states operated 2,614 residential settings housing people with intellectual or developmental disabilities and 1.8 million people live in nursing facilities: US Census Bureau, 'Characteristics of the Group Quarters Population by Group Quarters Type', Data Set: 2006–08 American Community Survey 3-Year Estimates Survey: American Community Survey, available at http://factfinder.census.gov/servlet/STTable?-geo_id=01000US&-qr_name=ACS_2008_3YR_G00_S2601B&-ds_name=ACS_2008_3YR_G00_. With respect to mental health facilities, there were 62,200 state and county mental hospital inpatient beds and 63,000 private inpatient beds reported in the 2010 US Census: 'Mental Health Facilities – Summary by Type of Facility', available at http://www.allcountries.org/uscensus/210_mental_health_facilities_summary_by_type.html. In addition, 35,741 people lived in large state intellectual or developmental disabilities institutions as of 2008: see K Charlie Lakin and others, 'Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2008', Research and Training Center on Community Living, Institute on Community Integration, College of Education and Human Development, University of Minnesota, 2009, 3, 6, available at http://rtc.umn.edu/risp08. According to a comprehensive study by Charlie Lakin and others at the Research and Training Center on Community Living's Institute on Community Integration of the University of Minnesota, there were an estimated 4,132,878 people in the US with mental retardation or developmental disabilities in 1995: Sheryl Larson and others, 'Prevalence of Mental Retardation and/or Developmental Disabilities: An Analysis of the 1994–95 NHIS-D', Research and Training Center on Community Living, Institute on Community Integration, College of Education and Human Development, University of Minnesota, 2000, 1, 8, available at http://rtc.umn.edu/docs/dddb2-1.pdf. Of those, about 49,105 people were in public institutions in 1995: see K Charlie Lakin and others, 'Marking the 10th Anniversary of *Olmstead*: Has it Made a Difference for People with Developmental Disabilities' (2009) 47(5) Intellectual and Developmental Disabilities 403, 406. By 30 June 2008, the number had dropped to 35,741 people: Lakin and others, ibid. But overall there has been a decrease. From 30 June 1999 to 30 June 2008, public institution populations decreased by about 14,100 people, or 28.6%, and private institution populations decreased by about 10,400 people, or 30.5%: ibid. Further, from 1990 to 2008, the number of individuals in public mental retardation institutions fell by 66% from 84,239 to 35,051: ibid.

activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities'.[91] This 'integration mandate', as it has become known, also requires all public entities to 'make reasonable modifications in policies, practices, or procedures … unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the services, program or activity'.[92]

In addition to these statutory mandates, several courts, including the US Supreme Court, have found a constitutional and statutory basis to question the continued use of institutionalisation, especially when community options were available. As early as 1972, the Supreme Court invalidated an Indiana law on constitutional grounds.[93] The law permitted the state to confine indefinitely 'a mentally deficient deaf mute' man who had been adjudged incompetent prior to going to trial. As the Supreme Court wrote in *Jackson v Indiana*, '[a]t the least, due process requires that the nature and duration of commitment bear some reasonable relation to the purpose for which the individual is committed'.[94]

In 1975, the US Supreme Court went one step further and held, in *O'Connor v Donaldson*, that 'a state cannot constitutionally confine without more a non-dangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends'.[95] Although the Court did not define what it meant by 'without more', this decision has been interpreted to mean that a person cannot be confined in an institution against his will without receiving treatment as a quid pro quo for confinement. Following *O'Connor v Donaldson*, other federal courts have applied this quid pro quo rationale to cases involving the involuntary confinement of people with cognitive disabilities as well.[96]

In 1978, the federal district court in Pennsylvania issued a groundbreaking decision in *Halderman v Pennhurst State School and Hospital* ('*Pennhurst*').[97] In this case, the court held that the United States Constitution not only prohibits states from institutionalising people with mental disabilities but also requires states to provide community services for them.[98] Drawing on the 14th Amendment requirements of due process and equal protection, the *Pennhurst* court observed that

> [i]nstitutions, by their very structure are a closed and segregated society founded on obsolete custodial models[, that] can rarely normalize and habilitate the mentally retarded citizen to the extent of

[91] 28 CFR § 35.130(d) (2001).
[92] 28 CFR § 35.130(b)(7) (2001).
[93] *Jackson v Indiana* 406 US 715 (1972).
[94] ibid 738.
[95] *O'Connor v Donaldson* 422 US 563, 576 (1975).
[96] Ferleger (n 24) 783.
[97] 446 F Supp 1295 (1977), 451 US 1 (1981) and 465 US 89 (1984).
[98] After a 32-day trial, [the district court] issued an opinion, reported at 446 F Supp 1295 (1977) ibid, making findings of fact and conclusions of law with respect to the conditions at Pennhurst. Its findings of fact are undisputed: 'Conditions at Pennhurst are not only dangerous, with the residents often physically abused or drugged by staff members, but also inadequate for the "habilitation" of the retarded. Indeed, the court found that the physical, intellectual, and emotional skills of some residents have deteriorated at Pennhurst': *Pennhurst*, ibid 1308–10.

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> community programs created and modeled upon the normalization and developmental approach components of habilitation.[99]

As one of the lawyers who brought the *Pennhurst* case wrote recently,

> [t]he commitment to alternatives to institutions, premised on constitutional rights, espoused in *Pennhurst*, was the groundwork for much other litigation, became support for various states' policies, and a rallying point for institutional residents, professionals in the field, and advocates.[100]

Although the district court decision in *Pennhurst* was appealed, more than once, including to the US Supreme Court, it has never been reversed.[101] However, it was not until more than two decades later, in 1999, when the US Supreme Court, for the first time, addressed specifically the right of people with disabilities to live in the community.[102] In *Olmstead*[103] Justice Ginsberg framed the issue in the case as 'whether the [ADA's] proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions'.[104] According to the Supreme Court, the answer to this question was a resounding but qualified 'yes'. Accordingly, the Supreme Court in *Olmstead* came as close as has any court in the US to declaring a right of all people with disabilities to live in the community as opposed to institutions. However, the Court stopped short of declaring an absolute right to live in the community. Moreover, unlike *Pennhurst*, which was decided on constitutional grounds, *Olmstead* was decided on statutory grounds.

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[99] ibid 1308–10.

[100] Ferleger (n 24) 765.

[101] ibid. As Ferleger, one of the lawyers who brought *Pennhurst*, wrote recently: 'Indeed, while the 1978 district court precipitated decision resulted in two Supreme Court decisions on other grounds, and a myriad of rulings on related issues, the constitutional holdings were not questioned on appeal or certiorari': ibid 764–65; for example, *Halderman v Pennhurst State School and Hospital* 465 US 89 (1984); *Pennhurst State School and Hospital v Halderman* 451 US 1 (1981); 49 F 3d 939 (3rd Cir 1995); 901 F 2d 311 (3rd Cir 1990); 707 F2d 702 (3rd Cir 1983); 673 F 2d 645 (3rd Cir 1982) (on remand); 673 F 2d 628 (3rd Cir 1982); 673 F 2d 647 (3rd Cir 1982); 612 F 2d 84 (3rd Cir 1979); 612 F 2d 84 (3rd Cir 1979) (affirmed in part and reversed in part); 612 F 2d 131 (3rd Cir 1979); 446 F Supp 1295 (ED Pa 1977) (original trial court decision).

[102] Prior to the Supreme Court's decision in *Olmstead*, the Third Circuit had decided the scope of the integration mandate under Title II in *Helen L v DiDario* 46 F 3d 325, 330–33 (3rd Cir) certiorari denied, 516 US 813 (1995). The Court in *Helen L* wrote that 'the ADA and its attendant regulations clearly define unnecessary segregation as a form of illegal discrimination against the disabled': ibid 333. The Court then reversed the district court and entered summary judgment in favour of the appellant. According to the Third Circuit, the Pennsylvania Department of Public Welfare violated the ADA by requiring the appellant to remain in the segregated setting of a nursing home instead of providing her with required home-based services. Relying on the 'integration mandate' of the Title II regulations, the unanimous three-judge Court of Appeals panel emphasised that 'the ADA is intended to insure that qualified individuals receive services in a manner consistent with basic human dignity rather than a manner which shunts them aside, hides, and ignores them'.

[103] *Olmstead* (n 15) 581.

[104] ibid 581.

3.2 THE SUPREME COURT'S DECISION IN *OLMSTEAD V LC AND EW*

In *Olmstead*, the US Supreme Court ruled that the State of Georgia's Department of Human Resources could not segregate two women with mental disabilities in a state psychiatric hospital long after the state's own treatment professionals had recommended their transfer into community care.[105] The lower courts had ruled that the state had violated the 'integration mandate' of Title II of the ADA, and Georgia appealed.[106] According to the Court, the continued institutionalisation of people with disabilities who are capable of living in the community, with or without services, may constitute illegal discrimination.[107]

The plaintiffs in this case were LC, aged 31, and EW, aged 47, both of whom had been hospitalised repeatedly over two decades. They brought the case in order to receive treatment in the community rather than in the state psychiatric institution.[108] LC sued, originally on her own, claiming that the State of Georgia had violated her right to be free from discrimination in the receipt of services provided by the state, as guaranteed under Title II of the ADA. Soon after her case was filed, another patient in the state institution, EW, intervened to join in the case with the same legal claim.[109] The State of Georgia argued that it was not discriminating against these women but that it lacked funds to provide services to them in the community rather than in the institution. The state also argued that granting the women's claims would 'fundamentally alter' its entire mental health system by requiring the closing of all state hospitals.[110]

The district court rejected Georgia's claims. It held that the state's actions violated Title II of the ADA by segregating both women in an institution rather than placing them in an integrated setting under the state's community-based services programme. On appeal, the Eleventh Circuit Court of Appeals affirmed the decision of the district court and remanded the case to determine whether the alleged additional expense to Georgia for community placement would 'fundamentally alter' the state's mental health system.[111] On remand, the district court found that the cost of providing placement in the community for these two women would not be excessive in relation to the State of Georgia's overall mental health budget.[112]

The US Supreme Court granted certiorari. In the Supreme Court, the two women were supported by a number of states and disability organisations as well as the US Solicitor General. In a 6:3 ruling, the Supreme Court rejected the State of Georgia's claims and affirmed the right of the women to receive care in the 'most integrated' setting appropriate. The Court held that the 'unjustified segregation of people in institutions, when community placement is appropriate, constitutes

[105] ibid 581.
[106] ibid.
[107] ibid.
[108] ibid 594.
[109] ibid.
[110] ibid.
[111] *LC by Zimring v Olmstead* 138 F 3d 893 (11th Cir 1998), affirmed in part, vacated in part, and remanded.
[112] ibid.

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a form of discrimination prohibited by Title II [of the ADA]'.[113] The court clearly recognised the connection between institutionalisation and discrimination when it wrote that

> [t]o receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.[114]

Not only was the denial of services in the community illegal under the ADA, but the negative effects of institutionalisation were evident, as the court wrote:

> Recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgments. 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 … Second, 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. Dissimilar treatment correspondingly exists in this key respect: in order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.[115]

As a result of the Court's holding in *Olmstead*, states are now required to place persons with mental disabilities in community settings rather than in institutions 'when the state's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities'.[116] Although the Court indicated that states should make 'reasonable accommodations' to their long-term care systems, it also stated that states are not required to make 'fundamental alterations' to their mental health systems.[117]

According to the Supreme Court, both the district and appellate courts had applied the wrong standard regarding the state's fundamental alteration defence. The Court found that the district court had erred when it compared the costs of treatment in the community with the costs of institutional care because such a comparison does not account for the costs associated with the state's continuing operation of institutions for those who do not satisfy the

[113] *Olmstead* (n 15) 600.
[114] ibid 601.
[115] ibid 600–01 (citing Brief for the American Psychiatric Association and the National Alliance for the Mentally Ill as Amici Curiae Supporting Respondents).
[116] ibid.
[117] ibid.

