

# 10-235-cv(L)

10-251-cv(CON), 10-767-cv(CON), 10-1190-cv(CON)

---

---

IN THE  
**United States Court of Appeals**  
FOR THE SECOND CIRCUIT

---

---

DISABILITY ADVOCATES, INC., UNITED STATES OF AMERICA,

*Plaintiffs-Appellees,*

v.

NEW YORK COALITION FOR QUALITY ASSISTED LIVING,  
EMPIRE STATE ASSOCIATION OF ASSISTED LIVING,

*Movants-Appellants,*

*(Additional Caption On the Reverse)*

---

*On Appeal from the United States District Court  
for the Eastern District of New York (Brooklyn)*

---

---

**BRIEF OF THE COALITION OF INSTITUTIONALIZED AGED AND  
DISABLED, COMMUNITY ACCESS, DISABLED IN ACTION, FRIA, THE  
GERIATRIC MENTAL HEALTH ALLIANCE OF NEW YORK, THE  
INSTITUTE FOR COMMUNITY LIVING, THE LONG TERM CARE  
COMMUNITY COALITION, THE MENTAL HEALTH ASSOCIATION IN NEW  
YORK STATE, INC., MENTAL HEALTH ASSOCIATION OF NEW YORK CITY,  
THE MENTAL HEALTH EMPOWERMENT PROJECT, INC., NATIONAL  
ALLIANCE ON MENTAL ILLNESS OF NEW YORK CITY, THE NEW YORK  
ASSOCIATION ON INDEPENDENT LIVING, THE NEW YORK ASSOCIATION  
OF PSYCHIATRIC REHABILITATION SERVICES, SCHUYLER CENTER FOR  
ANALYSIS AND ADVOCACY, THE TRUSTEES OF COLUMBIA UNIVERSITY -  
COMMUNITY SUPPORT SYSTEM PROGRAM AND VENTURE HOUSE AS  
*AMICI CURIAE* SUPPORTING PLAINTIFFS-APPELLEES**

---

---

*On the Brief:*

Peter K. Vigeland  
Michael Bongiorno  
David F. Olsky  
Omar Khan  
Natalie Rastin  
Leizel A. Ching

WILMER CUTLER PICKERING HALE AND DORR LLP  
399 Park Avenue  
New York, New York 10022  
212-230-8800

*Attorneys for Amici Curiae*

---

---

---

---

DAVID A. PATERSON, in his official capacity as Governor of the State of New York,  
RICHARD F. DAINES, in his official capacity as Commissioner of the New York State  
Department of Health, MICHAEL F. HOGAN, in his official capacity as Commissioner  
of the New York State Department of Mental Health, New York State  
Department of Health, New York State Office of Mental Health,

*Defendants-Appellants.*

---

---

**STATEMENT PURSUANT TO RULE 26.1  
OF THE FEDERAL RULES OF APPELLATE PROCEDURE**

*Amici Curiae* The Coalition of Institutionalized Aged and Disabled, Community Access, Disabled In Action, FRIA, The Geriatric Mental Health Alliance of New York, The Institute for Community Living, The Long Term Care Community Coalition, The Mental Health Association in New York State, Inc., Mental Health Association of New York City, The Mental Health Empowerment Project, Inc., National Alliance on Mental Illness of New York City, The New York Association on Independent Living, The New York Association of Psychiatric Rehabilitation Services, Schuyler Center for Analysis and Advocacy, The Trustees of Columbia University – Community Support System Program, and Venture House are non-profit corporations and associations. The parent corporation of The Mental Health Association in New York State, Inc. is Mental Health America. The remaining *Amici* have no parent corporations and are not owned, in whole or part, by any publicly held corporations.

## TABLE OF CONTENTS

INTRODUCTION AND STATEMENT OF INTEREST .....	1
ARGUMENT .....	8
I. For Over Thirty Years, Adult Homes Have Been the Subject of Government Investigations and Public Outcry.....	9
II. Residents of Adult Homes Continue To Suffer Discrimination On The Basis Of Their Disability.....	15
III. The Long-Standing Problems at Adult Homes Will Continue Unless the District Court’s Order Is Affirmed.....	18
CONCLUSION .....	22

**TABLE OF AUTHORITIES**

**CASES**

*Disability Advocates, Inc. v. Paterson*,  
653 F. Supp. 2d 184 (E.D.N.Y. 2009)..... *passim*

*Locher v. Unum Life Insurance Co. of America*,  
389 F.3d 288 (2d Cir. 2004) ..... 8

