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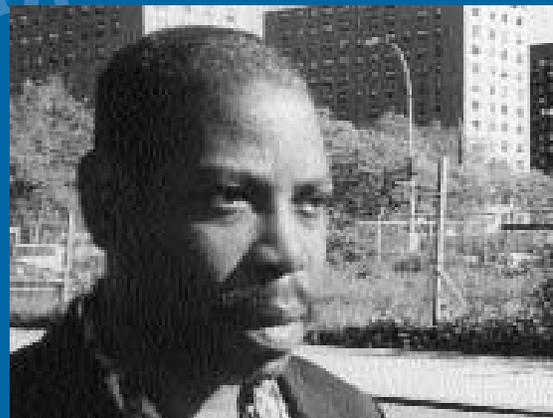
of

Dignified

dignity

Living

homes



independence

SCAA
Schuyler Center
SCAA

for Analysis and Advocacy

*Shaping New York State public policy
for people in need since 1872*

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Preface

The Schuyler Center for Analysis and Advocacy (SCAA) was founded in 1872 by pioneer social reformer Louisa Lee Schuyler who was outraged over press reports chronicling the dreadful conditions of the state’s hospitals and poorhouses where people with psychiatric disabilities were housed. Miss Schuyler organized her fellow citizens to demand change. Faced with pressure from the public and the press, the Legislature reluctantly passed a statute in 1881 granting SCAA the power to visit, inspect and examine public institutions, such as hospitals and poorhouses. The task was accomplished by “visiting committees” of ordinary New Yorkers that were established throughout the state by SCAA.

The committees reported their findings to the New York State Legislature and to the State Board of Charities, the precursor to today’s Department of Health, Office of Mental Health and Office of Children and Family Services. These meticulously detailed and disturbing reports on the living conditions, diet, medical care and supervision of persons living in government facilities directly led to some of New York’s most fundamental laws protecting vulnerable populations – including the landmark laws that made the state responsible for the care of persons with psychiatric disabilities – the State Care Law of 1890 and the State Care Appropriations Act of 1891.

On April 28, 2002, The New York Times ran the first in a series of articles highlighting the conditions in adult homes serving those with psychiatric disabilities. The series was the culmination of a yearlong effort by The New York Times, drawing from more than 5,000 pages of annual state inspection reports, 200 interviews with workers, residents and family members and three dozen visits to homes. It revealed that many homes have devolved into places of misery and neglect, just like the psychiatric institutions before them (Levy, 2002).

The information presented in the Times series was no revelation to SCAA or to many other advocates who have worked diligently for years to secure reforms for residents who have languished in adult homes. The series finally exposed to public scrutiny the deplorable living conditions at many of these institutions and offered touching stories of some the residents’ struggles for appropriate care and dignity. SCAA has been intensely involved in the process that created stimulus for change. Our efforts echo and confirm the ongoing principles and values undergirding the work of Louisa Lee Schuyler more than a century ago.

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The adult
Cause
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The homes
*Psychiatrically Disabled
in Adult Homes*

A report of SCAA

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Executive Summary

New York has struggled for decades to provide appropriate services and housing to persons living with psychiatric disabilities. When the state decreased the size of its state psychiatric hospital system it moved many people into communities where their housing options were often limited to adult homes.

For 30 years there were repeated warnings that poor conditions existed in adult homes and inadequate services were available for residents with psychiatric disabilities. Reports were written and investigations were conducted, but no major reform efforts were undertaken.

In April 2002, The New York Times ran a series of articles detailing squalid conditions and financial improprieties at some of the adult homes in New York City. The series prompted the state to make regulatory changes and mobilized advocates to develop reform recommendations.

In May 2002, the New York State Department of Health convened a new Adult Facilities Workgroup at the request of the Governor. The Workgroup, comprised of a variety of stakeholders, met frequently for months and their report was released in November of 2002.

The report contained a broad range of policy and financing recommendations:

- Implement an initial assessment of all residents.
- Implement a medication management system using nursing professionals.
- Implement an independent service coordinator initiative.
- Implement a peer bridger program.
- Expand the Assertive Community Treatment Teams (ACT) program.
- Expand support for legal and advocacy services.
- Improve enforcement and surveillance.
- Improve training and other workforce initiatives.
- Create at least 6,000 community-based beds.
- Limit new facilities to a capacity of no more than 120 beds and encourage existing facilities to reconfigure into small, home-like environments.
- Provide adequate funding and facilitation to ensure operators have capital to improve residents' privacy and downsize.
- Assist in development of new projects by facilitating access to capital funds.
- Monitor housing options for compliance with the Supreme Court decision in *Olmstead v. L.C.**

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- Improve the Limited Licensed Home Care Service Agencies (LLHCSA).
- Implement an ongoing advisory process to develop new housing models and monitor progress.
- Create a Commission on Adult Care Facilities directly accountable to the Governor.
- Enact laws to require review for character and competence by the Public Health Council for new operators/owners.
- Review the Supplemental Security Insurance (SSI) rate for adequacy and accountability.
- Create an initiative to move residents without psychiatric disabilities into appropriate programs for the frail elderly.
- Augment the personal needs allowance and create a clothing allowance.

New York State responded to the report by announcing a number of reforms, including immediate implementation of health and mental health assessments, additional care coordination, case management and peer support, a significant medication management initiative, creation of a centralized hotline to report abuses and interagency joint inspection teams. The State also announced creation of a new position to oversee coordination of adult home reform efforts.

The development of safe, appropriate housing remains the paramount issue for residents and advocates. Although housing was not significantly addressed in the State's initial response to the Workgroup's report, efforts will continue to convince policymakers that the success of the other reform efforts is critically dependent on the development of suitable housing.

SCAA has championed the cause of dignified living and appropriate medical treatment for New Yorkers with psychiatric disabilities since its founding in 1872. SCAA will continue to work to find solutions to the public policy issues surrounding adult homes and suitable care for persons with psychiatric disabilities in New York State.

