MEETING THE NEEDS OF ADULT HOME RESIDENTS WITH MENTAL ILLNESS

A Policy Paper by the New York State Coalition for Adult Home Reform

(List of supporting organizations in formation)

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Thirty years ago, tens of thousands of New Yorkers with psychiatric disabilities languished in the "back wards" of state psychiatric hospitals. Deinstitutionalization brought the promise of community reintegration to many, but the reality of that promise has, too often, been a bed in an adult home with little or no access to rehabilitation and recovery oriented services. Today, at least 11,000 New Yorkers with psychiatric disabilities languish in adult homes, our modern day "back wards."

The problems endemic to adult homes are well documented, but efforts to remedy the problems and implement recommendations have been largely ineffective. Documentation of the crisis in adult homes dates back to the Attorney General's 1977 report, *Private Proprietary Homes for Adults*, and includes the Adult Home Work Group's 2000 report, *There's No Place Like Home*, the New York State Commission on Quality of Care's 2001 report, *Exploiting Not-For-Profit Care in an Adult Home: The Story Behind Ocean House Center, Inc.,* and the recent series in the New York Times, *Broken Homes*.

Twenty-five years of tinkering with adults homes has resulted in twenty-five years of reports, commissions, complaints, abuses, and inaction.

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

Ineffective regulatory oversight has placed the residents of adult homes at serious risk and allowed hundred of millions of health care dollars to be spent in wasteful and possibly fraudulent ways. This position paper outlines long and short-term recommendations for fundamentally overhauling the adult home system, thereby substantially improving the quality of life for adult home residents and ensuring that hundreds of millions of dollars in public funds are spent wisely.

Protecting Residents Through Adequate Governmental Oversight

The regulations governing adult homes require fundamental change to respond to the needs of the current resident population. The New York State Office of Mental Health (OMH), in their April 1999 report on adult homes, identified 176 homes, out of 453 that exist statewide, as "impacted." By definition, at least 25% of the residents of impacted adult homes have a psychiatric disability. In practice, impacted homes house people with mental illness almost exclusively. The remaining 277 adult homes have a resident population that is more varied, but all have less than 25% residents with a serious mental illness.

According to the State, 11,000 of the 28,000 adult home residents in New York State live in impacted adult homes. Operators of impacted homes are required to contract with a mental health provider to have an on-site mental health service team. Advocates maintain that some homes misreport the number of residents with psychiatric disabilities to avoid being listed by the state as impacted, thereby avoiding OMH involvement and oversight and retaining private pay customers.

Impacted adult homes are essentially mental health residential facilities and should be regulated as such.

OMH already administers a successful continuum of mental health housing programs. Over 25,000 New Yorkers with psychiatric disabilities currently live in OMH supportive housing. The intensity of services available in these programs varies by model, ranging from twenty-four hour, seven day per week, on-site supportive services to independent subsidized apartments with off-site services. Over the past 30 years, OMH has developed the expertise and the infrastructure necessary to adequately oversee this range of mental health housing programs.

Currently, the oversight system for impacted adult homes is fragmented and ineffective, with the New York State Department of Health (DOH) carrying the bulk of the regulatory responsibility and OMH providing some oversight of mental health teams. In practice, impacted adult homes are a part of the community mental health housing continuum. OMH already has a proven track record of effectively administering the rest of the mental health housing continuum. Shifting regulatory responsibility for impacted adult homes from DOH to OMH would result in higher quality services for people with psychiatric disabilities and would allow DOH to focus resources on the remaining homes. Accordingly, DOH would be better able to ensure that residents of adult homes serving primarily the frail elderly receive the highest possible quality of care.