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Olmstead test for community placement.[118] Likewise, the Supreme Court thought the Court of Appeals erred by comparing the cost of providing care to the plaintiffs in the community with the state's entire mental health budget because such a comparison would necessarily result in a decision in favour of community care for certain individuals.[119] In rejecting these two methods, the Supreme Court set forth its own standard for applying the fundamental alteration defence, as follows:

> In evaluating a state's fundamental alteration defense, the District Court must consider, in view of the resources available to the state, not only the cost of providing community-based care to the litigants, but also the range of services the state provides to others with mental disabilities, and the state's obligation to mete out those services equitably.[120]

The Court suggested, therefore, that a state could prevail in establishing a fundamental alteration defence by demonstrating that it has a 'comprehensive, effectively working plan for placing qualified individuals in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the state's endeavours to keep its institutions fully populated'.[121] The question of what constitutes a fundamental alteration in a given case, however, will continue to be debated in states throughout the US that are seeking to increase community-based care for people with mental disabilities, as discussed in the next section of this article.

3.3 POST-*OLMSTEAD* CASES UPHOLDING THE RIGHT TO LIVE IN THE COMMUNITY

An analysis of US court decisions following *Olmstead* sheds light on the scope and potential impact of the *Olmstead* decision on the development of community alternatives to institutional care in the United States and perhaps elsewhere. In most such cases, lower courts have decided that 'evidence of active engagement and slow progress' by a state towards more community-integrated long-term care satisfies the ADA mandate.[122] Moreover, a 2009 report found that in the decade following the *Olmstead* decision, the federal government had provided no oversight of *Olmstead* enforcement efforts and that states had incurred no penalties for failing to make reasonable efforts to end unnecessary institutionalisation. The result of this inaction, the Report concludes, is that in the ten years following the *Olmstead* decision, little progress had been made in reducing the numbers of people with disabilities, nationwide, who live in institutions.[123]

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[118] ibid 604, fn 15.
[119] ibid 603–04.
[120] ibid 597.
[121] ibid 605–06.
[122] Sara Rosenbaum and Joel Teitelbaum, 'Olmstead at Five: Assessing the Impact', Kaiser Commission on Medicaid and the Uninsured, 2004, 1, 10, available at http://www.kff.org/medicaid/7105a.cfm.
[123] 'A Decade of Little Progress Implementing Olmstead: Evaluating Federal Agency Impact after 10 Years', Disability Rights Network, 30 September 2009, 3, 4 and 22, available at http://www.napas.org/images/Documents/Issues/Community_integration/NDRN_Decade_of_Little_Progress_Implementing_Olmstead.pdf.

That situation has begun to change, however. A recent decision by a federal district court in New York and efforts by the US Justice Department have signalled greater enforcement of the *Olmstead* decision throughout the US. The most significant decision in defining the potential impact of *Olmstead* is *Disability Advocates, Inc v Paterson* ('*DAI v Paterson*'), which was decided in 2009 by the Eastern District Court of New York but reversed by the Court of Appeals for the Second Circuit on the grounds of standing.[124]

In a 130-page decision, the Eastern District Court held in *DAI v Paterson* that New York State had denied thousands of individuals with mental illness in New York City the opportunity to receive services in the most integrated setting appropriate to their needs by placing them in adult care homes, which were referred to as 'community living programs' but which functioned like institutions.[125] The court found that the State of New York had failed to comply with the *Olmstead* decision and the ADA's integration mandate.[126] Accordingly, the district court ordered the State of New York to provide services to the plaintiffs 'in the most integrated setting appropriate to their needs, enabling them to interact with people who aren't disabled as much as possible'.[127] The district court was persuaded that the plaintiffs would be better served by living in supported housing, with mental health workers giving them the services they need when they need them, and at no greater expense to the state.[128]

The district court in *DAI v Paterson* carefully examined the parties' positions to determine, for itself, whether the community settings at issue satisfied the integration mandate of the ADA. In so doing, the court found that, although the State of New York called the homes at issue 'community placements', they 'gave the appearance of institutions', and were designed, just as institutions are, to accommodate large groups of people spending most of their time there.[129] As the experts testified, these so-called homes clearly resembled institutions because (1) all of the residents were people with disabilities; (2) the residents had to line up for meals and medication; (3) the residents received treatment by doctors and nurses on site rather than going to local health clinics; (4) the residents were assigned room-mates and could not choose their own; (5) the residents received calls through a main switchboard; (6) the rules of the home required visitors to sign in, and prohibited residents from having visitors in their rooms, except with permission; (7) most places also prohibited overnight guests or guests at meal time, and (8) the doors to these facilities were locked at night.[130] Such characteristics occur in institutions and not in one's own home.

[124] *Disability Advocates, Inc v Paterson* 653 F Supp 2d 184 (EDNY 2009) (Memorandum Order of Findings of Fact and Conclusions of Law); for media coverage of this case, see James Baron, 'State Discriminated Against Mentally Ill, Judge Rules', New York Times, 9 September 2009, A 24. Decided on appeal as *Disability Advocates, Inc v New York Coalition for Quality Assisted Living, Inc and Cuomo*, Docket Nos 10-235(L), 10-251(CON), 10-767(CON), 10-1190(CON) (2d Cir, 6 April 2012).
[125] *DAI v Paterson* (ibid) 187.
[126] ibid.
[127] ibid 208.
[128] ibid 219. See also the Court's Remedial Order and Judgment, 1 March 2010.
[129] *DAI v Paterson* (n 124) 199.
[130] ibid 199–202.

In reaching its decision, the district court found instructive the testimony of experts who contrasted the community placements at issue in this case with more homelike settings, such as supported housing, which provide permanent homes in buildings scattered throughout the city's regular housing stock. The court also found persuasive the expert testimony that the days of the 'linear continuum' (when people are moved from more to less restrictive residential settings) are gone in the United States, at least.[131] The State of New York had argued that some people choose to live in institutions and institution-like settings in the community, and that the state should not have to force people out of institutions if that is where they choose to live. The district court rejected the state's argument. According to the court, 'if provided with information about the nature of supported housing along with the programmatic and financial supports that would be available, the great majority of adult home residents will very likely choose to move to integrated settings'.[132] In fact, the court added 'as numerous witnesses testified … having a stable, safe, and permanent place to call home is a universal desire', and people with disabilities are no different from anyone else in this regard.[133]

In the subsequent remedial order on 1 March 2010, the district court ruled that

> in order to rectify the violations found by the court, [state officials] must change the way they manage their mental health system so that [adult home residents] have a choice – a real and meaningful choice – to receive the services to which they are entitled in supported housing instead of an adult home.[134]

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[131] One of the experts, Ms Rosenberg, testified that by 2004 the linear continuum 'was really being abandoned by both New York and most places'. According to Ms Rosenberg: '[t]he whole issue of a continuum is also an old idea. It used to be thought that people had to move from … large congregate settings to smaller congregate settings, to having a few roommates to eventually graduating to their own apartment. Nobody really thinks that much anymore. First of all, it would be like asking me to move every few months or every year or so just because I have to. So, it's quite disruptive, and also there is no evidence to show that people do better in the long run with you going through the continuum and, in fact, [people] could be placed directly in their own apartments with the right supports [and] can be quite successful': ibid 252. Dr Duckworth testified that 'the idea that people need to go through transitional housing, another move, another step, I think has been debunked pretty definitively in our field'. Ms Jones testified that the continuum approach is 'outdated', and the accepted approach in the states where she has worked is to provide individuals with permanent housing and add or subtract supports based on their specific needs. Mr Jones testified that the continuum model is 'archaic' and that New York's views on it have 'changed pretty significantly' in the last five to ten years: ibid 253 (citations to trial transcript omitted).

[132] ibid 263 (quoting testimony of expert Ms Jones).

[133] ibid 267–68. In fact, the district court noted that studies conducted by New York State itself revealed that '[p]eople who reported the most satisfaction with their housing choices also reported significantly higher overall quality of life': ibid 263, quoting OMH, Progress Report on New York State's Public Mental Health System, January 2001, 20.

[134] *Disability Advocates, Inc v Paterson*, Memorandum and Order, 03-CV-3209, 1 March 2010, 11. See also *Disability Advocates, Inc v Paterson Remedial Order and Judgment*. Accordingly the state must: (1) provide all qualified adult home residents the chance to move to supported housing within four years and ensure that appropriate services are in place that will support [residents'] success as tenants and their integration into the community; (2) create at least 1,500 supported housing units per year for three years, and create additional units as necessary after, to accommodate all current adult home residents and future individuals with mental illnesses being considered for adult home placement who would prefer to live in supported housing; (3) contract with supported housing providers to engage and educate adult home residents about their opportunities to live in their own housing with support services rather than in large, institutional adult homes. This education is necessary to overcome the fear and self-doubt that have been instilled in many residents during years of living in adult homes with no other options; (4) employ individuals in recovery from mental illnesses who are trained to assist others making

Had the Court of Appeals for the Second Circuit not dismissed the case on appeal, the State of New York would have been required to find individual or shared apartments or homes for the more than 4,300 mentally ill people (who are not considered dangerous to themselves or others) who want them.[135] However, on 6 April 2012, the Court of Appeals for the Second Circuit dismissed the case. The Second Circuit found that the DAI plaintiffs lacked associational standing required by Article III of the US Constitution. By so doing, the Court has vacated the district court decision and, in effect, sent the plaintiffs back to court, this time with individuals as named plaintiffs.[136]

Both before and since the dismissal of *DAI v Paterson*, the US Department of Justice (DoJ) has launched an aggressive effort to enforce *Olmstead*. In 2009, the DoJ reached a settlement with the State of Texas regarding conditions in the state's 13 facilities. The DoJ has also filed amicus briefs in *Olmstead*-type cases in Connecticut,[137] Virginia,[138] North Carolina,[139]

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the transition to assist current and future adult home residents wishing to move; and (5) undergo the oversight of a court monitor to ensure the obligations are met. See http://www.bazelon.org/News-Publications/Press-Releases/3-1-10DAI.aspx.

[135] *DAI v Paterson* (n 124) 187.

[136] *Disability Advocates, Inc v New York Coalition for Quality Assisted Living, Inc* (n 124). The US Ninth Circuit Court of Appeals decided a similar case and rejected the State of Washington's claim that the state's system of deciding who is eligible for community services was reasonable and concluded that 'policy choices that isolate the disabled cannot be upheld solely because offering integrated services would change the segregated way in which existing services are provided': *Townsend v Quasim* 328 F 3d 511, 519 (9th Cir 2003). See also *Fisher v Oklahoma Health Care Authority* 335 F 3d 1175 (10th Cir 2003); *Ball v Rogers*, No 00-67 2009 WL 13954235 (24 April 2009); *Pennsylvania Protection and Advocacy, Inc v Pennsylvania Department of Public Welfare* 402 F 3d 374 (3rd Cir 2005); and *Crabtree v Goetz*, No 08-0939, 2008 WL 5330506 25, 19 December 2008.

[137] *State of Connecticut Office of Protection and Advocacy for Persons with Disabilities v State of Connecticut* 706 F Supp 2d 266 (2010). The DoJ filed an amicus curiae brief in support of the plaintiffs and opposing a pending motion to dismiss the lawsuit. The case challenges the state's lack of community placements for persons with disabilities who are housed in large, private nursing homes: available at http://www.justice.gov/opa/pr/2010/May/10-crt-612.html.

[138] On 24 November 2009 the DoJ filed an amicus curiae brief in the federal district court in Richmond, Virginia, in *ARC of Virginia v Timothy Kaine* 2009 WL 4884533 (EDVa), 40 NDLR P 80. The brief opposes Virginia's motion to dismiss a case that challenges the state's decision to spend millions of dollars to construct a new, large, segregated facility for persons with intellectual disabilities who could be better served in the community in supported housing. On 24 November 2009, the Department also filed a brief in support of the plaintiff's proposed remedy in *DAI v Paterson and Others*, a case in which, as discussed above, the court had already ruled that placement of persons with mental disabilities in 'large adult homes' violates the Supreme Court decision in *Olmstead*: see http://www.justice.gov/opa/pr/2010/May/10-crt-612.html.

[139] The US DoJ has filed supporting documents in several post-Olmstead cases. In *Marlo M v Cansler*, it filed an amicus curiae brief in support of the plaintiff's motion for a preliminary injunction in a case alleging that the State of North Carolina's cuts in state supplemental funding put her at risk of institutionalisation in violation of *Olmstead*: *Marlo M v Cansler* No 5:09-CV-535, 2010 WL 148849 (ED NC 17 January 2010). In *Clinton L and Others v Cansler*, the DoJ filed a statement of interest in a case alleging that the State of North Carolina's decision to reduce reimbursement rates to plaintiffs with disabilities who are now living in the community will have the effect of eliminating medically necessary services that support them in their homes in the community, thereby placing them at risk of institutionalisation in violation of *Olmstead*, available at http://www.ada.gov/briefs/interest_clinton_br.pdf.