*The 1999 case of *Olmstead v. L.C.* affirmed the right of individuals with disabilities to receive public benefits and services in the most integrated setting appropriate to their needs. Under the decision, states are required to provide community-based services for persons with disabilities who would otherwise be living in institutions.



“I’m tired of wearing somebody else’s clothes. Even underwear we have to get from a thrift shop.”

Jovan Palan

respect

1891 Public Meeting of the State Charities Aid Association

May 1, 1891

A public meeting was held at Chickering Hall, in New York City, by the State Charities Aid Association to commemorate the enactment of the State Care Law which "removed over 2,000 insane persons from the poorhouses of the State."

Excerpts from the opening address:

Dr. Charles Chandler, President of the Association

Ladies and Gentlemen:

Under Chapter 323 of the Laws of 1881, a special provision is made for the appointment, by Justices of the Supreme Court, of visitors nominated by the [State Charities Aid] Association, with power to visit, inspect and examine the poorhouses and almshouses of their respective counties, such inspections being declared to be "for the purpose and with a view to public benefit." No other voluntary organization is devoting itself to this field... The influence for good of the Association has been shown first of all in the general improvement of the institutions visited by its county committees, and in the greater efficiency in the administration of our poor laws... The last and one of the most important reforms undertaken and brought to completion by this Association is the recent lunacy legislation (State Care Act of 1890, and State Care Appropriation Act of 1891), whereby the poorhouse system of caring for the insane has been abolished, and the State assumes henceforth the charge and maintenance of our dependent insane.

Hon. Joseph H. Choate

Ladies and Gentlemen:

...This terrible subject of insanity comes so near to the hearts and the homes of every family in this land, that everything relating to the amelioration of the condition of the insane and the bettering of their prospect, necessarily commands the attention of every thinking man.... These poor beings had no friend. It is the sad fact that when, among these indigent people, one of the family becomes insane and is committed to the almshouse, he is usually forgotten and neglected. Nobody to lift a voice for him throughout the State. When the attention of this Association and of its visiting committees was attracted to these unfortunates they at once sought to improve their condition. It is eleven years since we had to appeal to the Legislature for the right of visitation to these county almshouses, and that was only obtained after very serious opposition in the Legislature. Through these visiting committees the condition of these insane annexes to the poorhouses was gradually brought to light... Such a revolting condition of things can hardly be imagined to have existed in a Christian and civilized community within the last fifteen years – degradation, filth, want of food, want of clothing, want of light, want of care, want of attendance, want for everything that was calculated to mitigate in the least the misfortunes of the insane... It is not possible to conceive of a more degraded condition than that to which these twenty-two hundred people were reduced, under the laws of the State and by the sufferance of the five millions of people who make up its inhabitants... Agitation of this subject year after year, in a quiet way, by the committees of this Association, had very little effect; but at last, in the year 1887, they determined to make one resolute effort for reform, and it is the final success of that movement, after years of struggle, at first apparently unavailing, gradually commanding public confidence and public support, that this meeting has been assembled to commemorate.



THIS DORMITORY IS INDECENTLY CROWDED. BUT THERE ARE 400 APPLICANTS FOR ADMISSION TO ROME THAT CANNOT BE ACCOMMODATED.

Photo "Of the Conditions... in Institution for the Feeble-minded at Rome", from SCAA News, May, 1914, Vol. II, No. 4.

care *Evolution of A* Crisis adult

The plight of those with psychiatric disabilities, warehoused in poorhouses and county asylums, became so acute by the late 1800's that the volunteer members of SCAA's visiting committees agitated for change through the press and with personal appeals to legislators, the medical profession and prominent, public-spirited citizens. This campaign, maintained despite powerful opposition, gradually gained influence and momentum. It culminated, after two unsuccessful attempts, in the enactment of the State Care Law in 1890. This law required citizens with psychiatric disabilities to be removed from poorhouses and placed in new facilities designed to provide them with psychiatric care. The State Care Appropriations Act, passed the following year, provided funding for the initiatives.

When New York decreased the size of its large state psychiatric hospital system, starting in the late 1960s, advocates for those with psychiatric disabilities kept a watchful eye on the housing and treatment options that were created for former residents. Over time, advocates realized that the adult home housing option was unacceptable due to the lack of proper health, mental health and social services. Also apparent was the shockingly sub-standard physical condition of many of these settings, especially those lodging people with psychiatric disabilities. There were also growing concerns about corruption and misuse of monies designated for the residents.

In 1977, Charles Hynes, Deputy Attorney General, issued a report entitled *Private Proprietary Homes for Adults* that depicted appalling conditions, unscrupulous financial practices and maltreated residents in many adult homes. The report also highlighted the special needs of residents with psychiatric disabilities and revealed how limited state funding exacerbated the distressing situation (*There's No Place Like Home*, p. 3).

In the wake of the Hynes report, legislation and regulations were developed to address conditions in the homes. A law requiring joint visitation and inspection by the New York State Office of Mental Health and the New York State Department of Social Services (DSS) was enacted in 1977 to speak to the special needs of people with serious psychiatric disabilities residing in adult homes. In 1979, the Department of Social Services, the agency responsible for adult home licensure at the time, commissioned a document that presented detailed information on the characteristics of adult home residents and emphasized the urgent need for more case management and supportive services for residents with psychiatric disabilities. Subsequently, DSS formulated an action plan to address those problems. Due to leadership changes and the lack of consistent oversight and accountability, changes were not implemented (*There's No Place Like Home*, p. 4).



“I’m capable of living on my own and need the opportunity and help to move to more independent housing.”

Kimberly Valasquez

respect

What are Adult Homes?

Adult Care Facilities (ACFs) are generally viewed as personal care settings for persons with functional impairments occasioned by age or by physical or cognitive disability. Adult homes are one of five different types of ACFs.

Adult homes provide housing and supportive services for people who are unable, due to physical and/or psychiatric disabilities, to live independently. Although originally designed for the old and the infirm, the number of people with psychiatric disabilities residing in adult homes has increased 27% since 1979 (*There's No Place Like Home*, p. 2).