*Olmstead v. Zimring*,  
527 U.S. 581 (1999) ..... 8

**STATUTES, CODES & RULES**

42 U.S.C. §§ 12131-65 (2006)..... 2, 8

N.Y. Mental Hygiene Law § 45.07 ..... 12

**OTHER AUTHORITIES**

Charles J. Hynes, Deputy Attorney General, *Private Proprietary Homes for Adults: An Interim Report* (March 31, 1977) ..... 10

Charles J. Hynes, Deputy Attorney General, *Private Proprietary Homes for Adults: A Second Investigative Report* (March 31, 1979)..... 10, 11

Clifford J. Levy, *Here, Life is Squalor and Chaos*, N.Y. Times, Apr. 29, 2002 ..... 13, 14, 20

Clifford J. Levy, *For Mentally Ill, Death and Misery*, N.Y. Times, Apr. 28, 2002 ..... 13, 14

Clifford J. Levy, *Voiceless, Defenseless And a Source of Cash*, N.Y. Times, Apr. 30, 2002..... 13, 20

Clifford J. Levy and Sarah Kershaw, *Inquiry Finds Mentally Ill Patients Endured “Assembly Line” Surgery*, N.Y. Times, Mar. 18, 2001 ..... 13

Expert Report of Dennis Jones, April 6, 2006..... 11, 18

Expert Report of Elizabeth Jones, April 5, 2006 .....	17
Expert Report of Kenneth Duckworth, April 6, 2009.....	17, 19, 20
Letter from New York State Department of Health to Adult Care Facility Operators, DAL-HCBC-03-08 (December 10, 2003).....	20
New York State Commission on Quality of Care for the Mentally Disabled, <i>Adult Homes Serving Residents with Mental Illness: A Study of Conditions, Services, and Regulation</i> (October 1990).....	12, 19
New York State Commission on Quality of Care for the Mentally Disabled, <i>Exploiting Not-For-Profit Care in an Adult Home: The Story Behind Ocean House Center, Inc.</i> (December 2001) .....	12, 13
Office of Long-Term Care, New York State Department of Health, <i>Garden of Eden Home Inspection Report</i> (December 10, 2009) .....	17, 20
Report of the Adult Care Facilities Workgroup (October 2002).....	14, 15
William Castro <i>et al.</i> , <i>The Adult Home Industry: A Preliminary Report</i> (January 1979).....	9, 11

## INTRODUCTION AND STATEMENT OF INTEREST

*Amici Curiae* The Coalition of Institutionalized Aged and Disabled, Community Access, Disabled In Action, FRIA, The Geriatric Mental Health Alliance of New York, The Institute for Community Living, The Long Term Care Community Coalition, The Mental Health Association in New York State, Inc., Mental Health Association of New York City, The Mental Health Empowerment Project, Inc., National Alliance on Mental Illness of New York City, The New York Association on Independent Living, The New York Association of Psychiatric Rehabilitation Services, Schuyler Center for Analysis and Advocacy, The Trustees of Columbia University – Community Support System Program, and Venture House (“*Amici Curiae*”) are non-profit organizations dedicated to the provision of mental health and/or disability services to New York residents and to advocacy on behalf of those who receive such services.<sup>1</sup> With decades of experience in treating and working with individuals with disabilities, *Amici Curiae* provide the Court with a unique perspective on the treatment afforded in adult homes to individuals with disabilities.

The parties have consented to *Amici Curiae*’s filing of this brief.

---

<sup>1</sup> No party has authored the brief, in whole or in part. No person, party or party’s counsel – other than *Amici Curiae*, their members, or their counsel – contributed money that was intended to fund preparing or submitting the brief. *See* Local Rule 29.1(b).

*Amici Curiae* support the District Court's judgment below that the placement of individuals with disabilities into adult homes violates Title II of the Americans with Disabilities Act, 42 U.S.C. §§ 12131-65 (2006). *Amici Curiae* further support the District Court's remedial order requiring New York State to provide supported housing to any constituent of Disability Advocates, Inc., who would qualify for and choose supported housing. Adult homes have been the focus of government investigations and media scrutiny for decades and the evidence at trial proved the need for the relief ordered by the Court.

**The Coalition of Institutionalized Aged and Disabled** ("CIAD") provides residents in adult homes with the information and skills they need to advocate for themselves and protect their rights. CIAD was born out of a sense of disenfranchisement and isolation among residents of adult homes and nursing homes, and its leadership includes adult home residents and former residents. CIAD regularly visits adult homes and adult home residents in New York City.