Illinois,[140] Florida,[141] and New Jersey.[142] All of these cases seek to ensure that people with physical, psychiatric and developmental disabilities can leave institutional settings in order to live in supported housing, to receive services in their own homes, and to ensure the right of people with disabilities who are now living at home to remain there.[143]

Further, in January 2010, the US Justice Department (DoJ) filed a case against the State of Georgia in respect of its continuing reliance on the seven state institutions rather than developing community alternatives for people with developmental disabilities and for people with a diagnosis of mental illness.[144] Similarly, in May 2010, the DoJ sued the State of Arkansas for its 'systemic failure' in placing people with disabilities in institutions rather than pursuing less restrictive avenues for their care. According to the complaint, the State of Arkansas 'gives individuals with developmental disabilities the draconian choice of receiving services in segregated institutions or receiving no services at all'.[145] These cases are still pending.

More recently, on 6 July 2011, the US DoJ entered into an agreement with the State of Delaware that will guarantee housing in the community rather than in institutions for people with disabilities, thereby transforming the state's mental health system in order to comply with the decision in *Olmstead*.[146]

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[140] The lawsuit in Illinois alleges that the State of Illinois relies on facilities instead of offering services in community-based settings, in violation of *Olmstead*: see http://www.justice.gov/opa/pr/2010/May/10-crt-612.html.

[141] In Florida, the DoJ filed a statement of interest to support a plaintiff's lawsuit alleging that Florida failed to provide community-based services to a Medicaid-eligible individual with a spinal cord injury who is at risk of institutionalisation and who is required to relinquish her right to live in the community prior to receipt of needed services in a nursing home: see http://www.justice.gov/opa/pr/2010/May/10-crt-612.html. In June 2010, the district court in Jacksonville ruled that the State of Florida must provide the plaintiff with services that will allow her to remain in her home: see http://blogs.usdoj.gov/blog/archives/892. See also *Long v Benson* 2008 WL 4571903 (ND Fla) 14 October 2008.

[142] In New Jersey, the US DoJ filed a brief as amicus curiae, to support a motion by New Jersey residents with disabilities for summary judgment alleging that the State of New Jersey fails to serve individuals with disabilities in the most integrated setting appropriate to their needs in violation of *Olmstead*: see http://www.justice.gov/opa/pr/2010/May/10-crt-612.html.

[143] Other recent post-*Olmstead* cases in which the US DoJ has been involved in varying degrees include *Townsend v Quasim* (n 136); *Fisher v Oklahoma Health Care Authority* (n 136); *Pennsylvania Protection and Advocacy, Inc v Pennsylvania Dept of Public Welfare*, 402 F 3d 374 (3rd Cir 2005); and *Crabtree v Goetz* (n 136). See http://www.ada.gov/olmstead.

[144] See http://www.justice.gov/opa/pr/2010/October/10-crt-1165.html.

[145] The DoJ complaint applies to people who are in institutions, have been discharged from institutions or are at risk of institutionalisation. It alleges that '[t]he state has not given many residents, and/or their family/guardian, the opportunity to make an informed objection to receiving services in a setting less restrictive than the institution'. In terms of the state's failure to transition persons to the most integrated setting appropriate to meet their needs, the complaint alleges that '[m]ost residents do not proactively request a more integrated setting because the state does not properly educate residents on what community resources are available, or the possible benefits of community placements … The state does not adequately assess whether residents could be served in a more integrated setting appropriate to their needs … [and] the state does not properly educate staff at the institution on how to appropriately assess a resident for community placement … Institution staff typically tailor an assessment of a resident's appropriateness for community placement based upon their limited understanding of what community resources are available (or not available), rather than specifically what supports and services a resident needs in order to be adequately supported in the community': US Department of Justice, Office of Public Affairs, Press Release, 'Justice Department Obtains Comprehensive Agreement Regarding the State of Delaware's Mental Health System', 6 July 2011, available at http://www.justice.gov/opa/pr/2011/July/11-crt-881.html.

[146] US Department, Office of Public Affairs, Press Release, ibid.

Thus in the United States, the right to live in the community is neither absolute nor automatic, even with the passage of the ADA and the Supreme Court's decision in *Olmstead*. The Justice Department has had to sue or intervene in ongoing cases in order to require states to fulfil their legal obligations to provide services in the 'most integrated' setting, as required by the ADA and *Olmstead*. In the meantime, many people with disabilities throughout the US remain segregated in institutions, often even after the state's own professionals have determined that they are eligible and able to live in the community, with or without support services. However, the ADA has provided the legal basis for courts to examine carefully the right of all people with disabilities to live in the community rather than in institutions, unlike the situation in Israel, as discussed in the following section.

4. The Right to Live in the Community Under Israeli Law

4.1 The Israeli Equal Rights Law for People with Disabilities

The Israeli Equal Rights Law for People with Disabilities ('Equal Rights Law') is one of the most comprehensive disability anti-discrimination laws in the world today. It is modelled on the ADA and similar laws in Australia, Sweden and Canada. The law recognises, for the first time in Israeli law, that people with disabilities are a minority group who suffer from discrimination, segregation and mistreatment on the basis of disability.[147] However, because of opposition by the Minister of Finance at the time it was introduced, the Knesset Committee referred only five sections of the proposed law to the Knesset for approval.[148] These five sections were eventually adopted into law and include the general principles as well as a prohibition on discrimination in employment, accessibility of new and existing buildings and services, and transportation. To its credit, the law also creates the Commission for Equal Rights of Persons with Disabilities, which is one of only a handful of such Commissions in the world. The Commission is charged with implementing and promoting the law, preventing discrimination against people with disabilities, encouraging the integration and active

[147] Equal Rights Law (n 16).

[148] After several years in a legislative committee, the proposed Equal Rights of Persons with Disabilities Law passed its first reading in the Knesset in March 1996. Following the first reading, the Minister of Justice and the Minister of Labor and Social Affairs appointed a Commission on Comprehensive Legislation Concerning the Rights of People with Disabilities. This Commission (known as the Katz Commission, for its chair, the former Minister of Labor and Social Affairs, Dr Israel Katz) called for the enactment of a comprehensive and detailed law to 'narrow the existing gap between the reality of life for persons with disabilities and the principles of equality and human dignity, which are among the basic principles of Israeli society': see 'Report of the Public Commission on Comprehensive Legislation concerning the Rights of Persons with Disabilities', 19 July 1997. This Report provided the support and context for the passage of the new Israeli Equal Rights Law. On 23 February 1998, five of the ten sections of the draft law passed their final readings and became what is now known as the Equal Rights for People with Disabilities Act of 1998. These sections include the Basic Principles, General Principles, Employment, Public Transportation, and the creation of the Commission for Equal Rights of Persons with Disabilities. After years of debate, an amendment to the law covering access to public buildings and services passed the Knesset in March 2005.

participation of people with disabilities in society, and fulfilling the functions vested in it by law.[149] At the time of this writing, the regulations to enforce portions of the law are under consideration by the Knesset.

The proposed section on living in the community in the original version of the Equal Rights Law affirmed the right of all persons with disabilities to live in the community. It also guaranteed persons with disabilities personal assistance to promote independence and full participation in the community, including assistance with personal care, everyday activities and household tasks, as well as translation and interpreter services. The Explanatory Memorandum accompanying the law includes a discussion of the community living section and is unequivocal in its interpretation of what equality and dignity mean to people with disabilities living in the community. As the Memorandum states:

> The right to live in the community is an overarching right among the array of rights of people with disabilities. It is a test of the degree to which the aspirations of Israeli society to be considered a democratic society are met; a society in which human rights and dignity are guiding principles. The question whether an individual lives among people or is removed from society to distant and crowded frameworks only on account of his disability is a litmus test for the principle of equality. Social perceptions in the past brought about the exclusion of people with disabilities from society. Today there is wide consensus, in the world as well as within Israel, that these perceptions have no room in enlightened society, guided by the principle of human dignity. Since the 1960s, the professional, legal and moral recognition in democratic countries, of the right of people with disabilities to live within the community, is gaining ground. Leading professionals in Israel and worldwide have determined that the quality of life of people with the whole range of disabilities – whether mild or profound – is better when they live in arrangements in the community that are the norm for all in those societies. A concrete expression of this recognition comes in the form of closure of institutions and the increasing creation of alternatives within the community, together with the means to enable such individuals to lead their lives there.[150]

However, the section on community living in the Equal Rights Law was not approved by the Knesset when it accepted the law for its final reading in February 1998; nor was it accepted by the Knesset when it approved the final version of the law on 1 January 1999.[151] In fact, according to the Commission for Equal Rights of Persons with Disabilities, it will be some

[149] Equal Rights Law (n 16).
[150] Explanatory Remarks to the Equal Rights for Persons with Disabilities Draft Bill (Israel).
[151] Now, more than 15 years since the original Equal Rights Law was proposed, it has been only partially enacted. Further, not all of the regulations implementing the five sections of the law that have been enacted have been approved. For example, the regulations mandating accessibility of public transportation were signed in 2003 but the regulations on state participation in improving access in the workplace have yet to be signed. Indeed, only a portion of the regulations on accessibility and even fewer of the regulations on public services have been finalised in more than two years of work by a Knesset Committee: Interview with Commission staff Zvia Admon, and her email of 8 August 2010. Moreover, once the regulations are finalised, the law itself proscribes a long period of implementation. For public buildings and services the period is 12 years; or 11 years for health and emergency services. For private building, the implementation period is six years. However, private entities also have a defence of 'undue burden', which is not available to the public sector: Equal Rights Law (n 16).

time before the Knesset even considers the remaining sections of the law, including the section on community living;[152] this section, like other sections of the law, has been put on hold to allow time for the Ministry of Finance to consider its budgetary implications.[153]

Thus, in Israel – unlike in the United States, which has the 'integration mandate' in the regulations implementing the ADA – there is no explicit right to live in the community in the current version of the Equal Rights Law nor in the draft of its implementing regulations. However, the draft regulations of the Equal Rights Law require the state to ensure that all services it provides or funds are provided on a non-discriminatory basis. Further, additional legal protections exist to enforce the rights of individuals with disabilities to live in the community in Israel.

The first source of protection for the right of people with disabilities to live in the community appears in the opening section of the Equal Rights Law. This section describes the purpose of the law:

> to protect the dignity and freedom of a person with a disability, to enshrine her/his right to equal and active participation in society in all the major spheres of life, and, furthermore, to provide an appropriate response to the special needs of a person with a disability, in such a way as to enable her/him to live with maximum independence, in privacy and in dignity, realizing her/his potential to the full.[154]

Living in the community may be seen as the condition precedent for all other rights related to one's participation in the community.

In addition, Article 6 of the Equal Rights Law offers additional support for the right to live in the community since it requires '[s]trict attention … to the dignity and freedom of the person and to the protection of the person's privacy', and 'within the framework of services provided in society and aimed at the general public', while 'adjustments shall be made as required by the particular circumstances, and as stated in this Law'.[155] Accordingly, to the extent that the 'general public' receives services in the community, so should people with disabilities, as required by Article 6.

The chapter entitled 'Fundamental Principles' in the Equal Rights Law provides additional support for the right to live in the community by stating that the 'rights of people with disabilities and the obligation of Israeli society toward these rights are founded upon recognition of the principle of equality, man's worth – created in God's image – and on the principle of respect for all human beings'.[156] The chapter entitled 'General Principles' also recognises that a person with a

[152] Interview with Ahiya Kamara, Commissioner, Commission for Equal Rights of Persons with Disabilities, 22 July 2010, Jerusalem, Israel.
[153] ibid.
[154] Equal Rights Law (n 16).
[155] ibid.
[156] ibid.

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disability 'is entitled to make decisions relating to his life, according to his desires and priorities, all in accordance with the provisions of any law'.[157] Indeed, one could argue that if a person with a disability is not living in the community, then he or she cannot enjoy any of the other rights protected by the Equal Rights Law, including equal access to buildings and public services, employment and transportation.