Shifting regulatory responsibility for impacted homes from DOH to OMH will take time, but the crisis in adult homes requires immediate action. Current weaknesses in enforcement practices put residents at risk by failing to impose meaningful fines and allowing homes to continue to operate despite repeated deficiencies. **While significant regulatory changes are being pursued, we urge the State and Federal government to take immediate action to strengthen oversight and protect adult home residents.**

Interim Recommendations for Improving Governmental Oversight:

1. **Increase the number of DOH inspectors to ensure timely annual inspections and swift and thorough complaint investigations.**
2. **In all cases involving suspicious deaths of adult home residents or suspected civil rights violations, ensure that DOH expeditiously**

investigates and brings appropriate enforcement proceedings and/or refers to the appropriate enforcement agency.

3. **Impose increased and progressively greater civil penalties against homes that have been subject to repeated enforcement.**
4. **Ensure meaningful utilization of other enforcement mechanisms, such as closing homes to new admissions and revoking operators' licenses. Ensure all hospitals, discharge planners and community agencies are notified of admissions bans. Establish mechanisms for fining hospitals that fail to abide by admissions bans.**
5. **Include adult homes in current statute and regulations requiring review of character and competence by the State Hospital Review and Planning Council/Public Health Council prior to licensure. Include adult home stakeholders, as appropriate, on those bodies.**
6. **Rigorously evaluate the character and competence of potential receivers, and expeditiously appoint a receiver to operate all non-compliant adult homes until responsible operators can be found or until alternative housing models can be developed for the property.**
7. **Initiate a comprehensive OMH review to identify additional homes that have a resident population of at least 25% people with psychiatric disabilities.**
8. **Ensure regular, joint DOH/OMH inspections of impacted homes as required by New York State Law (18 NYCRR section 485.3)**
9. **Post all adult home inspection reports in a timely manner on the DOH website. Timely posting of inspection reports will allow consumers to make more informed decisions and will enable advocates to better monitor corrective actions. Nursing home inspection reports are already posted on the DOH website.**

Long-term recommendations:

1. **OMH, in collaboration with other key stakeholders, should develop new regulations for and assume the licensing and oversight authority of impacted adult homes.**
2. **OMH and key stakeholders should fully explore how the IMD exclusion will impact an overhaul of the adult home system and should recommend strategies for overcoming any barriers to reform related to the IMD exclusion.**

Addressing Residents' Most Immediate Needs

The recommendations contained in this paper will take substantial time to implement. In the meantime, we must take immediate steps to relieve the suffering of adult home residents currently living in extreme poverty. Each resident, who receives SSI or Safety Net benefits, currently receives a monthly Personal Needs Allowance (PNA) of $122. This PNA must cover all personal expenses, including clothing, personal hygiene items,

public transportation, air conditioning, and entertainment. The current PNA is simply not sufficient to meet residents' basic human needs.

Recommendations:

1. **Create an annual clothing allowance for adult home residents receiving SSI.**
2. **Increase the monthly SSI Personal Needs Allowance for adult home residents and ensure that residents receive a greater portion of annual increases in the PNA.**

Ensuring Fiscal Accountability

Despite the fact that New York State taxpayers spend hundreds of millions of dollars annually for Medicaid-funded services to adult home residents, the quality and coordination of those services are scandalously deficient. A December 2001 report by the Commission on the Quality of Care (CQC) found that, at one New York City adult home, an average of $27,000 in Medicaid funds was being spent per resident, per year for often ill-defined or duplicative physical and mental health services (see CQC Ocean House report). While a comprehensive review will be required, some preliminary figures suggest that health care providers may be billing Medicaid $2,000 - $4,000 per month per resident (see CQC Ocean House Report). In order to ensure fiscal accountability, further investigation is required to determine if such levels of medical and mental health services are necessary and appropriate.

In 1996, New York State initiated the Quality Incentive Payment (QUIP) Program. QUIP is a direct State subsidy to adult home operators that maintain compliance with DOH regulations. QUIP was initiated in 1996 when the State was unable to increases the SSI Congregate Level II rate. QUIP monies are intended to improve quality of life for adult home residents. Operators are required to submit a plan to DOH outlining how they intend to spend QUIP funds. Currently, there is no structural mechanism for ensuring that QUIP funds are spent in accordance with submitted plans. Since the beginning, many concerns have been raised regarding lack of resident input into QUIP plans, DOH oversight of QUIP expenditures and whether homes receiving QUIP funds are actually in compliance with DOH regulations.