**Community Access** provides a wide variety of services to more than 1,600 individuals with psychiatric disabilities each year, including job training, employment placement and other support services. Additionally, Community Access owns, leases and operates more than 800 units of permanent and transitional supportive housing for individuals with mental illness in New York City.

**Disabled In Action** (“DIA”) is a civil rights organization committed to ending discrimination against people with all disabilities. DIA fights to eliminate the barriers that prevent people with disabilities from enjoying full equality in American society. Founded in 1970, DIA is a democratic, membership organization consisting primarily of and directed by people with disabilities, providing an organizational basis for disabled activists to join in effective unified political action.

**FRIA** is a New York City-based non-profit organization dedicated to fostering the dignity and independence of seniors in long-term care settings, with a special focus on nursing home residents, and to ensuring that they receive prompt, high quality, compassionate care. FRIA seeks to accomplish this by helping friends and relatives become more informed and effective caregivers for their loved ones.

**The Geriatric Mental Health Alliance of New York** advocates for changes in mental health practice and policy toward elder adults with mental health issues.

**The Institute for Community Living** (“ICL”), a non-profit Human Service Agency founded in 1986, provides a comprehensive array of treatment and support services to thousands of New Yorkers who are coping with serious mental illness while living in the communities of their choice. ICL is accredited by the Commission on the Accreditation of Rehabilitation Facilities and has been the

recipient of many local and national awards over the years celebrating the services provided. ICL operates over 100 discrete programs within Brooklyn, Bronx, Queens, and Manhattan, including over 1400 housing options with each providing support to the individuals served.

**The Long Term Care Community Coalition** (“LTCCC”) is dedicated to improving care and quality of life for long-term care consumers. LTCCC researches policies, laws, and regulations affecting care for the elderly and disabled; advocates for state and national policies to improve care; addresses systemic problems in the delivery of long term care; identifies good practices and develops recommendations to improve care and dignity of the elderly and disabled, and to better conditions for professional caregivers; educates and empowers the elderly and disabled to advocate for themselves; and actively engages government agencies and elected officials in discussion and action on the needed changes.

**The Mental Health Association in New York State, Inc.** (“MHANYS”) and its local affiliates serve 54 counties in New York, working to ensure that New Yorkers have access to mental health services. MHANYS members include mental health consumers, family members, advocates, and professionals.

**Mental Health Association of New York City** (“MHA-NYC”) addresses mental health needs in New York City and across the nation. It is a local organization with a national impact and has a three-part mission consisting of

services, advocacy, and education. MHA-NYC identifies unmet needs and develops culturally sensitive programs to improve the lives of individuals and families affected by mental illness while promoting the importance of mental health.

**The Mental Health Empowerment Project, Inc.** (“MHEP”) is a recipient-run, non-profit organization organized in 1988 to develop and to strengthen self-help and mutual support activities throughout New York State. For twenty-three years, MHEP has placed a high value on promoting community partnerships and helping people find and connect with their personal power and the power of self-help. To that end, MHEP is committed to supporting and upholding the rights of people with a psychiatric diagnosis and fighting for their right to choice in all areas of their lives.

**National Alliance on Mental Illness of New York City** (“NAMI NYC-Metro”) is the largest affiliate of the National Alliance on Mental Illness. For more than thirty years, NAMI-NYC Metro has provided support, education, and advocacy to families and individuals whose lives are impacted by serious mental illness.

**The New York Association on Independent Living** (“NYAIL”) is a non-profit membership organization, representing Independent Living Centers throughout New York State, which works to remove barriers to the full community

integration of people with disabilities. Independent Living Centers (“ILCs”) are community-based providers of services, supports, and advocacy to people with all types of disabilities and of all ages, and are controlled by and largely staffed by people with disabilities. NYAIL works with ILCs, their partners, and people with disabilities to ensure their independence and civil rights, including the availability of community-based, fully integrated services and supports in the areas of health and long term care, housing, education, employment, and transportation.

**The New York Association of Psychiatric Rehabilitation Services**

(“NYAPRS”), founded in 1981, is a non-profit organization dedicated to improving services and social conditions for people with psychiatric disabilities or diagnoses, and those with trauma-related conditions by promoting their recovery, rehabilitation, and rights. NYAPRS membership includes over 100 community mental health service agencies and thousands of New Yorkers with psychiatric disabilities who support the efforts of tens of thousands of New Yorkers by providing a wide range of services that share a fundamental belief in the capacity for recovery, healing, independence, and community integration for every individual with a psychiatric disability.

