



Raising Expectations: Transitioning Adult Home Residents with Psychiatric Disabilities to New Housing

New York State Coalition for Adult Home Reform February 2011

The New York State Coalition for Adult Home Reform (NYSCAHR) works to improve the lives of the 12,000 people with psychiatric disabilities currently residing in adult homes. Since 2002, NYSCAHR has successfully coordinated the efforts of consumers and advocates to improve living conditions and strengthen supports in adult homes.

People with psychiatric disabilities living in adult homes have long been a neglected population. The new administration confronts a situation where thirty years of promises have been ignored or broken and where residents continue to languish in substandard housing. While a major court case to redress decades of wrongs is working its way through the system, NYSCAHR is committed to working with the Cuomo Administration to get at the heart of the problems inherent in a system that keeps these New Yorkers struggling every day for their independence and dignity.

Background

Adult Homes in New York

Over 28,000 individuals live in New York State's 453 adult homes. Licensed by the New York State Department of Health (DOH), adult homes provide housing and supportive services for people who are unable to live independently due to physical and/or psychiatric disabilities. Although adult homes were originally intended for the old and the infirm, nearly 40% of those living in adult homes have a diagnosis of psychiatric disabilities.

Most people with psychiatric disabilities live in homes where at least 25% of the other residents also have a psychiatric disability. DOH and the Office of Mental Health (OMH) refer to these homes as "impacted." In the majority of these homes, almost half of the residents have a psychiatric disability. While the number of adult homes serving persons with psychiatric disabilities has increased over the years, the total number of adult homes has decreased.

People with psychiatric disabilities usually move into an adult home after a hospitalization. Some have complex physical as well as mental disabilities that necessitate a supportive living environment and supervision. Often, people are referred to adult

homes because other housing alternatives, especially those licensed and funded by OMH, are unavailable at the time of discharge or are inappropriate. Unfortunately, in many cases, adult homes do not provide an appropriately supportive environment and it is often difficult for residents to leave even when they can thrive in more independent, supported housing.

A History of Serious Problems and Abandoned Reforms

New York has struggled for decades to provide appropriate services and housing to persons living with psychiatric disabilities. When the state decreased the capacity of its psychiatric hospital system, it moved many people to communities where their housing options were often limited to adult homes. Our current adult home system evolved from a convergence of issues: de-institutionalization policies; a lack of government planning, coordination and oversight; and a mental health community that was once voiceless and powerless.

While some adult homes provide adequate, and sometimes exemplary care for residents, the adult home industry has long been challenged by serious and deep-rooted problems. As far back as 1977, reports written by various state government agencies,

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the Legislature and advocates depict deplorable conditions, unscrupulous financial practices and mistreated residents.¹ For over thirty years there were repeated warnings that poor conditions existed in adult homes and that services were inadequate for residents with psychiatric disabilities. Reports were written and investigations conducted but no major reform efforts were undertaken.

In April 2002, *New York Times* reporter Clifford Levy documented the shocking extremes of misery and neglect experienced by residents of New York City's large adult homes. This Pulitzer Prize winning exposé briefly breached the information blackout about adult homes and generated numerous other media accounts about conditions in adult homes. The series was the culmination of a yearlong effort that drew from more than 5,000 pages of annual state inspection reports, 200 interviews with workers, residents and family members, as well as three dozen visits to homes. It revealed that many homes had devolved into places of misery and neglect, just like the psychiatric institutions that preceded them.² Newspapers and radio stations around the state picked up the story and several looked into conditions in their local areas. There were editorials, letters to the editor and an outcry from many quarters.

Governor Pataki soon asked the Department of Health to convene the *Adult Facilities Workgroup*—a panel of experts and stakeholders charged with making recommendations to the state. After nine months of meetings, that group produced a report containing a number of recommendations to improve the quality of life and provide housing options for people living in adult homes. Recommendations included expanding case management and peer specialist services, funding legal and law advocacy services, improving enforcement and developing a medication assistance system.³

The most significant set of recommendations detailed how the state could move more than 6,000 adult home residents with psychiatric disabilities to independent

housing in the community within five years. This included identifying residents who were ready to move to other housing, development of a mix of housing options and limiting bed capacity in existing homes. While several recommendations were implemented, there was little done specifically to address housing concerns of residents.

Through the efforts of NYSCAHR, Governor Spitzer created the *Adult Care Facilities Futures Group* in 2008. Facilitated by the Department of Health and the Commission on Quality of Care, this new group brought together state agencies, adult home residents and advocates to pursue adult home reform in a collaborative environment. However, it soon became clear that real change was not part of the plan. Instead of sweeping and significant reform, adult home residents were once again left with half-hearted efforts at cosmetic changes designed solely to appease advocates and residents.

The Lawsuit for Housing

In 2003, Disability Advocates, Inc. brought a lawsuit in US District Court, Eastern District of New York against New York State on behalf of about 4,300 individuals with psychiatric disabilities residing in or at risk of entry into adult homes in New York City, (*Disability Advocates, Inc. v. David A. Paterson, et. al.*). Members of NYSCAHR signed on the case as *amici curiae*, as a way to push New York State to develop additional housing options for adult home residents with psychiatric disabilities.