Recommendations to Ensure Fiscal Accountability:

1. **The Center for Medicare and Medicaid Services (formerly HCFA) and the NYS Attorney General should initiate investigations into possible misuse of Medicare and Medicaid funds.**
2. **NYS Attorney General should initiate an investigation into the possible misappropriation of residents' personal funds.**
3. **CQC should initiate a financial audit, similar to the audit of Ocean House, at other poor performing homes.**

4. **Require adult homes to undergo comprehensive financial audits and submit detailed expenditure reports to the appropriate regulatory agency on an annual basis.**
5. **Include funding for QUIP in the State's fiscal year '02-03 budget, only if the following accountability measures are in place:**
   - **Require resident input into how QUIP monies are spent.**
   - **Require adult home operators to submit a detailed plan for QUIP expenditures to DOH and CQC.**
   - **Require operators to submit a detailed report of actual QUIP expenditures to DOH and CQC.**
   - **Require DOH to monitor QUIP utilization during annual inspections.**
   - **Require DOH to submit QUIP expenditure reports to the Legislature.**
   - **Ensure all homes receiving QUIP funds are in compliance with DOH regulations.**

Providing Rehabilitation and Recovery Oriented Services

Unlike adult homes, OMH supportive housing is specifically designed to promote the rehabilitation of people with psychiatric disabilities. Services provided through the existing OMH housing continuum are designed to help consumers build independent living skills and move toward recovery. OMH has formal standards for all models in the supportive housing continuum and requires licensure for some models. OMH service standards emphasize consumer rehabilitation and recovery with all models seeking to maximize consumers' ability to become independent and move to a less service-intensive setting.

OMH requires supportive housing programs to provide a range of skills training in areas such as symptom management, budgeting, shopping, cooking, cleaning, medication management, and utilizing community services. In addition, OMH supportive housing programs provide or link residents to educational, pre-vocational, and vocational services intended to facilitate residents' return to the competitive job market and/or their attainment of career advancement goals. In stark contrast to OMH housing, adult homes rarely work with consumers to develop independent living and vocational skills. **In fact, many adult home residents lose skills after moving into the home.**

OMH uses quality assurance, case record and reporting standards to ensure that services meet residents' needs and to facilitate active governmental oversight. OMH monitors lengths of stay to ensure that consumers are able to move to more independent and less costly housing when appropriate and available. In the adult home system, there is no incentive for operators to assist consumers in moving to a more independent setting. Consequently, people languish in adult homes without opportunity to explore other housing options.

Many people with mental illness go to work and live independently. With access to appropriate services, adult home residents can achieve a similar level of independence.

Access to a variety of vocational programs and education and skills training is essential to helping people with psychiatric disabilities return to work. Offering adult home residents the opportunity to become self-sufficient will require ongoing efforts to create housing enriched with vocational and other rehabilitation and recovery-oriented services.

Interim Recommendations for Promoting Rehabilitation and Recovery:

1. **OMH should develop outcome measures, performance standards and quality improvement plans to ensure mental health providers are offering rehabilitation and recovery oriented services, including vocational services.**
2. **OMH should vigorously monitor provider compliance with standards during regular inspection visits.**

Long-term recommendations:

1. **New OMH adult home regulations should mandate rehabilitation and recovery oriented services, including vocational services, in impacted adult homes.**

Ensuring Access to Quality Housing with Supportive Services

Adult homes became a housing option for people with mental illness because of the lack of community residential programs at the time of deinstitutionalization. While there are now many more OMH-sponsored community living options, current housing stock is not sufficient to meet demand. As of April 2002, the vacancy rate in New York City's OMH supportive housing system was a mere 2.41% (as calculated by the Center for Urban Community Services' Residential Placement Management System). In the current context, adult homes are, therefore, the only option for many people. Over time, if better mental health residential options become available, many people would choose other models and the number of people with mental illness living in adult homes could decrease. High quality, OMH-administered adult homes would, likely, remain the residential option of choice for some people with psychiatric disabilities.