**The Schuyler Center for Analysis and Advocacy (“SCAA”)**, established in 1872, is a statewide, independent, non-profit public policy research and advocacy think tank based in Albany, New York. SCAA promotes the public

interest by advancing policies to improve health, welfare, and human services for all New Yorkers, with a special focus on low-income and vulnerable persons.

**The Trustees of Columbia University – Community Support System Program** operates a psychiatric day treatment program and provides supported case management for persons with mental illness in the greater Harlem area.

**Venture House** is a non-profit organization operating a Clubhouse, certified by the International Center for Clubhouse Development, for people with a mental illness in Jamaica, Queens since 1987. Venture House provides a recovery-based program focused on work and independence that includes employment opportunities, skill building, social and recreational opportunities, housing supports, and participation in a community of their own choosing. Venture House currently has an active membership of over 350 adults.

## ARGUMENT

For nearly thirty years, the State of New York has funneled individuals with disabilities into privately owned adult homes in violation of Title II of the Americans with Disabilities Act, 42 U.S.C. §§ 12131-65. *See Olmstead v. Zimring*, 527 U.S. 581, 597 (1999) (“Unjustified isolation, we hold, is properly regarded as discrimination based on disability.”). Initially intended as an *ad hoc*, temporary housing solution when the State began deinstitutionalizing its psychiatric hospitals in the early 1970s, these privately run for-profit adult homes nevertheless have endured as “de facto . . . satellite mental institutions.” *Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d 184, 197 (E.D.N.Y. 2009) (“*DAP*”) (SPA 87). For the past three decades, government investigations and newspaper reports have uncovered widespread resident abuse, neglect, fraud, and corruption at adult homes. State efforts at integrating the individuals consigned to these “little ghettos,” *id.* at 203 (SPA 93), have been largely unsuccessful.

The District Court’s factual findings – which were based on a five-week bench trial in which twenty-nine witnesses testified and three hundred exhibits were entered into evidence, and which the State and its supporting *amici curiae* address only in passing – should be affirmed. *See Locher v. Unum Life Ins. Co. of Am.*, 389 F.3d 288, 293 (2d Cir. 2004) (factual findings from bench trial are reviewed for clear error). Those findings confirm that the District Court’s order is

critical to preventing further violations of the ADA, and to transforming the culture of dependency that these facilities foster. Absent the remedy ordered by the District Court, individuals with disabilities who are qualified to live outside of an institutionalized setting – the vast majority of individuals with disabilities living at adult homes – will continue to suffer discrimination on the basis of their disability.

**I. For Over Thirty Years, Adult Homes Have Been the Subject of Government Investigations and Public Outcry.**

Most adult homes are privately owned, for-profit facilities that were originally conceived to service a “well-elderly population;” individuals requiring medical or psychiatric care were historically placed in nursing homes or in psychiatric facilities. William Castro, *The Adult Home Industry: A Preliminary Report* 13 (January 1979) (PX(1) at 576); *see also DAI*, 653 F. Supp. 2d at 197 (SPA 87). When the State of New York began deinstitutionalizing its psychiatric hospitals in the 1970s, patients were discharged directly into adult homes because

State and local authorities could not accommodate the sudden increase in demand for adequate community-based services. *Id.*<sup>2</sup>

Shortly after State psychiatric hospitals began discharging patients directly into adult homes, New York State and City officials initiated civil and criminal investigations of those facilities. Reports published by then-Deputy Attorney General Charles Hynes found that adult homes had been transformed into “de facto mental institutions” and “satellite mental institutions.” *See* Charles J. Hynes, Deputy Attorney General, *Private Proprietary Homes for Adults: An Interim Report* (March 31, 1977); Charles J. Hynes, Deputy Attorney General, *Private Proprietary Homes for Adults: A Second Investigative Report 1* (March 31, 1979)

---

<sup>2</sup> This practice of funneling individuals with mentally illness from State psychiatric hospitals continues today, such that twenty-eight of the forty-four adult homes in New York City that have more than 120 beds are considered “impacted,” meaning that a significant portion of the resident population have mental illness. *DAI*, 653 F. Supp. 2d at 195-96 (citing Department of Health 2008 Census Report) (SPA 64-67). As of December 31, 2008, more than eighty percent of the total resident population in these twenty-eight homes was reported as having mental illness. *Id.* Eighteen of these homes reported that more than ninety-five percent of residents have mental illness, and nine of these were homes in which every resident has a mental illness. *Id.*

(PX(1) at 453).<sup>3</sup> The reports noted “the existence of unhealthy, unsanitary and unsafe living conditions” and further that, “[i]nadequate food, in amount and nutritional value, is a continuing problem and the subject of frequent complaints. . . . Inadequate staffing is widespread and causes deficiencies in personal care services, housekeeping and maintenance.” *Id.* at 17.