There are 449 adult homes in New York State with 34,755 beds (*Report of the Adult Care Facilities Workgroup*, p. 2). Approximately 12,000 residents have a psychiatric disability. Most of these live in homes where at least 25% of the residents have a psychiatric disability. In the past twenty years, the number of adult homes with this ratio has increased, while the total number of licensed adult homes has decreased (*There's No Place Like Home*, p. 3).

Persons with psychiatric disabilities residing in adult homes are typically male, under the age of 65. In homes where there are a large number of residents with a psychiatric disability, as many as 69% of the residents are under age 65. In homes with few residents with psychiatric disabilities, only 3% of residents are younger than 65 (*There's No Place Like Home*, p. 3).

Most of the mental health services utilized by residents are in clinic and day treatment programs primarily focused on treatment and management rather than empowerment and recovery. Only 1% of residents are able to access sheltered work or supported employment programs. There are few services available for residents experiencing an alcohol and/or substance abuse problem. In times of crisis, residents are often hospitalized without receiving any therapeutic intervention before the hospitalization.

Most often, people with psychiatric disabilities move into adult homes after a hospitalization. Many have complex physical as well as psychiatric disabilities that necessitate the supportive living environment and supervision that an adult home should provide. Typically, people are referred to adult homes because other housing alternatives, especially those licensed and funded by the state Office of Mental Health (OMH), are unavailable at the time of discharge or are inappropriate for the individual being discharged.



“We should have more of a choice of housing depending upon our abilities.”

Irene Kaplan

care

adult

Efforts to Identify and Remedy the Problems

By the late 1980s many government officials and advocates had a clear idea of the rampant abuses in some adult homes. They knew that conditions were often poor and services inadequate, but no meaningful, sustained action had been undertaken to ameliorate the situation.

In 1990, in response to a request by the New York State Legislature, the Commission on Quality of Care for the Mentally Disabled (CQC) issued the report, *Adult Homes Serving Residents with Mental Illness*. Although CQC found that many homes were providing adequate and sometimes exemplary care and supervision, a significant number of homes had serious deficiencies that adversely affected the day-to-day living conditions, safety, supervision and health of residents (*Adult Homes Serving Residents with Mental Illness*, 1990).

In 1996, the state implemented the Quality Incentive Payment (QUIP) Program in recognition of the inadequacy of the Supplemental Security Income (SSI) rate. The SSI rate is paid for residents and given to adult home operators for the room, board and care of residents. QUIP, based on the adult home's compliance history with state standards and designed to pay for capital improvements, is the only direct subsidy the state pays to adult home operators. Since its inception, concerns have been expressed about the inadequacy of QUIP funds, poor oversight of expenditures, and whether or not homes receiving QUIP funds meet standards.

In 1997, the New York State Legislature directed the Office of Mental Health (OMH) to undertake a study of mental health service delivery to adult home residents. Although the report, completed in 1999, included recommendations for enhancing the coordination and delivery of mental health services to residents, no action was taken.

In March of 1999, SCAA and the National Alliance for the Mentally Ill in New York State (NAMI-NYS), in conjunction with the chairs of the Senate and Assembly Mental Health Committees, Senator Thomas Libous and Assemblymember James Brennan, hosted a symposium on adult homes serving residents diagnosed with psychiatric disabilities. After the symposium, a stakeholders' work group was formed to develop recommendations for improving the quality of life of this population.

The workgroup made recommendations in a June 2000 report, *There's No Place Like Home: Recommendations for Improving the Quality of Life in Adult Homes Serving People with Mental Illness*. The report addressed planning, oversight, financing and coordination by and among the state agencies responsible for monitoring adult homes serving residents with psychiatric disabilities, as well as ways to increase resident involvement in adult home life.

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What is the **IMD** Exclusion and Why is it Important?

In the federal Medicaid law, an Institution for Mental Diseases (IMD) is defined as a hospital, nursing facility, or other institution of more than 16 beds that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care, and related services. The regulations indicate that an institution is an IMD if its overall character is that of a facility established and maintained primarily for the care and treatment of individuals with mental diseases.

Since 1972 the federal government has excluded services to individuals between 22 and 64 years of age who live in an IMD from federal financial participation (FFP). This "IMD exclusion" was designed to ensure that states continue to have primary responsibility for funding inpatient psychiatric services. Importantly, no Medicaid payment can be made for services provided either in or outside the facility for IMD patients in the age group. Therefore, any resident between the ages of 22 to 64 living in an adult home that became classified as an IMD would lose his/her entire Medicaid eligibility.

The Center for Medicare and Medicaid Services (CMMS) uses five components to classify facilities as IMDs:

1. The facility is licensed as a psychiatric facility.
2. The facility is accredited as a psychiatric facility.
3. The facility is under the jurisdiction of the state's mental health authority.
4. The facility specializes in providing psychiatric/psychological care and treatment.
5. The current need for institutionalization for more than 50 percent of all patients in the facility results from mental diseases.

The CMMS guidelines imply that some of the adult homes could be classified as IMDs if they were transferred to the authority of the Office of Mental Health. Such a classification could jeopardize significant federal funds.

States have several options to avoid the IMD penalty: developing community-based services in homes or individual apartments; retaining current resident status in residential settings, regardless of size, so long as diagnosis, treatment or care were not provided in those settings; and limiting the size of facilities to less than 17 beds.



ce
"I need more money to live a dignified life."

Jean St. Hubert

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The report was released at the Adult Homes for the New Millennium: Models of Integration conference to bring together all of the stakeholders to share exemplary programs and practices. The one-day event, convened by SCAA, was held on June 22, 2000, at Hunter College in Manhattan. The sessions focused on quality of life and care issues for persons with psychiatric disabilities residing in adult homes. Dr. Rose Dobrof, nationally renowned founding director of The Brookdale Center on Aging, delivered the keynote address. She spoke eloquently about the need for partnerships among adult home operators, administrators, staff and the people they serve. She also spoke of the need to place adult homes formally and firmly within the state's mental health and aging networks.

Stakeholders proposed numerous legislative and budget initiatives for the 2001 legislative session to achieve the many recommendations contained in the *There's No Place Like Home* report. As in the past, these proposals fell on deaf ears in the Legislature and the Governor's office.