4.2 Additional Protection for the Right to Live in the Community

In addition to the Equal Rights Law, other Israeli laws and policies reinforce the right to live in the community for people with disabilities. For example, the Rehabilitation of the Mentally Disabled in the Community Law ('Rehabilitation Law') was enacted in 2000, following the failure of the third attempt in 1996 to reform Israel's mental health system.[158] This law was enacted specifically to include people with psychosocial or psychiatric disabilities in the life of communities by providing individualised rehabilitation programmes, which include community living options.[159] In addition to supported housing in the community, the Rehabilitation Law provides supported employment, education assistance, social clubs and other services.[160]

The Rehabilitation Law, together with the development of rehabilitation services in the community and the government's plan for reducing the number of psychiatric beds in the country, has had a dramatic effect on the right to live in the community for thousands of people with psychiatric disabilities in Israel.[161] From 1996 to 2006, the number of psychiatric beds in Israel declined by 50 per cent, from 6,599 to 3,453.[162] The length of stay in mental hospitals also declined by 60 per cent between 1995 and 2005 and persons discharged from inpatient services spent longer periods in the community before re-admission.[163] Moreover, the number of people with psychiatric or psychosocial disabilities living in the community had more than tripled by the end of 2007, from about 2,150 in 2000 to 7,284.[164] Further, more than half of the beds in psychiatric institutions have been emptied, and more than 13,000 people with psychosocial disabilities, who at one time would have

[157] ibid.
[158] Rehabilitation of the Mentally Disabled in the Community Law, 2000 (Israel).
[159] Uri Aviram, 'Promises and Pitfalls on the Road to Mental Health Reform in Israel' (2010) 47 Israel Journal of Psychiatry and Related Sciences 171, 174.
[160] ibid 175, citing Yehiel Shershevsky, 'Rehabilitation Package of Services for Mentally Disabled Persons in the Community' in Uri Aviram and Yigal Ginath (eds) *Mental Health Services in Israel: Trends and Issues* (Cherikover 2006) 357–87 (in Hebrew).
[161] Aviram (n 159) 171.
[162] ibid 174.
[163] ibid 174–75.
[164] The Ministry of Health estimates that, as of December 2007, approximately 7,284 people with mental illness lived in rehabilitation centres operated by the Ministry of Health: see 'Mental Health in Israel, Statistical Report 2008', Israel Ministry of Health, 2007, available at http://www.health.gov.il/download/forms/mentalReport2008.pdf. Between 120,000 and 160,000 adults in Israel are estimated to be consumers of mental health services: Naomi Struch and others, 'People with Severe Mental Disorders in Israel: An Integrated View of the Service Systems', Myers-JDC-Brookdale Institute, 2009, 1, 6, available at

been institutionalised, now receive rehabilitation services that enable them to live in the community.[165]

Recent research reveals, however, that although the number of patients in mental hospitals and their length of stay have declined markedly since 2000, the number of government mental hospitals in Israel has remained the same.[166] In other countries in which community schemes have been developed to replace institutional custodial care, the number of mental hospitals decreased so that the money saved followed the patients into the community. This has not been the case in Israel.[167] In fact, despite the substantial reduction in the number and rates of inpatient admissions in Israeli mental hospitals between 1997 and 2006, not only has there been no decrease, but there has been an increase in the Israeli budget for mental hospitals (as opposed to community care) during that period.[168]

A second law that was enacted in as early as 1969 – the Care for People with Mental Retardation Act – also includes a specific preference for community living as opposed to institutions, and establishes an entitlement to state support for persons with intellectual disabilities who live in the community, but only in programmes funded by the Ministry, and not in their own homes.[169] A 2000 amendment to this law specifically provides a preference for referring people in need of services to living arrangements within the community as opposed to

http://brookdale.jdc.org.il/?CategoryID=192&ArticleID=49; see also Aviram (n 159) 175, citing Shershevsky (n 160).

[165] Mental Health Services, Ministry of Health, 'Project for the Estimation of Rehabilitation of People with Disabilities in the Community', internal document, 8 June 2007. There is no question that development of housing in the community for people with mental illness has exceeded similar efforts for other populations of people with disabilities, particularly people with cognitive disabilities: interview with Kamara (n 152).

[166] Aviram (n 159) 171.

[167] ibid 177; see also Simon Goodwin, *Comparative Mental Health Policy: From Institutional to Community Care* (Sage Publications 1997); Martin Knapp and others, *Mental Health Policy and Practice Across Europe* (Open University Press 2007); Harvey Whiteford, Ian Thompson and Dermot Casey, 'The Australian Mental Health System' (2000) 23 International Journal Law and Psychiatry 403, 403–17; *Barbara D'Avanzo* and others, 'Discharges of Patients from Public Psychiatric Hospitals in Italy between 1994 and 2000' (2003) 49 International Journal of Social Psychiatry 27; Corrado Barbui and Michele Tansella, 'Thirtieth Birthday of the Italian Psychiatric Reform: Research for Identifying its Active Ingredients is Urgently Needed' (2008) 62 Journal of Epidemiology and Community Health 1021; Angelo Barbato and others, 'A Study of Long-Stay Patients Resettled in the Community after Closure of a Psychiatric Hospital in Italy' (2004) 55 Psychiatry Services 67.

[168] Unless and until the state budget for institutions is reduced, the claim of lack of funds for community living options and other services in the community is likely to continue: see Aviram (n 159) 177. According to Dr Uri Aviram, at that time the government hospitals had been under-budgeted and needed additional funds in order to stabilise their budgets. However, 'the timing of this increase', Aviram writes, 'makes one wonder whether this was not aimed, at least in part, at neutralizing the opposition of the strong lobby of the government psychiatric hospitals and of the Israel Medical Association to the planned reform': ibid. See also Uri Aviram, Dalia Guy and Israel Sykes, 'Risk Avoidance and Missed Opportunities in Mental Health Reform: The Case of Israel' (2007) 30 International Journal of Law and Psychiatry 163, 163–81.

[169] Care for People with Mental Retardation Act, 1969 (Israel), art 7(a)(b).

institutions.[170] Despite this law, however, more than 7,000 Israelis, or nearly 10 per cent of the disabled population, live in institutions or institution-like settings.[171]

Another law that is relevant to the right of people with disabilities to live in the community in Israel is the 1995 amendment to the Planning and Construction Law of 1965.[172] This law provides an incentive for the development of housing in the community for people with disabilities by exempting certain housing for people with disabilities in residential areas from the approval process. As the Explanatory Remarks to the 1995 amendment to the Planning and Construction Law provides:

> The approach today regarding groups who need treatment and care is to include them as much as possible within regular society, in work, study, etc … Including them in the life of the community is contingent on their actually living within the community. This goal of this amendment is to assist in the inclusion of these vulnerable groups in the community … and to remove any sense of excommunication and social banishment.[173]

The Planning and Construction Law has been the basis for a series of court decisions, all of which have upheld the right of people with disabilities to live in the community despite resistance by their neighbours or by the municipalities themselves. A common concern (in Israel and the US) expressed by neighbours of housing facilities for people with disabilities is the drop in property values after a congregate living scheme for people with disabilities opens in a residential neighbourhood. Although Israel has no comprehensive studies on the effect of housing for people with disabilities on property values, studies in the United States have refuted any connection between housing for people with disabilities and lowered property values.[174]

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[170] Amendment to the Care for People with Mental Retardation Act, 1969 (2000).

[171] A 2008 study by the Ministry of Social Affairs reports, for example, that approximately 1,500 children and 5,000 adults with developmental/cognitive disabilities or autism, and an additional 1,000 people with physical, hearing or vision impairments now live in institutions in Israel: see State of Israel Ministry of Welfare and Social Services, 'Report of the Commissioner on the Implementation of the Freedom of Information in the Ministry of Social Affairs and Social Services for 2008: Objectives, Operations, Budget and Structure', July 2009, (in Hebrew) available with the author.

[172] Amendment to the Planning and Construction Law, 1965 (Israel). The relevant article of this law was amended again in 2002.

[173] Explanatory Remarks to the draft bill amending the Planning and Construction Law, 1994 (Israel).

[174] Arlene S Kanter, 'Recent Zoning Cases Uphold the Establishment of Group Homes for the Mentally Disabled' (1984) 18 Clearinghouse Review 515; Kanter (n 71) 925. For additional information about housing for people with disabilities in the community, see http://www.planningcommunications.com/gh/group_homes.htm. Here a representative sample of 50 studies on the impact of housing in the community for people with disabilities has been completed. These studies look at property values, neighbourhood turnover and neighbourhood safety. No matter which methodology has been used, every study has concluded that group homes not clustered on the same block have no effect on property values, even for the houses next door, nor on the marketability of nearby homes, neighbourhood safety, neighbourhood character, parking, traffic, public utilities or municipal services. See also Robert G Schwemm, 'Barriers to Accessible Housing: Enforcement Issues in "Design and Construction" Cases Under the Fair Housing Act' (2006) 40 University of Richmond Law Review 753; Tim Iglesias, 'Managing Local Opposition to Affordable Housing: A New Approach to NIMBY' (Fall 2002) 12 Journal of Affordable Housing 78; Michael Allen, 'Why Not in Our Backyard' (2002) 45 Planning Commissioners Journal 1, available at http://bazelon.org/Where-We-Stand/Community-Integration/Housing/Housing-Resources.aspx#baz; Michael Allen, 'Separate and Unequal: The Struggle of Tenants with Mental Illness to Maintain Housing', National Clearinghouse for Legal Services, 1996, available at http://bazelon.org/Where-We-Stand/Community-Integration/

In cases colloquially referred to as NIMBY (not in my backyard) or LULU (locally unwanted land users), courts in the US[175] and Israel[176] have consistently rejected neighbours' objections to the location of residences for people with disabilities. The Israeli courts have based their decisions on their interpretation of a mandate for inclusion of people with disabilities in the community under either Article 63a of the Planning and Building Law (which authorises housing for special populations) or the human rights principles contained in the Basic Laws. For example, in two recent cases, Israeli courts have held that people with disabilities have a right to live in the community over the objection of their neighbours. Although both courts recognise that neighbours have a right to a minimal standard of living, the courts found that the housing at issue posed no risk to the owners' interests, and therefore ultimately ruled in favour of the rights of the residents with disabilities to live in the housing within their community.[177]

Accordingly, the Equal Rights Law, the Rehabilitation Act, the Care for People with Mental Retardation Act and the Planning and Construction Law all support the right of people with

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Housing/Housing-Resources.aspx#baz; Daniel Lauber, 'A Real LULU: Zoning for Group Homes and Halfway Houses Under the Federal Fair Housing Amendments Act of 1988' (1996) 29 The John Marshall Law Review 369.

[175] In the US, the Federal Fair Housing Amendments Act (FHAA) prohibits discrimination in housing including the application of restrictive zoning laws to housing for people with disabilities: see 42 USC § 3602(h). Accordingly, zoning boards, municipalities and other governmental entities that act in violation of the FHAA have been held liable. See the comprehensive report on the FHAA prepared by the Disability Rights Network of Pennsylvania for the following cases*: San Pedro Hotel Co, Inc v City of Los Angeles* 159 F 3d 470, 475 (9th Cir 1998); *Smith & Lee Associates, Inc v City of Taylor* 13 F 3d 920, 924 (6th Cir 1993), appeal following remand 102 F 3d 781 (6th Cir 1996); *Cohen v Township of Cheltenham* 174 F Supp 2d 307, 320–21 (ED Pa 2001); *US v City of Chicago Heights* No 99 C 4461, 1999 WL 1068477 at *3 (ND Ill 19 Nov 1999); *Remed Recovery Care Centers v Township of Worcester* No 98-1799, 1998 WL 437272 at *6–*7 (ED Pa 30 July 1998); *US v Borough of Audubon* 797 F Supp 353, 357 (DNJ 1991), affirmed without opinion 968 F 2d 14 (3rd Cir 1992); *Resident Advisory Board v Rizzo*, 564 F 2d 126, 146 (3rd Cir 1977), certiorari denied 435 US 908 (1978); available at http://drnpa.org/File/publications/discriminatory-zoning-and-the-fair-housing-act.pdf. See also *Cleburne* (n 71): Supreme Court invalidates a zoning scheme requiring the operators of a group home for people with mental disabilities to obtain a special use permit for institutions for the 'feeble-minded'. Although the Court rejected the home's residents' claim that they are entitled to heightened judicial scrutiny under the Equal Protection Clause, the Court nonetheless upheld their right to live in the community using the rational basis test.