Around the same time as the Hynes investigation, the New York City Council Subcommittee on Adult Homes conducted its own investigation. A preliminary report similarly found that the majority or a very large minority of adult home residents were former mental patients, thereby creating “satellite mental institutions.” *See* William Castro, *The Adult Home Industry: A Preliminary Report* 14 (January 1979) (PX(1) at 577). The report further found “the widespread use of adult homes as ‘dumping grounds’ for former mental patients.” *Id.* at 2.

Beginning in 1977, the State attempted to address the horrific conditions in adult homes through the legislation and regulation of these institutions. *See* Hynes, *Private Proprietary Homes for Adults: A Second Investigative Report* at 7 (PX(1)

---

<sup>3</sup> Numerous reports have “highlighted the fact that adult homes were neither established nor regulated with the needs of persons with serious mental illness in mind. The reports found adult homes to be stark and regimented environments with a fundamental lack of privacy and individual decision making for residents. In addition, these reports expressed serious concerns about living conditions, lack of connection to community mental health resources, and over utilization of some Medicaid services.” Expert Report of Dennis Jones (“Jones Report”), April 6, 2006, at 7 (SX(4) at 284).

at 418). Time and again, however, legislative efforts proved inadequate to cure the fundamental failings of adult homes. In 1989, ten years after the implementation of the initial regulations on adult homes, the New York State Commission on Quality of Care for the Mentally Disabled (“CQC”), an independent State agency, conducted an audit. *See* N.Y. Mental Hyg. Law § 45.07. The CQC found that a significant number of adult homes had “seriously deficient conditions that adversely affected the day-to-day living conditions, safety, supervision and health of the residents.” *See* CQC, *Adult Homes Serving Residents with Mental Illness: A Study of Conditions, Services, and Regulation* (October 1990) (PX(1) at 3):

The widespread deficiencies in these homes were usually first signaled by poor exteriors and yard maintenance even before reviewers entered the homes. Once inside, the inattention to basic living conditions for residents was pervasive. Routine maintenance had apparently been neglected long term, and often serious, long-standing plumbing and roof leaks further contributed to poor conditions. The terrible odors of these homes were usually the first sign to a visitor of the serious underlying housekeeping problems. Bathrooms and resident bedrooms, as well as common living areas in many of the homes, clearly had not been attended to for long periods of time.

*Id.* at 12 (PX(1) at 21).

Ten years later, in 2001, the CQC issued another report that was focused on the Ocean House adult home. The report documented widespread fraud and misuse of residents’ and State money. *See* CQC, *Exploiting Not-For-Profit Care in an Adult Home: The Story Behind Ocean House Center, Inc.* 1 (December 2001)

(PX(1) at 684). In addition to finding that treatment plans and activities were inadequate, the CQC's report revealed that despite the significant amounts of State and federal money spent on adult home residents, the quantity and type of services provided to these residents appeared to be driven more by greed than by residents' needs. *Id.* at *i* (PX(1) at 678).

In April 2002, shortly after the publication of CQC's report on Ocean House, Clifford Levy wrote a Pulitzer Prize-winning series of articles in the New York Times reporting on the "squalor and chaos" in large New York City adult homes, including the extraordinary number of deaths occurring in those facilities.<sup>4</sup> See Clifford J. Levy, *For Mentally Ill, Death and Misery*, N.Y. Times, Apr. 28, 2002, §1, at A1; Levy, *Here, Life is Squalor and Chaos*, N.Y. Times, Apr. 29, 2002, at A1; Levy, *Voiceless, Defenseless and a Source of Cash*, N.Y. Times, Apr. 30, 2002, at A1. At twenty-six of the largest and most troubled homes in the city, there were 946 deaths documented from 1995 through 2001. Of those, over a third were individuals under the age of 60, including 126 between the ages 20 and 49. Levy, *For Mentally Ill, Death and Misery*, Apr. 28, 2002, §1, at A1. The Times' analysis showed that the causes of death of these residents ranged from residents suffering heat exhaustion in their rooms during heat waves, to residents throwing