Two financing issues have bedeviled the various reform efforts. One is a 1972 federal law that excludes many of the services from federal Medicaid payments. According to the law, no Medicaid payment can be made for services provided either in or outside a facility designated as an Institution for Mental Diseases (IMD) for residents between the ages of 22 and 64.

The other is the level and distribution of the Supplemental Security Income (SSI) payments. Adult home providers receive federal and state funds through Congregate Care, Level II SSI for housing and care of residents. SSI can be the sole source of reimbursement that an adult home receives for indigent residents. This is particularly true in homes with large populations of people with psychiatric disabilities. Providers are required to furnish room and board, 24-hour supervision, personal care, case management, medication assistance, structured activities, laundry and housekeeping under this reimbursement schedule. The funds not used to pay the adult home rate are given as an allowance to the residents. This personal needs allowance must cover all personal hygiene items, clothing, transportation and any other purchases.

The federal payment is adjusted annually, but the state portion has not been increased since 1988. The current monthly payment is \$950 upstate and \$1090 downstate with \$122 allocated to the personal needs allowance. Increasing the state portion is expensive since it would cover all residents in Congregate Level II housing, which includes persons living in other types of supportive housing as well.

respect

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By late fall of 2001, advocates and the state agencies knew that *The New York Times* was preparing a series of articles, “Broken Homes”, on the conditions in adult homes. In December of 2001, Governor Pataki directed DOH, OMH and CQC to step up and better coordinate surveillance, increase fines and broaden the types of deficiencies that could be considered violations. Advocates received the announcement as a promising overture to reform, but given the extent of problems in adult homes and the lack of staff for implementation, the changes were viewed as a modest acknowledgement of the need.

Advocates for persons with psychiatric disabilities were also making plans in anticipation of *The New York Times* series. The New York State Coalition for Adult Home Reform (NYSCAHR) was formed and commenced a series of meetings to develop their own recommendations and strategize about how to leverage public reaction to the upcoming articles for long-term reform.

When *The New York Times* series chronicling the conditions in adult homes hit the newsstands in late April 2002, state agencies mobilized to respond to the questions that were raised about the poor conditions in many of the homes, the questionable financial practices of some operators, and the failure by state agencies to coordinate services.

On April 30, NYSCAHR held a press conference at the Legislative Office Building in Albany to release a white paper outlining their reform recommendations. The coalition had many concerns and related recommendations to improve care in adult homes, but three issues were highlighted as immediate needs:

- New York State must improve oversight of adult homes, especially those serving persons diagnosed with psychiatric disabilities. The state must devise a single locus of responsibility by adding staff and increasing the oversight tools it uses.
- \$1.5 million in funding must be provided to support adult home legal advocacy, in-home advocacy and peer advocacy.
- \$8.1 million must be provided to increase the personal needs allowance and create a clothing allowance for adult homes residents.

The expose in the Times and the press conference were immediately followed by numerous other media accounts on conditions in adult homes. 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.

conscience
“Being treated like a child undermines my self-respect.”

Leon Blaufarb



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Shortly thereafter, the Governor announced new regulations and released a program bill that would, among other provisions:

- Prohibit the referral of new clients to homes without valid operating licenses.
- Increase fines.
- Require state agencies to ensure that the adult home is the appropriate placement option before discharging someone from another program.
- Create joint surveillance teams from state agencies.
- Strengthen surveillance.

The Assembly Health Committee, the Mental Health Committee, the Aging Committee and the Committee on Oversight and Investigation convened hearings in New York City on May 10, 2002 and in Albany on June 6, 2002. A procession of residents, advocates, adult home operators and service providers recounted their observations and concerns at both hearings. At the Albany hearing, the Commissioners of DOH, OMH and CQC testified about their agencies' policies and procedures. Lawmakers quizzed them at length about what they knew regarding adult home conditions, what they could have done to prevent the situation and what they were planning to do now that problems had been made public.

SCAA President and CEO, Karen Schimke, testified that, "SCAA believes that now is the time to develop a housing model that recognizes that persons with psychiatric disabilities residing in adult homes need medical and supportive services that will allow them to safely live independently and, whenever possible, to become productive citizens. This model would be smaller than many of the current homes, offer appropriate medical and supervisory services and provide social, educational, recovery, rehabilitation and vocational supports."

On June 12, the Assembly released a report, *Adult Homes in Crisis: Plan for Reform*, that contained recommendations for immediate action to improve conditions of adult homes. The proposed changes included more effective inspections and enforcement and a full examination to develop systemic changes to remedy the state's failure to support quality care. The report also called for alternative community-based housing and services for the mentally ill and other at-risk people now in adult homes.

Also in June, the Assembly issued their version of reform legislation. Although the bill contained proposals that were in the Governor's program bill, several additional provisions based on the findings from the hearing were also included. For example, the bill had provisions that would provide money for new performance measures in adult homes and require the state to post adult home violators on the web. The Senate never developed its own legislation but it did introduce the Governor's bill. No legislation was enacted, or even discussed among the three parties, despite public pressure.

Meeting the Needs

of Adult Home Residents with Mental Illness: Recommendations by the New York State Coalition for Adult Home Reform

In April 2002, the New York State Coalition for Adult Home Reform (NYSCAHR) released a policy paper containing recommendations to improve conditions for residents with psychiatric disabilities living in adult homes. NYSCAHR was formed in early 2002 to develop an advocacy strategy for adult homes issues.

According to NYSCAHR, adult homes were never intended to serve people with psychiatric disabilities. Consequently, they have not been designed or regulated to supply adequate mental health services. Due to a severe shortage of more appropriate community housing options, at least 176 adult homes statewide have become defacto mental health housing programs. NYSCAHR believes that the homes lack the regulations, services and governmental oversight needed to meet the needs of the actual resident population.

NYSCAHR called for both short-term and long-term measures in the areas of

- Governmental Oversight
- Needs of the Residents
- Fiscal Accountability
- Rehabilitation and Recovery Services
- Access to Quality Housing with Supportive Services
- Advocacy and Peer Services



NYSCAHR Press Conference, April 30, 2002.