[176] Courts in Israel have consistently upheld the right of a facility or home for people with disabilities to open, even when such places are more like institutions than homes: see s 63(a) of the Planning and Construction Law, 1965. See also Local Affairs Court (Karmiel), Case 104/02, *State of Israel and the City of Karmiel v KSR Kidum*, 25 April 2004; Magistrates Court (Haifa), Case 21735/00, *Yehoshua Michaeli v KSR Kidum*; *Ministry of Welfare and Social Services in the Matter of Nave Adir Hostel*, 11 November 2009; Magistrates Court (Jerusalem), Case 512/02, *Peled and Others v ALUT* (*National Society for Autistic Children)*, 28 April 2003; Magistrates Court (Herzliya), Case 902/03, *Tunir Meir v AKIM*, 15 June 2005; District Court sitting as an Administrative Court (Tel-Aviv-Jaffa), Case 1073/07 17, *Yehudit Katz v Bar-Dror Housing and the Planning and Building Committee – Central District*, October 2007.

[177] In *Yehoshua Michaeli v KSR Kidum* (ibid) the plaintiffs and the city of Karmiel objected to the opening of a hostel for 18 teenagers with different disabilities (including ADD, learning disabilities, Down's syndrome) in a residential neighbourhood. The neighbours claimed that the hostel violated art 63 of the Planning and Construction Law. The court found no evidence of falling property values or danger and found in favour of the hostel. In the second case, *Peled and Others v ALUT* (ibid), the neighbours of an existing home for 14 autistic children sought to have the home closed down on the grounds of nuisance (noise and dirt) and falling property values. The court ruled in favour of ALUT, finding no evidence of nuisance or an adverse effect on property values.

disabilities to live in the community. Despite these laws, however, many such people not only still live in institutions in Israel, but for those who live in community settings, many of those settings function more like institutions than 'homes', as will be discussed below in Section 5 of this article.

4.3 Decisions by the Israeli High Court of Justice on the Rights of People with Disabilities in the Community

In addition to the role of the Knesset in enacting legislation to protect the rights of people with disabilities in Israel, the Israeli High Court of Justice has begun to review cases that allege infringements of the rights of people with disabilities. The first such case was decided in 1996, prior to the enactment of the Equal Rights Law. In this case, *Shahar Botser v Municipality of Makabim Local Authority*,[178] former Chief Justice Aharon Barak of the High Court determined that the failure of a school to make certain areas of the school accessible for a student wheelchair user constituted discrimination.[179] Basing his decision on the principles of equality and human dignity found in Israel's Basic Laws, Chief Justice Barak wrote that

> [t]he disabled person is a human being who deserves equal rights. He lives neither outside society nor on its margins. He is a normal member of the society in which he lives. The purpose of the regulations at issue is not to improve the quality of his isolation, but to integrate him – sometimes through the use of corrective special measures – into the ordinary fabric of social life.[180]

Several years later, the Israeli High Court of Justice was asked to apply the principles of equality and human dignity in the Basic Laws as well as the non-discrimination principle of the Equal Rights Law in the case of *Lior Levy v State of Israel*.[181] On 15 April 2007, Bizchut, the Israel Human Rights Organisation for People with Disabilities, filed this case in the High Court of Justice on behalf of five young people with severe disabilities and their families, demanding that the state place these young people in apartments in the community, with support as needed.[182]

Lior Levy, the named petitioner in the case, is one of five young people with intellectual and physical disabilities, who, together with their families, requested the Ministry of Social Affairs to provide them with supported housing in their local communities so they could move out of their family homes, where they had lived all their lives. One of the petitioners, Michael, was 21 years old when the case was filed and, according to his family, he was ready to live with other people of his age. He has had cerebral palsy since birth, and is labelled as 'mentally retarded'; he cannot speak and uses a wheelchair. Since his parents are now elderly, it was time for Michael to move

[178] HCJ 7081/93 *Shahar Botser and Others v Makabim Re'ut Local Authority and Others* [1996] IsrSC 50(1) 19 (in Hebrew).
[179] ibid, para 2.
[180] ibid, para 8.
[181] *Lior Levy* (n 1).
[182] ibid.

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into a supported apartment with other people his age, and which would be staffed by professionals to provide him the support he needs.[183]

The Ministry of Social Affairs refused to place Michael, Lior and the other young people in their own apartments in the community. Instead, the Ministry offered to move them into a 24-person hostel, where they would ostensibly receive the services they needed. In response to the petition, the Ministry claimed that for these petitioners, '[l]iving in an apartment may endanger the[ir] lives and they are safer in an institution with a 24-hour on-call nurse and a medical team available'.[184] Michael's sister, who looks after him and takes him for walks and grocery shopping, responded to the Ministry's position by stating in an interview that '[i]nstitutions are impersonal, he will cry there and be shy. They won't let him go out on walks. In an apartment he could watch television or go out whenever he wants to'.[185]

The petitioners submitted lengthy briefs and expert affidavits supporting the right and the appropriateness of community living for these five young people. They presented expert affidavits on the developing international right to live in 'real homes' in the community, as well as case law from the United States.[186] However, before the Court could reach a decision on the legality of the state's criteria for community placement, the state agreed to change its policy which had automatically excluded from consideration for community placement people with disabilities who needed extensive support services, such as the young people in this case. The Ministry agreed to adopt a new policy, which now provides that people with severe disabilities may be eligible for housing in the community but only 'if their medical and behavioural needs may be met in the community'. The issue remains, of course, as to who will decide whose medical and behavioural needs can or cannot be met in the community, and how such decisions will be made. Following the Ministry's decision to change its policy, the Court wrote in a brief decision:

> The respondents presented updated information about the criteria. The update includes detailed examination of every case that is brought before the commission. Restrictions that existed prior to the update were reduced. The relevant conditions are the lack of medical assistance and violent behaviour. The respondents also decided to open new hostels in which will live between 16–24 residents in the community. In their view, it provides a balanced solution to the problem.[187]

Accordingly, the Court ruled that 'the petition has achieved its goal',[188] but left open the option of returning to the Court in the event that the state did not move swiftly to find appropriate community placements.

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[183] ibid.
[184] ibid.
[185] Ruth Sinai, 'Disabled Petition for Right to Live Outside Institutions', Ha'aretz, 19 April 2007.
[186] The author provided an expert affidavit in this case, when it was filed in 2007, on the area of international and US law on community living.
[187] *Lior Levy* (n 1).
[188] ibid.

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Although the involvement of the Israeli High Court of Justice in the *Lior Levy* case has ended, the dispute has not. Following the Court's decision, the Ministry of Social Affairs informed the young adults and their families that they had located a building that could be used as a hostel for 24 residents in an Israeli-Arab village, Beit Tsafafa. The petitioners argued that the proposed hostel is not consistent with the Court's decision regarding their right to live in the community because, as Jewish Israelis, they would not be able to interact easily with their Arab Israeli neighbours, whose culture and language are different from their own.[189]

At first, the petitioners' objection appears to be discriminatory. But unlike in the United States, where diversity within and among neighbourhoods is valued and segregation is prohibited by US law, Israeli law recognises and legitimates separate neighbourhoods, based on religious and ethnic identity. Thus, the family objected that, because government-supported homes consisting only of Jewish residents in Israeli-Arab villages generally do not exist in Israel, the Ministry's decision to locate this facility in an Arab village was discriminatory on the basis of the proposed residents' disability. Shortly thereafter, a public rally organised by the families and their supporters resulted in the government's decision to back down from its recommendation to place the petitioners in the proposed hostel in Beit Tsafafa. The state agreed to offer an alternative community living option. However, as of 1 May 2012, none of the five residents live in their own apartments: one plaintiff died, two others still live with their parents, and the fifth plaintiff lives at the Aleh Institution.

The outcome of the Israeli High Court's decision in *Lior Levy* is mixed. On the one hand, the policy of the Ministry of Social Affairs that had automatically excluded from consideration for community living any person with a disability who needed extensive support services is no longer in place. Adults with even severe disabilities are now eligible for housing in the community so long as their medical and behavioural needs may be met. The issue remains, of course, as to who will decide whose medical and behavioural needs can or cannot be met in the community and how such decisions will be made.

On the other hand, the Court upheld the Ministry of Social Affairs' position that hostels (or any large congregate facility for as many as 24 or more people) qualify as housing in the community. The petitioners had argued that placing them in a hostel with 24 strangers was not consistent with their right to live in the community, and that it is more like an institution than one's 'home'. The Court ruled for the state on this issue, and concluded that the proposed hostel is 'a reasonable and moderate solution, not far off from the apartment setting the plaintiffs were seeking'.[190] In so doing, however, the Court failed in its duty to consider the expert and other evidence presented in the case that established, as a legal matter, the difference between life in a hostel of 24 people and a real home in the community.

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[189] ibid.

[190] ibid 4562. By way of contrast, for example, the Ninth Circuit Court of Appeals in the US, in *Townsend v Quasim* (n 136), rejected the State of Washington's claim that its system of deciding who is eligible for community services was reasonable. Criticising the state, the court concluded that 'policy choices that isolate the disabled cannot be upheld solely because offering integrated services would change the segregated way in which existing services are provided'.

The Israeli High Court of Justice in *Lior Levy* seemed to accept at face value the state's position regarding the reasonableness of placing the petitioners in a large institution-like hostel. The Court refused to carefully evaluate the arguments against the Ministry's position or discuss the evidence presented regarding the quality of life for people in a large hostel, or any of the evidence presented to the Court by Bizchut and its experts regarding the families' preferences and the needs of the adult children.[191] In fact, unlike the recent US district court decision in *DAI v Paterson* as well as the US Supreme Court's decision in *Olmstead*, the Israeli High Court of Justice did not even mention the components of community living which were at stake in this case. In both *Olmstead* and *DAI v Paterson*, the respective courts carefully examined the meaning and scope of the right to live in the community to determine whether or not what the state calls 'community living' is actually a setting that allows people with disabilities to experience life in the community and that 'fosters community interaction with nondisabled persons to the fullest extent possible'.[192] As the court in *DAI v Paterson* held, the state's 'failure to provide placement in a setting that enables disabled individuals to interact with non-disabled persons to the fullest extent possible violates the [law]'.[193]

The High Court of Justice in *Lior Levy* originally ruled that community living is 'indeed a part of the greater right to equality of people with disabilities and of their rights to dignity and active participation in the community', and 'a real revolution for the rights of people with disabilities, reflecting the face of society and the state of human rights within it'.[194] But, in the end, the Court refused to require the State to comply with the petitioners' request for typical housing in their local community. As such, the significance of the *Lior Levy* decision is arguably undermined by the Court's own failure to provide a practical remedy to enforce the petitioners' right to live in the community. It will now be up to the Ministries, in co-operation with NGOs, to formulate and implement a policy to enforce the right of all people with disabilities to live in the community with choices equal to others, as the CRPD provides.

In a second related case, decided on 21 June 2011, the High Court of Justice was presented with a petition by Bizchut against the Ministry of Health and the Ministry of Welfare and Social Services alleging violence, abuse, neglect and humiliation of the residents at Illanit, a private institution which houses 140 adults with mental, cognitive or intellectual disabilities or autism between the ages of 20 and 70.[195] According to court records, Illanit had been operating since the 1950s, but six years ago the Israeli government decided to close it based on its own

[191] For example, the petition stated that Michael, one of the named petitioners, does not require constant medical treatment despite his severe disabilities. As his sister stated, 'he has never required urgent treatment and when he is sick the family takes him to the doctor at the health maintenance organisation': Sinai (n 185).

[192] 28 CFR § 35.130(d), cited in both *Olmstead* and *DAI v Paterson*. The court in *DAI v Paterson* went even further to state that '[t]he question is not whether the people with disabilities have *any* opportunities for contact with non-disabled persons. That ignores the "most integrated setting" and the "fullest extent possible" language of the regulations': *DAI v Paterson* (n 124), 190–93, 223.

[193] *DAI v Paterson*, ibid 223.