---

<sup>4</sup> The New York Times earlier reported on "assembly line" prostate surgery being performed on unwitting residents of Leben Home. See Clifford J. Levy and Sarah Kershaw, *Inquiry Finds Mentally Ill Patients Endured "Assembly Line" Surgery*, N.Y. Times, Mar. 18, 2001, §1, at 1.

themselves from rooftops, to residents succumbing to routinely treatable ailments such as burst appendixes and seizures. *Id.*

Inspection reports for many adult homes during the same seven-year period frequently noted “filthy and vermin-ridden rooms.” *Id.* The reports also noted the poor, and often fraudulent, record-keeping by administrators involving the residents’ money and care. For example, a 2001 State inspection of an adult home in Brooklyn noted that the operator was “routinely threatening residents.” *Id.* A 1999 inspection report from another adult home in Brooklyn documented that investigators refused fully to examine rooms because they were so foul. *See Levy, Here, Life is Squalor and Chaos*, at A1. Another report noted that an inspector encountered dead cockroaches when looking into medication boxes. *Id.*

In the spring of 2002, at the Governor’s direction, the State of New York commissioned another comprehensive review of adult homes. This review concluded that these facilities are inappropriate settings for individuals with mental illness and that these individuals should be served in integrated community-based programs. *See Report of the Adult Care Facilities Workgroup (October 2002) (SX(4) 30-143)*. In particular, the report stated:

Although [the adult home] model may be effective and appropriate for some elderly New Yorkers who are physically frail, it does not provide adequate care and quality services to residents with psychiatric disabilities. Documented problems with quality of care and quality of life for a small segment of the industry date back to the 1970’s.

*Id.* at i (SX(4) at 33).

## **II. Residents of Adult Homes Continue To Suffer Discrimination On The Basis Of Their Disability**

As the District Court extensively documented in its opinion, adult homes still “have . . . some of the elements of a homeless shelter and some of the elements of a state hospital.” *DAI*, 653 F. Supp. 2d at 203 (SPA 93). Indeed, former Office of Mental Health (“OMH”) Senior Deputy Commissioner Linda Rosenberg testified the homes were “little ghettos” with residents “sitting out front [of] the adult home, smoking, going back in, sitting in the lobby, [with] not much going on and not much exposure to the rest of the world.” *Id.* Susan Bear, the Assistant Executive Director of a large New York City mental health provider (and witness for the State), similarly described the adult homes located in Coney Island as “community-based psychiatric ghettos.” *Id.* at 218 (SPA 102).

Adult homes implement strict, regimented programs that are designed to control nearly every aspect of the residents’ daily living. Their residents “line up to receive meals, medication, and money at inflexibly scheduled times during the day,” and “have next to no privacy or autonomy in their own daily lives, and they are discouraged, and most often prohibited, from managing their own activities of daily living, such as cooking, taking medication, cleaning, and budgeting.” *Id.* at 199, 224 (SPA 89-90, 114); *see also id.* at 214-15 (SPA 104-05). The failure to

comply with the home's daily regimen is met with swift punishment and retaliation. One resident testified about meal times at his facility being so strict that residents who were late did not eat. JA 166. The staff at adult homes have been known to refuse to provide medication if a resident misses the prescribed time for dispensing medication. JA 183, 187. Residents who fail to take their medication on time or to participate in the day programs organized by the homes are threatened with being sent to the hospital, kicked out of the home, sent to a nursing home, and denied their daily personal needs allowance. *Id.*

Privacy at the homes is nonexistent. Meals, medication, phone calls, and mail deliveries are announced over a public address system. *DAI*, 653 F. Supp. 2d at 200 (SPA 90). The residents' mail is routinely opened before they receive it, particularly if the mail appears to pertain to pending litigation against the homes. JA 185-86. Staff at adult homes have copies of all the room keys and often simply enter the residents' bedrooms without knocking. Adult homes restrict when and where residents may receive visitors, requiring visitors to sign in and state the purpose of their visit. *DAI*, 653 F. Supp. 2d at 201 n.72 (SPA 91 n.72); JA 186. One of the resident witnesses at trial explained that when Clifford Levy, reporter for the New York Times, visited him, he attempted to take Mr. Levy to his room and "was literally followed by staff who emphatically told [him that he really didn't] want this person going in [his] room." JA 164.