Left to Right: David Seay, National Alliance for the Mentally Ill-NYS; Karen Schimke, SCAA; Harvey Rosenthal, NY Association of Psychiatric Rehabilitation Services; Ray Schwartz, Venture House; Geoff Lieberman, Coalition for Institutionalized Aged and Disabled; Karen Burkoff, Adult Home Resident

Spotlight: Thirty Years of Advocating for Residents

The Coalition of Institutionalized Aged and Disabled (CIAD) is a non-profit, consumer-led advocacy organization of adult home and nursing home residents and residents' councils that was established in 1973. CIAD organizes resident councils, educates residents about their rights, and promotes their participation in the affairs of their own residences as well as broader public policy issues.

Organizing: For many years, CIAD's organizing work has focused on building resident councils at adult home facilities. CIAD's Adult Home Project Director and lead organizer, George Gitlitz, is the only advocate who regularly visits adult homes and adult home residents in New York City.

Leadership Trainings: CIAD and residents have developed a leadership-training course to build confidence in residents as leaders.

Complaint Handling: The work of organizing among residents also includes helping to resolve individual complaints, and/or assisting individuals to find specific services.

Policy Advocacy: Because of the history, membership, and direct organizing activities of CIAD, the organization has developed the knowledge base and credibility to be a strong advocate in the policy arena.

Public Education/ Research: CIAD also has developed an array of policy and educational materials for residents, families and other advocates.

CIAD Executive Director Geoff Lieberman is a member of the Department of Health Adult Care Facility Workgroup and a member of the Financing and New Models Sub-Workgroups. His expertise in the needs and desires of the residents ensured that the voices of those most affected by the proposed changes were heard. The photos of residents used in this publication are presented courtesy of CIAD.

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CIAD Executive Director Geoff Lieberman was a member of the Department of Health Adult Home Workgroup and a member of the Financing and New Models Sub-Workgroups.

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Commission on *Quality Care* for the Mentally Disabled Releases Report: *A Study on Layering of Services*

In August 2002, the Commission on Quality Care for the Mentally Disabled released *Adult Homes Serving Residents with Mental Illness, A Study on Layering of Services*, a report that identified the actual cost of care to residents in adult homes. Unlike previous reports on adult homes, the new study looked at mental health and medical care rendered outside the adult home as well as many of the newly established “on-site” services that have emerged in the last decade.

The Commission recognized that many providers operate safe, comfortable housing with access to medical and health care services. However, the report found,

“After examining the complex services for 2,100 residents with mental disability at the largest homes in the New York City area, it seems obvious that resources need to be redirected to promote quality care. Absent reform, residents will continue to receive medical care under a system in which services are often not sought by the recipient, but initiated by the practitioner; in which providers fail to communicate with one another on treatments and medication, even on such matters as the need for surgery; and in which the primary care physician plays no role in assuring that necessary services are coordinated effectively” (*Adult Homes Serving People with Mental Illness*, p.i).

According to the document, a key element to the success of any reform initiative will be to ensure that residents of adult homes who are in need of a different level of care are identified and assisted in making the appropriate transition. Those who remain should be afforded access to mental health facilities/programs focused on habilitation and recovery, not just maintenance.

The report concluded that although only \$28 per day is spent on housing for a resident of an adult home when SSI and Medicaid expenditures are combined almost three and one-half times that amount, or about \$37,000, is spent per year per resident for all the services. However, these funds are spent on services that are costly, fragmented, at times unnecessary and appear, in many instances, to be designed to make money. In summary, “the Commission found a fundamentally flawed service system that addresses separate aspects of a resident’s life. Despite the investment of substantial public money, residents are being short-changed when the reality of their living conditions and services is examined” (*Adult Homes Serving People with Mental Illness*, p.i).

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Care *adult* The Adult Care Facilities Workgroup

In late May 2002, the New York State Department of Health convened the Adult Care Facilities Workgroup. The Workgroup's membership was comprised of a broad array of stakeholders and was charged to deliver a plan for adult home reform by September.

Three sub-workgroups were formed:

The New Models Sub-Workgroup charged with identification of more appropriate, effective models of housing plus services delivery for adult home residents with psychiatric disabilities.

The Health/Mental Health Services Coordination Sub-Workgroup charged with identifying the barriers to successful service provision and coordination and developing strategies for overcoming these barriers.

The Payment Sub-Workgroup charged with reviewing current payment processes and alternative payment mechanisms, and using this information to create payment strategies and cost estimates for the recommendations developed by the other two sub-workgroups. The group was also charged with reviewing current payments to suggest improvements that could be redirected to fund program reforms.

The three groups supplemented their expertise by adding members from consumer and advocacy groups, unions, adult care facility operators and owners, health and long-term care providers, management consultants and policy analysis organizations. With support from staff at the DOH, OMH, CQC, OMH, the Office of Mental Retardation and Developmental Disabilities (OMRDD) and the Division of Housing and Community Redevelopment, the sub-workgroups met through the summer on a rigorous schedule. The full Workgroup met at least monthly during the summer and fall to collect information from the sub-workgroups and to learn more about the state's interim activities.



“I’m poor and need clothes. I am not able to work in the community.”

John Williams

rights Release of the Report health



“I could live a better life if I got rehabilitation and recovery services.”

Tom Avera

On November 23, 2002 the final report of the New York State Adult Care Facilities Workgroup was released at a meeting in Albany that drew a large audience. Representatives of the three sub-workgroups were asked to present the key recommendations that had been submitted in early October.

Introduced at the meeting were a series of principles that the sub-workgroups had used to guide their deliberations:

- The goal must be to improve lives, not just to save resources.
- All residents should be provided with all the services, housing choices and options that are available to other persons with psychiatric disabilities as well as all New York State citizens.
- All residents must have as much privacy as possible and be offered services in an environment of dignity and respect.
- All persons with psychiatric disabilities must be housed and receive services in the most integrated, community-based settings possible, in full compliance with the Olmstead decision.