[194] *Lior Levy* (n 1) 4563.

[195] HCJ 2815/11 *Bizchut and Others v Ministry of Health and Ministry of Welfare and Social Services* ('*Illanit*') (judgment given 21 June 2011).

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investigation that revealed systematic abuse and mistreatment of the residents. The institution was never closed, however. Consequently, Bizchut, together with MK Ilan Gilon and others, visited Illanit in the summer of 2010 and found there unacceptable conditions, including walls smeared with new and dried faeces, residents laying naked on the ground, residents tied to chairs for hours, serious bruising and evidence of beatings on the bodies of residents, and an overall atmosphere of neglect and disregard for the residents' welfare. Bizchut submitted its report to the Ministry of Welfare and Social Services, which responded by informing Bizchut that it would be prohibited from visiting any institutions in Israel. In its decision in this case, the High Court of Justice required the Ministry to allow Bizchut to visit Illanit, but refused to address the underlying claims regarding the objectionable living conditions.

Based on the decisions of the Israeli High Court of Justice in *Lior Levy* and *Illanit*, it appears that the Court will defer to the Israeli government on the question of what constitutes community living as well as how to protect the welfare of people in institutions, even institutions which may subject its residents to human rights abuses, as alleged by the petitioners in *Illanit*. Perhaps future cases will be resolved differently. Like the United States, Israel has signed the CRPD and plans are under way for Israel's ratification of the CRPD. One can only hope that the new Convention will set the standard from which a new interpretation of the human rights protection for people with disabilities will apply in both Israel and the US. Indeed, the CRPD has the potential to play a major role in bolstering domestic disability laws and curtailing the limitations placed on the right to live in the community. The road to ratification of the Convention by Israel and the US may be long, but their signatures to the CRPD have already created a bona fide obligation on these countries to refrain from acts that would defeat the object and purpose of the treaty.

5. THE MEANING AND SCOPE OF THE RIGHT TO LIVE IN THE COMMUNITY

5.1 THE MEANING OF THE RIGHT TO LIVE IN THE COMMUNITY

As illustrated by the previous discussion of the cases of *Lior Levy*, *Olmstead* and *DAI v Paterson* the right to live in the community for people with disabilities is not yet firmly established in either US or Israeli law. Indeed, the complexity of the issue has raised some serious questions about the very meaning and scope of the right to community living.

While it is true that not all people with disabilities are capable of living on their own, that is not what the right to live in the community requires. Living in the community generally means the opportunity to live in housing, as independently as possible, and with support, as needed. People with disabilities, like people without disabilities, need help at times with certain tasks, or to make certain decisions, and some people need more help and more often than others. Yet even people with the most challenging physical and/or mental disabilities, who cannot speak or communicate in traditional ways, may be able to express their preferences.

Those who provide services to people with disabilities, as well as family members or guardians, sometimes assume that if a person cannot communicate by talking or writing the person

has no opinions, likes or dislikes. Accordingly, programme models have been developed in the United States and Israel based on the idea that all people with disabilities, especially those with severe disabilities, need a safe place to live, eat and sleep, which may be provided just as easily (and supposedly more cost-effectively) in institutions or congregate living facilities, rather than in typical residential housing or apartments.

Recent studies show, however, that when people with communication disorders do communicate with assistance, they are able to express just what they want to do and with whom.[196] Indeed, people with all types of cognitive and communication impairments can do many activities including communicating, eating, moving, and even thinking – albeit perhaps in ways that are different from those considered to be normal for 'non-disabled' people. The question for courts and legislatures, therefore, becomes whether such differences should be the basis to deny a person the right and opportunity to live in a home in the community. As research has shown, people with disabilities, even those with severe disabilities who cannot walk or talk on their own, can still benefit by community living, by interaction with their neighbours and, in some cases, by developing personal relationships and learning to make decisions about their own lives.[197]

Further, even if a person with a disability never interacts with others in his or her neighbourhood, does that justify depriving that person of the opportunity to live in his or her own home in the community as a matter of law? The right to live in the community, as envisioned in the CRPD, is not based on whether or not the person is *able* to live in the community, or even whether or not the person will *benefit* from living in the community, according to the judgment of a professional.[198] Professional judgment is relevant to decisions about medical or therapeutic treatment, but not to the decision of where a person – with or without disabilities – should live. That is, arguably, a personal decision, not a medical decision. Nor should people with disabilities be required to give up their right to live in the community in order to receive treatment or support services. To require a person to move into an institution or other institution-like setting in order to receive the services or supports they need from the state constitutes discrimination, per se, as the

[196] See, for example, Institute on Communication and Inclusion at Syracuse University, available at http://soe.syr.edu/centers_institutes/institute_communication_inclusion/default.aspx; and for information about research on communication by people who, in the past, were considered unable to communicate, see http://soe.syr.edu/centers_institutes/institute_communication_inclusion/About_the_ICI/Research.aspx.

[197] See, for example, Michael Wolf-Branigin, 'Self-Organization in Housing Choices of Persons with Disabilities' (2006) 13(4) Journal of Human Behavior in the Social Environment 25, available at http://u2.gmu.edu:8080/dspace/bitstream/1920/3442/1/Self-Organization_in_Housing_Choices_of_Persons_with_Disabilities.pdf;
Thomas Nerney, Richard F Crowley and Bruce Kappel, 'An Affirmation of Community; A Revolution of Vision and Goals: Creating a Community to Support All People Including Those with Disabilities', University of New Hampshire Institute on Disability, 1995, available at http://www.centerforselfdetermination.com/docs/sd/communityPrint1.pdf; Nancy N Eustis, 'Consumer-Directed Long-Term Care Services: Evolving Perspectives and Alliances' (2000) 24 Generations 10, 38; RL Pennell, 'Self Determination and Self Advocacy: Shifting the Power' (2001) Journal of Disability Policy Studies 15.

[198] Some may regard this statement as controversial. The fact remains that absent a showing that a person with a disability is unable to express his or her preferences regarding the type of housing he or she prefers, the legal presumption should remain that the person has a right to choose where to live and with whom. Of course, professionals as well as family members may help individuals to make such decisions. But absent a showing of impossibility, as a legal matter, such decisions are the person's alone.

Court found in *Olmstead*. It also violates the individual's fundamental right to live in the community, with dignity, equality and self-determination, as provided in the new CRPD, the ADA, as well as the Equal Rights Law and the Basic Laws of Israel.

5.2 Defining the Scope of the Right to Live in the Community in Israel

There are many schemes in Israel that call themselves community living, but which in fact separate people, based on their disability, from the rest of society. Although such programmes seek to create housing for people with disabilities outside of traditional institutional settings, none of them comply fully with the CRPD's vision of 'the right of community living, with choices equal to others'.

For example, in Israel there is now under way a proposal by an organisation known as Alin Beit Noam to build a new multipurpose campus located on forest land in the middle of the country. This new campus, to be called Ilanot Kadima, will offer a day-care centre and housing units for adults with intellectual and physical disabilities as well as apartments for people without disabilities, such as students from nearby colleges. The proposed campus will also include a recreation centre, a spa, a pool and an adventure park, all of which will be open to the residents and the general public. The founder of this new scheme believes that 'if we cannot bring them to the community, then we will bring the community to them'.[199]

The $22 million project will be funded by the Ministry of Social Affairs, donations and user fees. The plans for this new campus were interrupted initially by an objection filed by the Society for the Preservation of Nature in Israel (SPNI).[200] The SPNI, an organisation that works to protect Israel's natural resources, sought to stop the development of the project because of its location on public green space. Bizchut, the Human Rights Center for People with Disabilities, joined with the SPNI to stop the development of the proposed campus, claiming it is discriminatory by unnecessarily moving people with disabilities to a segregated setting. Bizchut believes that rather than develop an isolated campus community – albeit one that will be open also to some non-disabled people – the Ministry and the programme operators should instead provide additional opportunities and support for people with disabilities to live successfully in existing communities.[201]

One of the arguments for the creation of the proposed campus is that the parents of some of the prospective residents complained that their adult children have been unhappy and lonely in their current living arrangements in the community. Consequently, the Disability Rights Clinic of Bar Ilan University, a law clinic dedicated to advancing the rights of people with disabilities, offered its support to the campus project in order to protect, in their words, 'the right of these families to choose'.[202] The case was decided in favour of Alin Beit Noam.

[199] Interview with Director of Beit Noam, Yitzhak Bar Haim, 2 May 2010, Alin Beit Noam, Kiryat Ono, Israel.
[200] SPNI, Opposition to Developmental Proposal No. V2/130/1-4 (Beit Noam), filed 25 September 2009.
[201] Interview with Esther Sivan, Director of Bizchut, 7 May 2010, Jerusalem, Israel.
[202] Interview with Karine Elharrar, Director of Bar Ilan Disability Clinic, 3 August 2010, Jerusalem, Israel.

This issue that relates to preserving the right of people with disabilities (or their parents, in this case) to choose an institution or institution-like setting is problematic. As the court found in *DAI v Paterson*, many people with disabilities are not aware of all the choices available to them. For example, rather than establish a campus far away from any community, perhaps efforts should be undertaken to combat the feeling of loneliness and isolation in the community that these family members reported. Indeed, Article 19 specifically recognises the obligation of the state to ensure that community services 'are responsive to their needs', including, I would argue, their need for support and activities to avoid the loneliness that some people with disabilities may experience.

Further, while it is true that some people with disabilities do not interact with their neighbours, many do and become part of their neighbourhoods. Indeed, that is true for people with and without disabilities alike. It is also true that people with disabilities report loneliness and isolation more often in institutions, surrounded by hundreds of people, than they experience in their own homes or apartments in the community. For example, in 2001, a study by Brookdale Institute found that about one quarter of the residents of sheltered apartments and hostels had a close relationship with a fellow resident, compared to only 8 per cent of the residents of the institutions.[203] What are the factors that contribute to such loneliness or, on the other hand, to successful integration in the community by people with disabilities? These are questions that are ripe for research.

Perhaps most importantly from a policy point of view, however, is the question of who is to blame for the fact that people with disabilities are lonely in the community. Whose responsibility is it to provide opportunities for people with disabilities to interact with their neighbours? For example, if an individual with a disability feels lonely and is not comfortable or able to introduce himself or herself to the neighbours, then is the proper response to move the person to another setting? On the contrary, rather than uproot the person, the proper response should be to hire and train professionals to facilitate the interaction between the person and his or her neighbours. Indeed, that is part of what learning to live in the community means. Unfortunately, instead of assisting individuals with a disability to develop relationships with people in the community, the person with a disability is often 'blamed' for his or her failure to become part of the community, and not given any option other than moving back to an institution or, as in the case of Ilanot Kadima, to a remote campus.

Thus, in Israel, as in the US and elsewhere, there are many examples of housing for people that is referred to as housing in the community, but is not actually a home at all.[204] As the expert in *DAI v Paterson* testified, a 'segregated setting for a large number of people that, through its

[203] Dalya Mandler and Denise Naon, 'The Quality of Life of Severely Physically and Mentally Disabled People in Community-Based Residences', JDC Brookdale Institute, 2001.

[204] In the US, a recent report on board and care homes for people with psychiatric disabilities found that even small board and care homes operate much like institutions, with residents being required to line up for medicine or to receive their disability check, enjoying little privacy, and little choice with respect to room-mates, meals or activities: 'Transforming Housing for People with Psychiatric Disability Report', US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, 2004, 2, available at http://www.acbhcs.org/housing/doc/SAMHSA_group%20homes.pdf.

restrictive practices and its controls on individualization and independence limits a person's ability to interact with other people who do not have a similar disability' is not a home but an institution.[205] According to this concept of a home in the community, housing arrangements such as the proposed 24-person hostel in *Lior Levy*, the proposed Ilanot Kadima campus, as well as countless examples of hostels in Israel and group homes in the US are more like institutions than real homes.