Living conditions in the homes remain at sub-standard, and often deplorable, levels. A recent inspection report for the Garden of Eden facility detailed a bed bug infestation that had long gone unnoticed, notwithstanding the fact that several residents had visible bite marks and many more reported prolonged distress and discomfort. Office of Long-Term Care, New York State Department of Health, *Garden of Eden Home Inspection Report 8-15* (Dec. 10, 2009) (“Garden of Eden Inspection Report”). The expert reports submitted by DAI noted that residents frequently complain about many of the same problems that were brought to light in the Hynes investigation in the late 1970s, including the staff’s failure to provide adequate meals, or even to maintain basic cleanliness and hygiene at the adult homes. *See, e.g.*, Expert Report of Elizabeth Jones, April 5, 2006 at 6-7. Residents are actively discouraged from seeking employment, administering their own medication, or otherwise exercising any independence and autonomy in the homes. Expert Report of Kenneth Duckworth, April 6, 2009 (“Duckworth Report”) at 13-16 (SX(4) at 400-01).

Several witnesses testified at trial as to the improper financial relationships between the homes and health care providers, which were also highlighted in the CQC Reports. Ms. Rosenberg described the fiscal dependency between adult home operators and the providers that rent space in the homes to provide Medicaid-billable services to adult home residents. *DAI*, 653 F. Supp. 2d at 287-

88 (SPA 176-77). She testified that some adult home residents were at times unaware that they had home health aides – aides who were employed by the agencies owned by the adult home operators and whose services were billed to Medicaid. *Id.* She also described layering of “all of the medical services, all of the support services that could be billed through Medicaid that the adult home operator [ ] brought into the home,” with the most egregious instances involving unnecessary cataract surgery. *Id.* Similarly, Dennis Jones, former top mental health official for the states of Indiana and Texas and current federal court monitor for the District of Columbia’s mental health system, identified Medicaid over-utilization as a problem in adult homes. *Id.*

### **III. The Long-Standing Problems at Adult Homes Will Continue Unless the District Court’s Order Is Affirmed.**

As Mr. Jones noted, “decades of experience have shown that efforts to improve adult homes are likely to have little effect” because the potential for fraud and abuse is inherent in the adult home model of care. Jones Report at 8 (SX(4) at 285). The record evidence made clear the State’s reluctance to institute reform that would bring the State in compliance with Title II. Indeed, in the year before the District Court’s ruling, officials *continued* the State’s referrals of psychiatric patients to adult homes notwithstanding the pending litigation. *DAI*, 653 F. Supp. 2d at 198 (Director of Case Management Services for the Office of Mental Health

assured facilities operators “in whatever way we can help to facilitate referrals to the adult home we would work with you and do that”) (SPA 88).

Individuals with disabilities placed in adult homes have no meaningful choice in their lives because, as the District Court found, “residents have expressed fear that they will be subjected to retaliation if they do not follow the Adult Home’s rules or complain about the Adult Home, and some have been arbitrarily penalized.” *Id.* at 201 (SPA 91). The residents’ intimidation and fear of reprisal is borne of the power differential between the staff and the residents, which can result in sanctions, and in some cases, overt abuse, for voicing complaints against the homes. Duckworth Report, at 11-12 (SX(4) at 398-99).

The intimidation and fear of retaliation reported by DAI’s experts and the resident witnesses are not isolated instances, but rather a pervasive feature of the adult home care system. The CQC’s 1990 Report found that residents filed “relatively few complaints despite the abundant, egregious, and persistent violations in some of these homes,” because they were “wary of provoking the wrath of the provider and jeopardizing their ‘home.’” New York State Commission on Quality of Care for the Mentally Disabled, *Adult Homes Serving Residents with Mental Illness: A Study of Conditions, Services, and Regulation* 42 (October 1990) (PX(1) at 49). The Times’ investigation revealed that there have also been reprisals against staff members and State inspectors who reported the

falsifying of records and other misconduct at adult homes. *See, e.g.*, Clifford J. Levy, *Here, Life Is Squalor and Chaos*, N.Y. Times, April 29, 2002 at A1; Clifford J. Levy, *Voiceless, Defenseless And a Source of Cash*, N.Y. Times, April 30, 2002 at A1. In a December 2003 letter to adult home facility operators, the Department of Health (“DOH”) stated that it “continues to receive complaints of threats and retaliation against residents by facility operators or staff when they have had contact with advocacy organizations, advocates or other parties.” Letter from New York State Department of Health to Adult Care Facility Operators, DAL-HCBC-03-08 at 2 (December 10, 2003). The latest inspection report for the Garden of Eden home illustrates the extent to which the homes exploit and abuse their control over residents:

Resident #1 through Resident #11 each expressed to the investigator that they were afraid to express their fears and anxieties to the operator and administrator because they were terrified of retaliation . . . . Each of the 11 residents detailed the operator’s threats to them being put out onto the street, forced to go to a hospital, forced to go to a nursing home, if they ever expressed their dislike . . . .