The Services Coordination Sub-Workgroup identified the following challenges:

- Mental health services have been experienced by both residents and operators as too limited in their type, quality and capacity to support residents towards recovery and self-determination; they have been particularly experienced as non-responsive during times of crisis.
- Over-reliance upon on-site provision of services has fostered an institutional environment; inadequate transportation and escort services have hampered efforts to access community-based services and supports.

The group believed that several proposals would best provide immediate improvements in assuring the safety and promoting the health and recovery of adult home residents. Members also stressed that, for the recommendations to have real meaning, policymakers must view them in total and not in piecemeal fashion.

conscience

crisis

- New York State should immediately implement an assessment initiative aimed at gathering information about adult home resident demographics, strengths and care needs, health, mental health, vocational and functional status and the entities engaged in providing care and services.
- New York State should immediately implement a medication management administration and oversight initiative in adult homes, provided by nursing professionals.
- New York State should immediately implement an Independent Service Coordinator/Case Manager initiative for residents of adult homes with a psychiatric disability, utilizing the OMH blended case management model.
- New York State should immediately implement a Peer Bridger Initiative that will make available trained professionals with successful mental health recovery histories to provide personalized support to residents with psychiatric disabilities. Bridgers would help residents move towards recovery and, as desired, transition successfully from adult homes into their home communities.

The report of the New Models Sub-Workgroup highlighted two recommendations that should be implemented in the first year of a program:

- New York State should augment personal resources for all residents receiving SSI through increases in the Personal Needs Allowance (PNA). In addition, a clothing allowance should be created. Both would foster self-sufficiency and responsibility, as well as hope and motivation.
- New York State should comparatively review, with the help of the advisory group, the current SSI rate paid to adult care facilities. The review should include adequacy and accountability to assure the best possible service to residents.

The members of the sub-workgroup were committed to the concept that housing should be provided in community settings. The new models and their variations were grouped in the report as scattered site, mixed use, and congregate housing. Since these models have already been implemented for other individuals with psychiatric disabilities, they could and should be made available to current adult home residents.

The sub-workgroup recommended moving at least 6,000 residents from adult homes into community settings of various kinds. Further, the 6,000 who are assumed to remain in adult homes should reside in substantially reconfigured homes in terms of size and service provision.



respect

Several of the group’s numerous housing development recommendations were presented:

Projected Timeline for Movement of Adult Home Residents into Supported Housing

Timeline	# of Persons With MI Placed in Alternate Housing	Cumulative Persons With MI Placed in Alternate Housing	Scattered Sites New	Mixed Housing Sites Units	
				Existing	New
10/02-3/31/03	20	20	0	0	20
4/03-3/04	1530	1550	1530*	0	0
4/04-3/05	800	2350	730	70	0
4/05-3/06	930	3280	730	0	200
4/06-3/07	970	4250	320	0	650
4/07-3/08	875	5125	225	0	650
4/08-3/09	875	6000	225	0	650

- New York State must develop and implement housing options according to the timetable shown in the chart. Appropriate resources for capital, housing and services need to be made available by the state for multi-year implementation. A down payment to jump-start this process should be available now and included in the 2003-04 budget and in the budgets for subsequent years.
- New York State must limit the capacity of new adult care facilities to no more than 120 beds.
- New York State should encourage existing adult care facilities over 120 beds to reconfigure into smaller, home-like environments, develop mixed use housing, and improve resident privacy by providing single rooms with private baths phased in over a 10-year period.

conscience
independen
 crisis

- New York State should encourage, with necessary financial compensation, conversions of and improvements to existing facilities, and should assist in the development of new projects by facilitating access to capital funds through funding pools, public/private partnerships and prioritization of projects seeking Section 8, HUD and other federal funding. This recommendation should be reflected in the 2003-04 *Executive Budget*.

The workgroup report noted that, “New York State is on a collision course with the federal Olmstead court decision. However, even if that weren’t true, the recommendations of this diverse group of stakeholders are reasonable, responsible, and critical to the well-being of a vulnerable and forgotten number of New York citizens.”

The Payment Sub-Workgroup announced the costs and savings assigned to each of the recommendations of the other sub-workgroups. Cost estimates for some of the recommendations include:

- Between \$5.4 - \$10.8 million for assessments of all adult home residents.
- As much as \$63 million for medication management by nurses, although a portion can be billable to Medicaid.
- Between \$22 and \$27 million for the independent service coordinators and almost \$5 million for peer bridgers.

Costs for all the new housing recommended by the New Models sub-workgroup were not developed since the multi-year time frame for implementation called for only a small number of residents to be transitioned in the first year. According to the final document, long range cost impacts cannot be completed until there is further analysis of the final reports of the other two sub-workgroups. The report did identify about \$20 million in savings from adjustments to current service rates and stricter controls on use of services.

The Commissioner of Health announced that the Workgroup would remain intact and meet quarterly to provide advice and help oversee implementation of the recommendations. She also announced that a new position would be established to spearhead the implementation of the recommendations.

The state outlined activities it had already undertaken to improve adult homes since the release of The New York Times articles. Staff unveiled:

- A new toll-free hotline residents and family members can use to report problems in homes or violations of resident’s rights.

rights

- A new poster to be sent to all homes that outlines resident's rights and the toll-free number.
- A new policy to post press releases on surveillance findings and evaluations of facilities on the Department of Health website.

Finally, the state announced several new initiatives to begin to implement some of the workgroups' many recommendations, including:

- Clinical, psychiatric and functional assessments by highly qualified and trained health and mental health care providers.
- Improved case management and coordination to assure that appropriate care and services are delivered.
- Enhanced medication management and coordination to assure that appropriate care and services are delivered.
- Improved social and recreational services.
- Increased advocacy and legal support.

The response to the Workgroup report was predictably wide-ranging but overall there was guarded optimism that, for the first time in many years, the issues confronting adult home residents were receiving attention from the state agencies.