In September 2009, the federal judge ruled that the individuals represented in the case were not receiving services in the most integrated setting appropriate to their needs. The judge also found that the residents were segregated from their communities and that their interactions with others were impeded by living in what amounted to institutions. Because of these factors, the judge ruled New York State was in violation of the integration mandate of the Americans with Disabilities Act and the Supreme Court's Olmstead decision.⁴

NYSCAHR Priorities

1. New York State should drop the appeal of the Disability Advocates, Inc. (DAI) lawsuit.

The state must drop further appeals of the DAI lawsuit in the interest of swiftly implementing the remedy imposed by the court. Residents shouldn't be kept waiting for the opportunity to begin their new lives.

2. Develop a detailed plan for the development of housing to ensure people with psychiatric disabilities end up in the best possible environment.

Implementation of the remedy to the lawsuit will require planning if it is to be successful. Developing an integrated, comprehensive system from the different types of housing and supports needed to successfully move residents out of adult homes will be complicated. The plan must include a rigorous data component to track the progress residents make toward self-sufficiency, not just the number of people moving. New housing is an opportunity to recover and develop independence.

3. Fund advocacy for adult home residents.

For many years the residents of adult homes were ignored by public policy and the agencies charged with protecting them. The Coalition for Institutionalized Aged & Disabled (CIAD) gives residents a voice in the public policy debates that impact their lives and also helps them assert their rights. CIAD must be funded for \$100,000 so they can continue their mission—without this funding, residents will lose their closest ally in their fight for independence and their ability to get information about their rights will be diminished.

4. Don't cannibalize the mental health budget to pay for housing required by the DAI settlement.

The problems in adult homes go back over thirty years so a remedy should not penalize other mental health consumers by reducing their access to services nor should the development of future services be curtailed. Instead, the state should explore how to reinvest existing adult home spending into new housing and look for savings generated in the SSI program as adult home beds are closed.

5. Maintain quality in adult homes.

Even after the development of new housing options, individuals with psychiatric disabilities and others will live in adult homes. Regardless of new options, some residents may choose to stay and others may want to wait a little longer to move. Quality in adult homes must be maintained during and after the disposition of the lawsuit. Funding for the QUIP and EnAble programs must be maintained along with resident council approval of projects.

As a remedy, Disability Advocates proposed that the state create 1,500 units of supported housing per year for up to four years and require adult home staff to adequately inform residents of housing options. They also requested that the state appoint a monitor to oversee compliance. In contrast, New York State proposed to educate adult home

residents about housing opportunities and assess residents to determine whether they were eligible and clinically appropriate for supported housing. The plan proposed only 1,000 new housing units over five years. The remedy was contingent on the Legislature passing budgets that would include adequate funding for the housing.

Advocates, including NYSCAHR members, reacted critically to the plan calling it “woefully inadequate” and an “embarrassing outrage.” Residents felt slighted and dismayed given the years of injustice they had already endured. The judge agreed and declared the state’s plan “unreasonable” and “inadequate to address the violations found by the Court.” In March of 2010, the Court issued a remedial order and judgment that requires, among other conditions, that the state move all qualified adult home residents who wish to relocate to supported housing within four years. In response to that order, the state has issued an RFP for supported housing, although it has also appealed the ruling.

NYSCAHR had been a strong advocate for the court case advanced by Disability Advocates. Housing choice and options remains the top concern for NYSCAHR. Once again, NYSCAHR members have signed on as *amici curiae* in this new appeals process. If New York State had proceeded to implement the housing recommendations proposed in 2002 by the Adult Facilities Workgroup, over 6,000 persons would already be in supported housing and the protracted court process would have been unnecessary.

Endnotes

¹ New York State Department of Social Services, *The Needs and Problems of Adult Home Residents in New York State: A Plan for Action*, February 1979.

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New York State Department of Health, *Assisted Living in New York: Preparing for the Future*, Report to the Governor and Legislature, May 1999.

New York State Commission on Quality of Care for the Mentally Disabled, *Adult Homes Serving Resident with Mental Illness: A Study on Layering of Services*, August 2002.

New York State Coalition for Adult Home Reform, *There's No Place Like Home: Recommendations for Improving the Quality of Life in Adult Homes Serving People with Mental Illness*, 2000.

New York State Assembly, *Broken Promises, Broken Lives*, Committee on Mental Health, Mental Retardation and Developmental Disabilities, October 2002.

Schuyler Center for Analysis and Advocacy, *The Cause of Dignified Living*, 2003.

² The five article series by Clifford J. Levy ran in the *New York Times* from April 28 to April 30, 2002.

³ “Report of the Adult Care Facilities Workgroup,” Submitted to Antonia C. Novello, MD, MH, Dr.PH, Commissioner of Health, October 2002.

⁴ Court case reference

New York State Coalition for Adult Home Reform Members

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Coalition for Institutionalized Aged and Disabled
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