5.3 ARGUMENTS IN FAVOUR OF THE RIGHT OF PEOPLE WITH DISABILITIES TO LIVE IN THEIR OWN HOMES

Most people with disabilities throughout the world live in their own homes or with their families. They work, go to school, have children and contribute to society. But many people with disabilities also face social isolation and even exclusion from their own families, particularly those who live in institutions – some for their entire lives. In the United States alone, at least 989,581 persons with disabilities currently live in institutions.[206] In Israel, out of 700,000 people who receive state support, at least 70,000 live in institutions.[207]

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[205] Statement of expert, Elizabeth Jones, quoted in *DAI v Patterson*, 8 September 2009 (transcript of testimony of Elizabeth Jones) 21. For a comprehensive discussion of why some community housing is essentially an institution, see the court's decision in *DAI v Patterson*, No 03-CV-3209, 20–49 (NGG) (EDNY 8 September 2009).

[206] Institutions include state-operated institutions for people over 16 with developmental disabilities, state-operated psychiatric hospitals, privately operated residential facilities for persons over 16 with intellectual or development disabilities (I/DD), and nursing facilities for persons with 'disabilities' (meaning I/DD, mental illness and physical disabilities): David Braddock, 'State of the States', 2010 (preliminary data, on file with author).

[207] See Commission for Equal Rights of People with Disabilities, Annual Report 2009. The percentage of people with disabilities in Israel is at least as large as that of the US. As of 2003, approximately 400,000 or 10% of Israeli adults have one or more disabilities: Victor Florian and Nira Dangoor, 'Selected Issues in Israel's System of Rehabilitation' (1999) 19 Society and Welfare 193 (in Hebrew). A more recent survey reveals that 1.5 million or 24% of people in Israel consider themselves as having a disability that ranges from limiting their abilities to no limitation on their daily living skills: interview with Denise Naon, Director of Disability Research, 20 July 2011 at Brookdale Institute, Jerusalem Israel. With respect to children and young persons, 177,000 or 7.7% of all children in Israel have a disability such as deafness, paralysis, 'retardation', learning disabilities and severe behavioural problems, cancer or other chronic diseases that require medical or para-medical care on a regular basis. Of these, there are some 93,000 (4% of all children) whose main disability is a learning or behavioural and some 72,000 (about 40%) suffer from more than one disability, such as physical disability and mental retardation, or sensory and learning disability. Of the 177,000 children with a disability, some 18,000 (about 10%) received the Disabled Child Benefit from the National Insurance Institute in 2003. In towns classified as having a very low socio-economic profile, the proportion of children with disabilities is particularly large, at 11% as opposed to 7.7% of the total population of children in Israel: Denise Naon and others, 'Children with Special Needs – Stage I and Stage II: An Assessment of Needs and Coverage by Services', Research Report RR-355-00, JDC Brookdale Institute, 2000, (in Hebrew). The proportion of children with disabilities is higher in Arab towns (8.3%) than it is in Jewish towns (7.6%). It may be assumed that the actual gap is greater owing to the absence of an appropriate system for identification and diagnosis of children with learning disabilities in the Arab sector: ibid. The Ministry of Health's most recent estimates, as of December 2007, report that approximately 7,284 people with mental illness live in rehabilitation centres operated by their Ministry. However, the 2008 Israeli Report to the UN Committee on the International Convention on Civil and Political Rights states that approximately 3,000 people with mental illness live in mental hospitals, an additional 3,000 people in hostels, and an additional 4,000 people in their own apartments. A total of between 120,000 and 160,000 adults in Israel are estimated to be consumers of mental health services: see Struch and others (n 164) 228.

The reliance on institutions for children and adults with disabilities, particularly those with intellectual or psychosocial disabilities, is the result of several factors. First, in most countries throughout the world, institutions were developed as a way to protect society from those who were considered to be dangerous or misfits – people whom society decided were better off 'out of sight and out of mind'.[208]

A second reason for the creation and continued use of institutions for people with disabilities relates to the perceived cost benefits of institutions over community living options. The costs of providing care and services to people with disabilities in institutions or other congregate living settings is thought to be less expensive than providing care and support to people in their own homes or in typical apartments in residential neighbourhoods. However, the evidence is unclear; it does not establish the cost efficiency of congregate living facilities as opposed to supported housing options in the short or long term. Indeed, little evidence exists to support the conclusion that community living for people with disabilities, even those with the most severe disabilities, is more costly over time than maintaining institutions.[209] Israel's own leading research institute, the Brookdale Institute, found that the monthly costs of maintaining people with disabilities in institutions may be far greater than the cost of maintaining them in the community, including in small supported apartments.[210]

Comparing the costs of institutions, hostels and other housing options for people with different types of disability is difficult, if not impossible. Of the many studies that have been conducted, each includes different populations, different factors and variables, not to mention different cultures and values. For example, when determining the cost of a person in an institution, such costs per resident may include a percentage of the facility's overall budget for food, building and upkeep costs, custodial care, staff time, rehabilitation and other services, medication and health care. But each of these factors may have different funding streams, so the calculations may depend on who is counting which expenditures in which budgets. If the Ministry of Welfare and Social Affairs is estimating institutional costs from its own budget, it may not count costs that are provided by other sources within the government or from NGOs, donations, or parental contributions.

[208] In a recent report to the UN General Assembly, the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, Manfred Nowak, highlighted concerns about people with disabilities in institutions when he commented that disabled people are 'often segregated from society in institutions' and 'deprived of their liberty for long periods of time including what may amount to a lifelong experience, either against their will or without their free and informed consent. Inside these institutions persons with disabilities are frequently subjected to unspeakable indignities, neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence': Statement by Manfred Nowak – Special Rapporteur on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, UNGA 63rd sess, Item 67(a), 28 October 2008.

[209] See, for example, Ted Houghton, 'The New York/New York Agreement Cost Study: The Impact of Supportive Housing on Services for Homeless Mentally Ill Individuals', Corporation for Supportive Housing, 2001, 6–7, available at http://www.csh.org/index.cfm/?fuseaction=Page.viewPage&pageID=3251.

[210] Mandler and Naon (n 203) 59: the monthly costs of institutions were found to range from 7,976 NIS to 11,534 NIS per month as opposed to hostels (7,927 NIS per month) and apartments (ranging from 9,140 NIS to 12,283 NIS per month.

Further, people in institutions may receive many services by the staff employed by the institution. But if the same people were living in the community, they may choose not to avail themselves of so many services, resulting in what would appear to be higher costs for the institution. Moreover, a common argument that has been expressed among Israeli officials is that once the government begins to offer services in the community rather than requiring people to move into institutions or hostels to receive services, many more people may want to receive such services, thereby requiring a higher expenditure for a new group of people seeking community services.[211] Yet, little evidence exists in Israel or elsewhere to support the conclusion that community living for people with disabilities, even the most severe disabilities, is more costly over time than maintaining institutions.[212]

In fact, of those studies that have found institutions to be more costly than community living options, the results may be owing to the fact that such studies compared the costs of supporting people with severe disabilities and intensive needs in institutions with people who have less intensive needs, receive fewer services and live in the community. In addition, people who work in institutions are more likely to be unionised (in the US) and are paid much higher salaries than those who work in the community for barely the minimum wage. In Israel, this is an important difference since many community schemes for people with disabilities rely on volunteers who are not paid salaries at all, but are funded through the National Service or other programmes that recruit volunteers within Israel and from other countries, such as Germany. If the salaries and benefits were the same for people who work in institutions and those who work in the community, the cost differentials would be less or disappear entirely.

Another factor that is often ignored in the calculations that compare the costs of institutions and community care is the cost of maintaining the institutional system itself. Such costs include the Ministries' overheads, government staff who administer the programmes, as well as annual reports and auditing functions of the government. Research on costs also often fails to factor in the costs of having a person live in an institution versus the taxes that a person who lives in the community and develops skills to obtain a job may pay one day. Of course, specific cost estimates depend on how programmes are designed and implemented; it is certainly possible to create those that are not cost-effective. However, the most important variables that are often not measured in studies comparing the cost of institutional and community living are the many non-tangible benefits of enhanced freedom and participation of people with disabilities or, at the other extreme, the human cost when proper planning is not carried out.[213]

Finally, research into the cost of institutions and community living has not yet even begun to compare the costs relating to self-directed supported housing schemes in which the money

[211] Interview with Denise Naon (n 207).
[212] See, for example, Houghton (n 209) 6–7.
[213] See Mental Disability Rights International, 'Torture Not Treatment: Electric Shock and Long-Term Restraint in the United States on Children and Adults with Disabilities at the Judge Rotenberg Center', Child Rights International Network, 20 April 2010, available at http://www.crin.org/resources/infodetail.asp?id=22455. This report is the basis for a complaint filed by Disability Rights International, in Washington, DC with the Inter-American Commission on Human Rights regarding conditions in a private institution in Massachusetts.

goes directly to people with disabilities to purchase their own services in the community, as occurs in the US. Such home-care costs are typically cheaper per person than institutional costs.[214]

In short, the issue of costs is not easy to resolve mathematically. Instead, the issue boils down to a question of values. As my colleague, Professor Steve Taylor, Co-director of the Syracuse University Center on Human Policy, Law and Disability Studies – who has worked to promote community living for people with intellectual disabilities for more than three decades – has written,

> I gave up on making the economic argument to support community living years ago. That's not the point. The issue has to do with freedom and community participation. No one has ever demonstrated that institutions are more cost-effective. So, how can the segregation and confinement of people with disabilities be justified on policy grounds? My position is that the government should make available the money paid for institutions for people to live in the community.[215]

A third reason for the continued use of institutions and even large hostels for people with disabilities in Israel, in particular, relates to parentalism.[216] This view is based on the government's decision to 'take care' of people who it deems are unable to care for themselves. The parentalistic view of disability reveals that the continued use of institutions and hostels is not so much about coercing people into particular living arrangements, as it is about the perception by the government that people with disabilities simply do not have the same 'right' as non-disabled people to live where they want and with whom.[217] According to this view, it is the role of government to protect people with disabilities from dangers that may lurk in the community. But such concerns about the potential dangers or risks for people living in their own homes are without merit for several reasons.

First, the view that people with disabilities are at greater risk in the community than they are in secured facilities assumes that the government has no power to develop and provide services that can support people living in their own homes in the community in order to prevent them

[214] For example, in Oregon, nursing homes cost $5,900 per month while community-based services cost only $1,200 on average. Nonetheless, in some places, home-care workers are being cut over the more expensive nursing home programmes because the state receives federal reimbursement for nursing home care but not for home-care services: see John Leland, 'Cuts in Home Care Put Elderly and Disabled at Risk', New York Times, 20 July 2010, available at http://www.nytimes.com/2010/07/21/us/21aging.html?_r=1&th=&emc=th&pagewanted=all.

[215] Email from Dr Steve Taylor, Syracuse University, 28 August 2010 (on file with the author).

[216] I use the term 'parentalistic' as a gender-neutral term since such views are espoused by men and women alike.

[217] As early as 1966, Jacobus tenBroek observed that one's physical limitations have less to do with where one lives and how one lives than do the attitudes of the public about people with disabilities, generally. As he wrote in his seminal article, Jacobus tenBroek (n 71) 841–42: 'The actual physical limitations resulting from the disability more often than not play little role in determining whether the physically disabled are allowed to move about and be in public places. Rather, that judgment for the most part results from a variety of considerations related to public attitudes, attitudes which not infrequently are quite erroneous and misconceived. These include public imaginings about what the inherent physical limitations must be; public solicitude about the safety to be achieved by keeping the disabled out of harm's way; public feelings of protective care and custodial security; public doubts about why the disabled should want to be abroad anyway; and public aversion to the sight of them and the conspicuous reminder of their plight': ibid 842.

from becoming placed in danger. It is true that in the US, as elsewhere, many people who left institutions in the 1970s and 1980s did not have adequate community support. However, to the extent that the US or other countries may have erred in the past by their failure to develop adequate support systems for people in the community, is no reason to assume that Israel cannot learn from others' mistakes and prevent similar problems from occurring.

Further, the fact remains that for many people with disabilities in the US and elsewhere, de-institutionalisation brought not loneliness, danger or homelessness, but rather the opportunity to live in their own homes and pursue their life dreams. In fact, in the US, 12 states have now closed *all* of their institutions for people with intellectual disabilities,[218] and at least 17 states have expended more than 80 per cent of their budgets on people with intellectual disabilities living in the community.[219] No increased danger to the former residents has been reported. Similarly, in Italy – which has now closed all its mental hospitals and which has an extensive system of case management and support for people with psychosocial disabilities – fears about risks to the clients have not materialised. In fact, what such arguments fail to recognise is that far more neglect and abuse occurs in institutions than is experienced in the community, particularly against women with disabilities.[220] Having said that, however, government officials and families often have in mind only the best intentions toward people with disabilities. They send people to institutions in order to provide a safe and stable environment for those whom they see as unable to take care of themselves. But such intentions, even the best, may not justify depriving people with disabilities of the opportunity to live in their own homes in the community, as a matter of law, just like people without disabilities.