By January of 2003, policymakers, advocates and state agencies were faced with trying to implement adult home reform as a significant budget deficit loomed over the state. Although the state continued to discuss the progress being made on some of the reform efforts they had undertaken, the prognosis for a new housing program was grim. While there was no commitment for new resources to fund the proposed recommendations, advocates remained committed to their mission: that persons with psychiatric disabilities living in the state's adult homes would not be abandoned by the system as they had so many times in the past.

“We need a better inspection and enforcement process that increases the participation of residents in all aspects of the process.”

Woody Wilson



crisis

care

Spotlight on
**Protecting
Residents:**
CQC

adult



*Gary O'Brien, Chair
Commission on Quality of Care
for the Mentally Disabled*

capable

The Commission on Quality of Care for the Mentally Disabled (CQC) serves people with mental disabilities and their families by providing independent oversight of the quality and cost-effectiveness of services provided by all mental hygiene programs in New York State. It administers five federal formula grant programs through which it provides legal and non-legal advocacy services to persons with disabilities to assist them in obtaining the services and protections of federal and state laws. The Commission also has the responsibility for programmatic and fiscal oversight of adult homes which serve residents with psychiatric disabilities and administers an adult advocacy program which provides legal and other advocacy services to such residents.

The Commission, which was created in the wake of New York State's settlement of a major class-action lawsuit at Willowbrook State School for the Mentally Retarded, consists of a full-time chairman and two unsalaried members, each appointed by the Governor and confirmed by the Senate to serve for staggered five-year terms. The Commission has a staff of approximately 100 and an annual state purposes appropriation of approximately \$3 million.

The Commission has been given the responsibility of monitoring this entire system of services, and of reporting to the Governor, the Legislature and the public on the manner in which laws and policies to protect the rights of mentally disabled citizens are being implemented. The Commission's independent oversight role is an essential "safeguard" for a vulnerable class of people. Through its responses to complaints, investigations of deaths, alleged abuses or improper care, policy studies and fiscal investigations, the Commission identifies weaknesses in the system that impairs the quality of care. It makes recommendations for change in policy, practice, laws and regulations and helps impart the "lessons learned" from its oversight activities to all providers.

independent

The Commission makes extensive use of volunteers. Two of the Commission members are volunteers. All 15 physicians on the Mental Hygiene Medical Review Board are volunteers. The award-winning Surrogate Decision-Making Committee program relies on hundreds of volunteer medical and legal professionals, family members and advocates to make major medical care decisions on behalf of incompetent persons.

respect

Interagency Adult Home Initiative

The following summary of the Interagency Adult Home Initiative was presented at the Adult Facilities Workgroup meeting on November 23, 2002:

Health and Safety

Creation and continuation of activities by state regulatory and monitoring agencies to maximize the health and safety of adult home residents. For example:

- Interagency joint inspection teams
- A centralized hotline
- Priority investigative teams
- Streamlined enforcement
- Fines
- Additional surveyors hired
- Training of surveyors
- QUIP review
- Resident council requirements
- Public release of adult home surveys
- Increased education and information dissemination
- Strengthened regulation
- The governor's adult home program bill

Appropriateness of Care/Medical Necessity

- Health and Mental Health Assessments
Assessment of residents for the purpose of gathering baseline information on their current health and mental health status, the current array of programs and providers, and an indication of residents' functional status and community living skills.
- Health Care Coordination
Provision of access to primary care providers who are responsible for the delivery and coordination of primary health care, as well as authorizing access to other physical health care. As an added component, such providers would be responsible (either directly or through an affiliation) for the coordination and authorization of mental health specialty services.

care

adult

- Case Management

Creation of an independent case management function to ensure that residents are informed of community treatment, rehabilitation, vocational, housing and support options. Case managers will also be responsible for conduction assessments as appropriate, assisting residents in making informed choices regarding their various options, as well as assisting residents in accessing selected services.

- Peer Support

Peers are intended to promote and support residents' recovery. They will assist residents in understanding their living and treatment choices, coordinating such efforts with the case managers. Peers will help residents to advocate for themselves and to utilize peer-run supports.

Quality of Life

- Social and Recreational Services

Development of enrichment activities, both within adult homes and in the community
Providers of such services are encouraged to hire peers

- Advocacy

Residents will be supported in their ability to advocate for themselves, as well as their ability to access legal services and an ombudsman program

Quality of Care

- Medication Administration/Management

Creation of a system which ensures that medication is administered by qualified personnel, as well as the accuracy and timeliness of medication process

- Wellness Self-Management Demonstration

Establishment of a demonstration program to provide targeted resident training to improve wellness self-management skills (i.e., psychoeducation, social skills training, cognitive behavioral training, and coping skills training)

- Housing

Explore housing options
Create interagency housing task force
Cap size of new homes at 120 beds

dignity

homes

independence

respect

rights *Perspective*

Adult Homes:

A Crisis of Conscience

By Michael B. Friedman, CSW

The recent New York Times coverage of the dreadful conditions in some adult homes in New York State did not surprise me. For those of us who have been active in mental health over the past 30 years or so, it's an old story that makes new headlines every few years. But this time the revelations provoked a crisis of conscience in me. I realize that I have paid too little attention to adult homes as an advocate and that I did too little about them when I was Director of the Hudson River Region of the New York State Office of Mental Health at the end of the Cuomo administration.

During those years I took pride in moving people to the community from the state hospitals for which I was responsible. We considered adult homes part of the community.

Of course we took steps that were meant to be protective. Staff from my office visited the adult homes to which we sent residents. We stopped referrals to those which were poor and did not improve care quickly. We encouraged, and funded, working relationships between adult homes and local mental health providers to be sure that people with psychiatric disabilities got the mental health services.

Many people got quite decent care.

But the fact remains that by our actions we supported a mental health policy that is fundamentally wrong – a policy of "transinstitutionalization" in contrast to the professed policy of deinstitutionalization.

Community mental health is about integrating people with mental illnesses into the community. Transinstitutionalization is about meeting arbitrary goals in one institutional system by transferring people to another institutional system. In the beginning it was a policy of desperation, a policy adopted because New York State did not provide special housing in the community for people with serious mental illnesses. Later, the use of adult homes became a policy of convenience, making it possible to reduce the perception of the need for more community-based housing.