As government oversight improves, poor performing adult homes will experience increased pressure to improve the quality of their services and physical plant. It is reasonable to expect that some operators will choose to close their homes rather than meet higher standards. Others will be forced to close. The State must begin to plan for how an already extraordinarily tight community mental health housing system will absorb the residents of adult homes that close.

Continued reliance on adult homes as a housing resource for people with psychiatric disabilities may raise *Olmstead* compliance issues for the state.

Sixty-seven percent of residents in New York City's impacted homes live in a home with 200 or more beds. These large homes tend to have "institutional" qualities, such as a

lack of individualized services, little opportunity for residents to have input into the services and conditions in their home, minimal interaction between residents and the surrounding community, and a lack of privacy. The larger impacted homes also tend to be segregated by disability status, with most homes housing people with psychiatric disabilities almost exclusively. In *Olmstead v L.C.,* the United States Supreme Court found that unnecessary segregation and institutionalization constitute discrimination and violate the Americans with Disabilities Act's integration mandate. The integration mandate requires the State to provide services in the most integrated setting appropriate to the needs of an individual with a disability. Because larger impacted adult homes tend to be both institutional and segregated, continued reliance on these homes as a housing resource for people with psychiatric disabilities could constitute discrimination and raise *Olmstead* compliance issues for the State.

Providing appropriate housing to adult home residents will be an enormous challenge. Adult home residents may not fit neatly into any of the existing community mental health housing models. Meeting the diverse and complex needs of adult home residents with psychiatric disabilities will require thoughtful and creative use of the existing housing continuum as well as the development of new units and perhaps new models.

With proper capital, operating, and service funding streams in place, some existing adult home properties could be converted into permanent supportive housing. Existing funding streams like HOME Investment Partnership (HOME), Low Income Housing Tax Credits (LIHTC), Federal Home Loan Bank (FHLB), and Community Development Block Grant (CDBG) could be used to acquire, rehabilitate, lease, and/or construct facilities. Existing funding streams, including Medicaid, HOME, LIHTC, CDBG, the SRO Support Services Program, and OMH residential support services funding could provide converted projects with funding for operating and service expenses. Increasingly, developers of supportive housing recognize the benefits of integrated or mixed population projects housing people with different kinds of disabilities together with formerly homeless people and low-income people who are neither formerly homeless nor disabled. Projects of this kind may also benefit from existing capital, operating and service funding streams like Supportive Housing Program (SHP), Shelter Plus Care (S+C), Section 8 Mod Rehab, Mainstream Housing for People with Disabilities, Housing Opportunities for People with AIDS (HOPWA), Homeless Housing Assistance Program (HHAP) and Operating Support for AIDS Housing (OSAH). Initiating a third New York/New York agreement between New York City and State would make significant additional funds available to offset capital, operating, and service expenses for projects in New York City.

Housing designed to serve adult home residents with psychiatric disabilities should include the following elements:

- Housing should be permanent and lease-based providing residents a stable living environment and the protections and rights of tenancy.

- Housing should be consistent with Olmstead requirements.
- On-site services should be rehabilitation and recovery oriented.
- On-site services should seek to link residents with appropriate community-based services, including vocational services.
- Some transitional on-site, low-demand services should be targeted for people who will have difficulty succeeding in permanent supportive housing, including people who are using substances and/or not currently engaged in mental health treatment. These services should be designed to help residents access the treatment and build the skills they need to succeed in permanent supportive housing.