Garden of Eden Inspection Report at 1-3. Efforts to make adult homes cleaner, safer, and more rehabilitative do not change the power dynamic within adult homes. Duckworth Report at 11-12 (SX 4 at 398-99).

Even when the residents are able to overcome their fear of retaliation and approach the staff about alternatives, they often find themselves confronted with a hostile administration with contrary interests. JA 157-58. Adult homes are

private, for-profit entities for which the principal source of revenue – federal and State funding – depends on the extent to which the residents, as the vehicles for that funding, can be persuaded to remain at the adult home. *DAI*, 653 F. Supp. 2d at 256, 259 (SPA 146, 149). Most adult home residents pay for all or part of the cost of their housing with Supplemental Security Income (“SSI”), which is jointly funded by the State and the federal government. *Id.* at 283 (SPA 173). The homes also receive Quality Incentive Payments (“QuIP”) – grants awarded to adult homes based on the number of SSI-eligible residents living in the home. QuIP funds go directly to adult home owners and operators, not to adult home residents, for capital improvements and for the training and education of adult home staff. Legislative appropriations and grants for improving the infrastructure of the adult homes are yet another source of income. Through the “EnAbLE” program – Enhancing Abilities and Life Experiences – DOH has provided further grants of up to \$100,000 to adult homes to provide certain activities and services within the facilities. *Id.* at 292-93 (SPA 182-83). Finally, as noted in Section II *supra*, the homes also share in the Medicaid payments received by on-site or affiliated health care providers.

Adult home operators therefore have financial interests that are directly at odds with assisting residents in locating and applying for alternative settings. At trial, residents described their unsuccessful attempts to obtain assistance from

social workers or treatment professionals at adult homes – one testified as to receiving “very, very little” information despite repeated requests specifically for information on alternative housing. JA 157. Given this evidence, the District Court was correct to conclude that “Adult Homes (and the treatment providers employed by them) have no incentive to assist them in moving to alternative housing. . . . [C]ase managers and other providers have actually *discouraged* Adult Home residents who seek to move.” *DAI*, 653 F. Supp. 2d at 259 (SPA 149).

### CONCLUSION

For the reasons stated herein and in the briefs submitted by Disability Advocates, Inc. and the United States, this Court should affirm the District Court’s judgment and remedial order to end the decades-long discrimination against individuals with disabilities living in adult homes.

Submitted October 13, 2010  
New York, New York

/s/ Peter K. Vigeland  
Peter K. Vigeland  
Michael Bongiorno  
David F. Olsky  
Omar Khan  
Natalie Rastin  
Leizel A. Ching  
WILMER CUTLER PICKERING  
HALE AND DORR LLP  
399 Park Avenue  
New York, NY 10022  
Counsel for *Amici Curiae*

## CERTIFICATE OF COMPLIANCE

This brief contains 4,980 words, excluding the parts of the brief exempted by Fed. R. App. P. 32(a)(7)(B)(iii), and consequently complies with Fed. R. App. P. 32(a)(7)(B).

This brief complies with the typeface requirements of Fed. R. App. P. 32(a)(5) and the type style requirements of Fed. R. App. P. 32(a)(6) because this brief has been prepared in a proportionally spaced typeface using Microsoft Office Word 2003 (part of the MS Office Professional Edition 2003 edition) in Times New Roman 14-point font.

/s/ Peter K. Vigeland  
Peter K. Vigeland

## CERTIFICATE OF SERVICE

I hereby certify that on this 13<sup>th</sup> day of October, 2010, I caused to be served a copy of the attached Brief via the CM/ECF System as required under L.R. 25.1 (h)(2) upon all Filing Users.

Additionally, I caused a courtesy pdf version and two courtesy paper copies of the foregoing Brief to be sent via electronic mail and overnight delivery service to:

Christopher M. Egleson  
Akin Gump Strauss Hauer & Feld LLP  
One Bryant Park  
New York, New York 10036

Cecelia C. Chang  
Assistant Solicitor General  
Office of the Attorney General of the State of New York  
120 Broadway  
New York, NY 10271

/s/ Peter K. Vigeland  
Peter K. Vigeland