When I say that housing people with serious mental illnesses in adult homes is the wrong policy, I mean that putting people in large, congregate living facilities – even if they are well supervised – violates the most fundamental insights and goals of the community mental health movement. The goal of community mental health is to help people lead decent lives as full-fledged members of the general community. Well-supervised adult homes do not, and cannot, fulfill that goal; and, therefore, reforming adult homes by making sure that they are safer and that they provide more services is not enough.

care

How have I missed this obvious truth until now?

Coincidentally, I have just read Jonathan Glover's book, *Humanity*, which reviews atrocities committed during the past century and explores what made it psychologically possible for people to participate in atrocities. Two of his observations about why people carry out bad – even shameful – social policy helped me to understand our tolerance of the use of adult homes for people with serious mental illnesses. First, he notes that fragmentation of decision-making results in no one feeling responsible for the overall policy. We each do our piece, making the best of a situation which is beyond our control. I took pride in the extent to which my Regional Office instituted some protections. I had done the best I could.

It is time to stop the moral drift, time to stop patching a flawed system, time for a fundamental change in policy. The goal should be for all people with serious mental illnesses who need supervised or supported housing in the community to get housing in small, homelike settings or in independent living settings with supports. These settings should have a rehabilitative structure designed to promote recovery, independence, and full integration into the community.

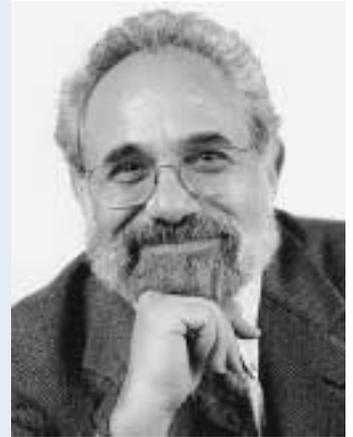
It will take years to achieve these goals. But some actions can be taken immediately.

Obviously it will take years to achieve these goals. But some actions can be taken immediately which will move in the right direction.

- **First**, the New York State Office of Mental Health (OMH) should take full responsibility for adult homes with a preponderance of people with mental illnesses. (Proposals of the kind that are now surfacing for state agencies to share responsibility are futile because of the power of entrenched bureaucracy.)
- **Second**, OMH should establish a policy that rejects the use of adult homes for people with serious mental illnesses.
- **Third**, OMH should develop a long-term plan to create appropriate housing. This plan will need to include new housing as well as reconfiguration of existing homes.
- **Fourth**, during the transition, OMH should institute model programs emphasizing rehabilitation and recovery in the adult homes that remain open.
- **Fifth**, OMH should be responsible for developing adequate systems of oversight and enforcement.

Each time terrible conditions in adult homes have been revealed in the past, we have tinkered with the system. I realize now that I had become inured to it and cynical about it. This time I hope we will all face the truth, that a major change in policy is the only reform that will make a long-term difference.

(Michael B. Friedman is the public policy consultant for the Mental Health Associations of New York City and of Westchester County. He is the former Regional Director of the Hudson River Region of the NYS OMH. This article is excerpted from an editorial that appeared in Mental Health News, Summer 2002. The opinions expressed are Mr. Friedman's own and do not necessarily reflect the views of SCAA.)



Michael B. Friedman, CSW

respect

Timeline

1977

Deputy Attorney General, Charles Hynes, releases the report, *Private Proprietary Home for Adults*. A law requiring joint visitation by the Office of Mental Health and the Department of Social Services was enacted.

1979

New York State Department of Social Services commissions a report on characteristics of adult home residents. The Department develops a plan of action to address problems identified by the report.

1990

The Commission on Quality Care for the Mentally Disabled issues the report *Adult Homes Service Resident with Mental Illness* at the request of the New York State Legislature.

1996

New York State implements the Quality Incentive Payment (QUIP) Program to improve the physical plant in adult homes.

1997

The New York State Legislature requests the Office of Mental Health to undertake a study of the delivery of mental health services to residents of adult homes. The report is completed in 1999.

1998

Oversight authority for adult homes is transitioned to the Department of Health from the former Department of Social Services.

1999

SCAA, the National Alliance for the Mentally Ill in New York (NAMI-NYS) and the Senate and Assembly Mental Health Committees host a symposium on adult homes serving residents with psychiatric disabilities. A stakeholders workgroup is formed to develop recommendations for improving the quality of life for these residents.

2000

The stakeholders workgroup releases its report, *There's No Place Like Home: Recommendations for Improving the Quality of Life In Adult Homes Serving People with Mental Illness*.

2002

New York Times articles appear and the state responds with the creation of the New York State Adult Care Facilities Workgroup.

care

SCAA's

Continuing Role

SCAA believes that New York State must develop a housing model that recognizes that persons with psychiatric disabilities can reside in non-congregate settings supported with medical and other services that will enable them to live safely and independently and become productive citizens. Models already exist that would be smaller than many of the current homes, would offer appropriate services and would provide social, educational, recovery, rehabilitative and vocational supports. Developing more sites using these models and creating more options would enable this population to live in environments that would truly be homes, not warehouses.

A century ago New Yorkers proudly extolled the mental health system they created following the efforts of reform agitators like our founder. They based their system on what the science of the day told them was the best care and treatment for persons with psychiatric disabilities. New York must now develop models of services based on what today's scientific evidence says is the best care for persons with psychiatric disabilities. Fundamental to such a system is substantially increased housing – housing located in the community.

SCAA has championed the cause of dignified living and appropriate medical treatment for New Yorkers with psychiatric disabilities since its founding. SCAA will continue to work to find solutions to the public policy issues surrounding adult homes and suitable care for persons with psychiatric disabilities in New York State.



"I don't want to be threatened when I stand up for my rights."

Karen Burkoff

respect

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SCAA's Mission

SCAA promotes the public interest by advancing policies to improve health, welfare and human services in New York State. Priority emphasis is given to promoting wellness, mitigating disabilities, combating poverty and fostering personal independence.



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for people in need since 1872*

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