Interim Recommendations for Ensuring Access to Quality Housing:

1. **OMH, in collaboration with other key stakeholders, should identify existing capital, operating and service funding streams that could be used to convert poor performing adult homes into permanent supportive housing and to provide on-going supportive services to residents in those homes.**
2. **New York State and New York City should initiate a New York/ New York III agreement to develop additional units of supportive housing for homeless mentally ill people. Residents of adult homes that are at risk for closure should be made NY/NY eligible.**

Long-Term Recommendations

1. **Engage key stakeholders in a long-term planning process to develop additional community housing, thereby decreasing reliance on adult homes. This process should include plans to develop new funding streams to support capital, operating, and service expenses in permanent supportive housing.**
2. **OMH should create a bed closing plan to move people with psychiatric disabilities out of large adult homes and into more integrated community settings.**
3. **OMH should partner with non-profit organizations experienced in developing and administering supportive housing to initiate a demonstration project and begin the process of converting some of the poorest performing homes into permanent supportive housing.**
4. **Conversions may require substantial renovations to the physical plant. In order to facilitate the conversion process, the following steps should be taken immediately to decrease the census at homes identified for conversion:**
   - **Stop new admissions into the home.**
   - **Offer intensive, on-site assistance to residents interested in seeking placement in another adult home or in the community mental health housing system.**
   - **Due to the difficulties associated with rehabilitating an occupied building, in some cases, vacant properties could be identified,**

rehabilitated, converted into permanent supportive housing, and used to temporarily house adult home residents whose homes are undergoing substantial rehabilitation.

ADVOCACY AND PEER SERVICES

Due to the lack of rehabilitation and recovery oriented services available in adult homes, residents with psychiatric disabilities often experience the same debilitating effects of institutionalization experienced by patients in State psychiatric hospitals. Many residents, who have spent substantial time in the shelter or State hospital systems, arrive at adult homes already believing that they have little ability to shape the environment in which they live. Others, particularly in the larger homes, learn quickly that complaints about quality of life in the home yield few results and that it is better not to complain. Because mental health providers sign service agreements directly with adult home operators and can be removed at the whim of the operator, in many cases, mental health service staff fails to act as advocates on the residents' behalf.

For most residents, adult homes are viewed as the end of the line, and little assistance is available to help them achieve their life's goals or to access other housing options. In this environment, where residents feel they have little voice and are often afraid to complain about the quality of services, the presence of attorneys and other advocates not employed by the home is crucial to help residents exert their rights, resolve quality of life issues, and access services available in the community.

Recommendations:

1. **Fund the expansion of non-legal advocacy and resident council development by groups like the Coalition of Institutionalized Aged and Disabled ($600,000 total cost).**
2. **Fund the expansion of legal advocacy services by groups like MFY Legal Services, Inc. ($600,000 total cost).**
3. **Develop a Peer Bridger program to assist adult home residents in utilizing community-based services, including alternative residential programs ($300, 000 total cost).**
4. **Supplement funding for legal and non-legal advocacy by creating licensing fees and using fines collected from homes out of compliance with the regulations.**

Conclusions

New York State's adult home residents with psychiatric disabilities deserve better than what we offer them today. Since the reports of the 1970's first called attention to residents suffering in adult homes, New York State has failed to implement substantive adult home reform measures to ensure that people with psychiatric disabilities can live in a truly integrated and dignified manner in our communities. Like all of us, people who live in adult homes have dreams and ambitions. Adult home residents deserve services that enable them to achieve those dreams and to obtain their fullest human

potential. Since the beginning of deinstitutionalization, New York State has relied on adult homes to provide seemingly low-cost, community housing to people with psychiatric disabilities. But, without adequate governmental oversight and fiscal accountability measures, the costs, both human and financial, have been greater than ever suspected. We call, today, on New York State to take swift action to implement the recommendations outlined in this paper and to ensure that the hundreds of millions of dollars already being spent on adult homes are put to the best possible use so that all adult home residents, with or without psychiatric disabilities, receive the high quality services they deserve.

New York State Coalition for Adult Home Reform

(List in Formation)

Community Access

Coalition of Institutionalized Aged and Disabled

Mental Health Empowerment Project

MFY Legal Services, Inc.

National Alliance for the Mentally Ill - New York State

New York Association of Psychiatric Rehabilitation Services

Schuyler Center for Analysis and Advocacy

Venture House