Second, this parentalistic view assumes that all people with disabilities are the same; they are not. Clearly, people with disabilities have very different needs and capabilities. Some people may have medical, social, rehabilitation or psychological services, or all three. Other people may have no medical needs but may need services that are accessible; at the other extreme are people who are so severely affected by stroke or other diseases that they cannot live without 24-hour nursing care. However, in between are the millions of people who have a range of impairments who need some services, but not for 24 hours a day. Yet, based on its parentalistic impulse, the state will

[218] The 12 states are as follows (the date given indicates the year in which the last institution closed): District of Columbia (1991), New Hampshire (1991), Vermont (1993), Rhode Island (1994), Alaska (1997), New Mexico (1997), West Virginia (1998), Hawaii (1999), Maine (1999), Minnesota (2000), Indiana (2007) and Oregon (2009). Thirty-eight states, including the District of Columbia, also have closed at least one institution: 'Status of Institutional Closure Efforts in 2005', Policy Research Brief, Research and Training Center on Community Living, Institute on Community Integration, College of Education and Human Development, University of Minnesota, vol 16, No 1, 2005.

[219] Correspondence from Steve Gold, 'Comparing *Olmstead* Implementation Among Disabilities', Information Bulletin No 322 (9/2010), 8 September 2010 (on file with the author).

[220] See, for example, Mary Ellen Young and others, 'Prevalence of Abuse of Women with Physical Disabilities' (1997) 78 Archives of Physical Medicine and Rehabilitation S34, S35; James Schaller and Jennifer Lagergren Frieberg, 'Issues of Abuse for Women with Disabilities and Implications for Rehabilitation Counseling' (1998) 29 Journal of Applied Rehabilitation Counseling 9. See also US International Council on Disabilities, 'Abuse of Human Rights of People in Social Care Institutions: Access to Justice for People with Disabilities', 11 December 2009, available at http://www.usicd.org/index.cfm/news_abuse-of-human-rights-of-people-with-disabilities-in-social-care-institutions-access-to-justice-for-people-with-disabilities.

choose to take care of these people in institutions or institution-like settings, and as cheaply as possible.[221]

In Israel, the parentalistic view that people with disabilities need to be taken care of in communal settings rather than in their own homes may be deeply imbedded in Israeli culture. Israel's history of socialism whereby the government provides care and resources to those in need, as well as Israel's communal child-raising culture within the kibbutz movement, may help to explain the Ministry's tendencies towards institutions and congregate living.[222] Israel's history of taking in countless children after the Holocaust and placing them in youth villages, as well as the youth villages that continue today for children from abusive families, may also account for Israel's approach to providing services for people with disabilities in communal settings rather than in individual homes, with supports as needed. Such policies, however, can no longer be justified by the communitarian impulses of the early Israel state. Today, socialism has been replaced by privatisation in most areas of life, including on the kibbutz. Further, on those kibbutzim that still exist, there are no longer children's houses where children live apart from their parents. The fact remains that the vast majority of Israelis (without disabilities) today live in their own homes or apartments. Nonetheless, many people with disabilities, even those capable of living on their own (with or without supports), are required to live in institutions or hostels, segregated from society, in order to receive the services they need. As a result, the right of people with disabilities to live in their own homes in typical residential neighbourhoods remains illusory for a large segment of Israel's disabled population.

6. CONCLUSION

In this article, I have argued for the right of all people, regardless of the type or severity of their impairments, to live in their own homes, with supports as needed. This right to live in one's own home, regardless of one's disability, is protected, I have argued, by international human rights laws as well as the domestic laws of the United States and Israel. The long history of institutionalisation, followed by the development of community living options that essentially repeat the patterns and isolation of institutions, to which people with disabilities have been subjected in the US, Israel and elsewhere, is inconsistent with the goals and requirements of the CRPD. Courts and the legislatures in Israel and the US have begun to address the issue of whether or not people with disabilities should have choices equal to others regarding where and with whom they live. Further, realisation of the right of all people with disabilities to live in their own homes also

[221] See, for example, Daphne Gloag, 'Severe Disability: 2 – Residential Care and Living in the Community' (1985) 290 British Medical Journal 368.

[222] See, for example, Shmuel Noah Eisenstadt, *The Transformation of Israeli Society: An Essay in Interpretation* (Westview Press 1985) Pt 2; Sammy Smooha, *Israel: Pluralism and Conflict* (University of California Press 1978). For a discussion of the kibbutz movement, see Ernest Krausz (ed), *The Sociology of the Kibbutz* (Transaction 1983); Bruno Bettelheim, *Children of the Dream: Communal Child-Rearing and American Education* (Simon and Schuster 1997).

realises the promise of the 1948 Universal Declaration of Human Rights that 'all human beings are born free and equal in dignity and rights'.

In 1894, years before his appointment to the US Supreme Court, Louis Brandeis appeared to testify at public hearings in Boston, Massachusetts, which were investigating conditions in public poorhouses that housed many people with and without disabilities. In his testimony, Mr Brandeis discussed the meaning of 'home' in contrast to the poorhouses he had visited. His words ring true even today:

> That place may be as clean today, or any day, as any place in Christendom; the food may be as good, the air may be perfect; you may have beds in woven-wire mattresses as good as any that can be found; the attendants and the discipline and work may all be there. But that place as it presented itself to us is as far from a home as one pole is from another. It is the very opposite of a home in every particular.[223]

Now, more than two centuries later, the right of people with disabilities to live in their own homes has still not been realised. In Israel, as in the US, many people with disabilities are forced to relinquish their home and family life to enter institutions in order to receive the treatment and support they need. This pattern continues today, despite evidence that many such people have a higher quality of life when they live independently in the community as opposed to when they do not.[224]

Further, in Israel as in the US, some assistance to help individuals and families to remain in their own homes is available, but not enough to meet the need.[225] For example, the Ministry of Labor and Social Affairs, as well as the National Insurance Institute, provide funds to help families in Israel keep their children at home, with cash benefits and funding for home renovations to increase accessibility, respite care, and other medical and therapeutic services. The Ministry of Health also has been proactive in developing supports and funding programmes

[223] *Documents of the City of Boston for the Year 1894*, Vol 6 (Rockwell & Churchill, City Printers 1895) 3632–33, quoted in David Ferleger, 'Disability Rights: A Vision of the Future', Jacobus tenBroek Disability Law Symposium: Equality, Difference, and the Right to Live in the World Conference, Baltimore, MD, 15–16 April 2010, 3, available at http://bbi.syr.edu/projects/tenBroek/documents/ferleger_TenBroek_speech.pdf.

[224] See, for example, Julie Robison and others, 'Community-Based Versus Institutional Supportive Housing: Perceived Quality of Care, Quality of Life, Emotional Well-Being, and Social Interaction' (2011) 30 Journal of Applied Gerontology 275, online version available at http://jag.sagepub.com/content/30/3/275; Dalia Mandler and Denise Naon, 'Integrating People with Disabilities into the Community: Learning from Success', JDC, Brookdale Institute of Gerontology and Human Development, Jerusalem, 2002 (on file with the author) (a study of 15 people with disabilities who live independently in the community, and their life stories were examined with regard to occupation, housing, family, social life and education); Susan L Parish and others, 'Family Support for Families of Persons with Developmental Disabilities in the US: Status and Trends', Policy Research Brief, The College of Education and Human Development, June 2001, 12, cited in Chris Plauche Johnson, Theodore A Kastner and the Committee/Section on Children with Disabilities, 'Helping Families Raise Children with Special Health Care Needs at Home' (2005) 115 Pediatrics 507, 509.

[225] See Social Services Law, 1958 (Israel). This assistance comes from two sources, the Ministry of Social Affairs and the National Insurance Institute, according to Israel's Social Services Law. Funds provided to individuals and families of people with disabilities may cover personal aids, therapy services, respite services as well as funding for home modifications to make a home or an apartment accessible. However, if a person is considered to be 'too disabled' for in-home services, then an out-of-home placement will be provided in lieu of services to help keep the person at home.

for people living in the community through its supported housing scheme. But even these schemes and the benefits they provide are often insufficient to provide the ongoing support needed by many individuals and their families. Further, if a government ministry decides that the family member is 'too disabled' for in-home placement, or if adult children wish to leave home and live in supported housing on their own, as in *Lior Levy*, lack of government support and access to services may remain an insurmountable obstacle towards achieving that goal.

While many countries have a long way to go to even begin to develop a system for community-based services, other countries, such as the US and Israel, already have such a system in place. Nonetheless, concerns about lack of funds remain a barrier to the development of the in-home services that many people with disabilities need. Lack of funding as well as misplaced funding priorities are certainly part of the problem, as discussed above. But in those US states that have closed institutions and used the money from the institutions to support people living in typical housing in the community, funding is not a barrier.[226] Moreover, even in those states, such as New York, where many institutions still exist, supported community housing for people with disabilities has been found to be more cost-effective.[227] Indeed, housing in the community has been found not only to be cost-effective in many places in the short term, but also may present cost savings over time as people with disabilities who live in the community become more independent and self-sufficient within their communities.[228]

The challenge now for policy makers, self-advocates and their allies is to change existing policies and practices to fully implement the right of all persons with disabilities to live in their own homes in the community, with supports as needed. It will take time before institutions and

[226] According to Braddock (n 206), 12 states have closed all of their institutions (see n. 218) and 38 states have closed at least one institution: 'Status of Institutional Closure Efforts in 2005' (n 218). Research also indicates that between 1996 and 2000, all states except Missouri and North Dakota reduced their public institutional populations: David Braddock (ed), *Disability at the Dawn of the 21st Century and the State of the States* (American Association on Mental Retardation 2002). However, there is wide variation between states with regard to trends in de-institutionalisation. The states with the greatest percentage reduction (40–86%) in public institution populations between 1996 and 2000 were Kansas, Maine, Minnesota, New York, Oregon and Tennessee: ibid. During the same time period, 15 other states reduced their institutional populations by less than 15%. These states are Arkansas, Delaware, Florida, Illinois, Iowa, Kentucky, Mississippi, Missouri, Nebraska, Nevada, North Carolina, North Dakota, Ohio, Texas and Washington: ibid. See also Robert W Prouty, Gary Smith and K Charlie Lakin (eds), 'Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004', Research and Training Center on Community Living, Institute on Community Integration, College of Education and Human Development, University of Minnesota, July 2005, available at http://rtc.umn.edu/publications/index.asp#risp. In contrast, 13 states have not closed any public institutions; these states are Arkansas, Delaware, Idaho, Iowa, Louisiana, Mississippi, Nebraska, Nevada, North Carolina, Utah, Virginia, Wisconsin (although Wisconsin is now very close to doing so) and Wyoming: Braddock, ibid. The states which continue to support an 'extensive network of public institutions' are Arkansas, Louisiana, Mississippi, North Carolina and Virginia: ibid.

[227] *DAI v Paterson* (n 124) 283–98.

[228] ibid 306. The judge stated that supported housing was less expensive than adult homes: 'The annual cost to the state of serving an adult home resident in supported housing is on average $146 cheaper than the cost of serving that resident in an adult home.' In addition, the judge noted that the total cost for a mentally ill person in supported housing was $40,253 a year, compared with $47,946 for a resident in an adult home. A chart in the decision showed that the Medicaid cost for an adult home resident was nearly double the cost for someone in supported housing: ibid.

institution-like facilities are phased out and all people with disabilities are living in their own homes. But there has been progress in the international and domestic legal arenas. The CRPD recognises the right of all people with disabilities to 'live in the community, with choices equal to others'. It is now time to fully implement this mandate and provide real homes for people with disabilities in communities where they choose to live and where those of us with and without disabilities will have the benefit of getting to know them as neighbours. Only then will people with disabilities, in the United States, Israel and throughout the world, begin to realise their rights under their own countries' laws as well as the UN Convention on the Rights of People with Disabilities.