



Submitted electronically to: REGSQNA@health.state.ny.us

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Re: Proposed Amendment of Parts 486 and 487 of Title 18 NYCRR (Adult Homes)

Ms. Ceraolo:

MFY Legal Services, Inc.,¹ New York Lawyers for the Public Interest² and the Urban Justice Center³ are organizations that provide free legal services to people with disabilities and people living in institutions in New York. We write to provide recommendations in response to the request for comments on proposed amendments to Title 18 NYCRR Sections 486 and 487 (“proposed regulation”), which would limit the percentage of residents with serious mental illness in adult homes with a certified capacity of 80 or more beds to less than 25 percent of the resident population.

We applaud the New York State Department of Health (“the Department”) for taking this important step toward providing adult home residents with opportunities to live in the community. We agree with the assessment of the New York State Office of Mental Health

¹ MFY Legal Services, Inc. (MFY) is a not-for-profit law firm that provides free legal representation to poor and low-income people, including individuals with mental illness, in a variety of civil legal matters in New York City. The Adult Home Advocacy Project of MFY, established in 1992, focuses on protecting the rights of people who live in institutional adult homes through individual legal representation, law reform litigation, and legislative advocacy.

² New York Lawyers for the Public Interest (NYLPI) was founded in 1976 to serve the legal needs of underserved, underrepresented New Yorkers and their communities. Through community lawyering, NYLPI puts its legal, policy and community organizing expertise at the service of New York City communities and individuals. NYLPI's Disability Justice Program works to promote and protect the civil rights of people with disabilities, advocating for better programs and policies in public schools, less restrictive residential opportunities, and access to public services and all venues across New York City.

³ The Urban Justice Center (UJC) serves New York City's most vulnerable residents through a combination of direct legal service, systemic advocacy, community education and political organizing. UJC's attorneys, advocates, and social workers provide representation to individuals with disabilities in a variety of institutions, including hospitals, jails, prisons, nursing homes, and adult homes.

(“OMH”) that “certain housing settings in which there are a significant number of individuals with serious mental illness are not conducive to the recovery or rehabilitation of the residents.” We also agree with the Department’s assessment that providing community-based housing for people living in adult homes will decrease their overall utilization of Medicaid-funded services. This finding has been made time and again in reports issued by the New York State Commission on Quality of Care and Advocacy for People with Disabilities and by a federal court. We commend the Department’s plan to transition people with disabilities into community housing in order to prevent waste of taxpayer dollars in the Medicaid program.

We write this letter to provide you with recommendations that would enhance the Department’s goal of addressing the significant concentration of individuals with serious mental illness in large adult homes. These recommendations are based on our extensive experience serving the legal needs of people with disabilities and people living in institutionalized settings, including adult homes.

A. The Department Must Ensure that a Sufficient Amount of Community Housing is Available Prior to Implementation of the Regulation

We were pleased to learn of a new “Request for Proposal” (RFP) issued by the OMH which would provide housing in community settings for 1,050 adult home residents in Brooklyn and Queens. However, even with that sizeable allotment for Brooklyn and Queens, in those counties there still will be nearly 2,300 adult home residents with serious mental illness who lack access to available supported housing.

Further, many other counties will require a sufficient amount of housing in the community in order for this transition to be successful. A lack of available supported housing, coupled with the arduous process involved in accessing existing housing, have long been major barriers to adult home residents seeking to move to less restrictive settings.

We have serious concerns about the Department’s proposal to implement such a drastic change across the State without a parallel commitment to providing sufficient opportunities for integrated, community housing. We urge the Department to work with the OMH to ensure that a sufficient amount of community housing is made available for each relevant county prior to the implementation of this regulation to ensure that residents of adult homes have the opportunity to live in the most integrated setting appropriate to their needs.

B. The Department of Health, and Not the Adult Homes, Should Draft and Implement Each Compliance Plan

The proposed regulation at § 487.13(c) requires the operator of each transitional adult home to submit a Compliance Plan to the Department. We recommend that this provision be amended to require each transitional adult home to follow a Compliance Plan designed by the Department – not the adult home – in conjunction with the residents of the home, the OMH,

local supported housing providers, and the operator of the home. This will ensure a balanced approach where all involved parties will have the opportunity to provide input.

In the past, residents have successfully moved to community settings when housing providers and State agencies, rather than the adult homes, have led the charge. During the closure of Seaport Manor, for example, all 346 residents were assessed by the OMH and housing providers and placed in appropriate alternative housing, the majority of which was supporting housing. Similarly, after Pacific House Residents for Adults surrendered its license and notified residents that they would simply have to leave the home within 30 days, the Department – not the facility – ensured that each resident was assessed by a housing provider and received housing of their choice. As a result, all of the residents ended up in supportive housing.

C. The Regulation Should Include a Deadline for Implementation of the Compliance Plans

The proposed regulation at § 487.13(c) requires operators to submit compliance plans designed to lower each facility's mental health census "over a reasonable period of time." The regulation should be amended to ensure that the compliance plans will be fully implemented within a specific time frame. We recommend that full implementation be required within three years after the effective date of this regulation. This will enhance accountability and provide a guide for consumers and housing providers, rather than an open-ended time frame.

D. The Regulation Should Include Guidelines for Compliance Plans that Include Resident Participation and Choice

The proposed regulation must ensure resident participation in forming the Compliance Plan for the home in which they live. This will enhance resident autonomy and choice and ensure their participation in decisions that will directly impact their lives.

To accomplish this, as described in section B. above, the regulation should be amended to have the Department develop compliance plans with the participation of residents. However, if the Department retains the requirement for adult home operators to develop compliance plans, then operators should be required to solicit input from residents and resident councils during their development and incorporate that input into the compliance plans. The regulation should also be amended to ensure that adult home operators provide residents, family members, and medical and mental health providers with notice and information about, as well as physical copies of, the compliance plans during implementation.

The proposed regulation at § 487.13(c) requires operators to submit a Compliance Plan designed to lower the mental health census of each home through "discharge of residents with appropriate community services to alternative community settings." We recommend adding the phrase "of the resident's choice" at the end of this provision. Adding resident choice as a qualifier will help ensure that residents are not placed in alternative settings based solely on the need of the operator to follow the Compliance Plan, but will take into account a resident's choice of housing.

E. The Regulation Should Include Guidelines for Transparency and Accountability

The Department should adopt policies to ensure transparency, accountability, and oversight of the process. For example, each Compliance Plan should be posted online for monitoring by residents, their family members, advocates, the long-term care ombudsman program, elected officials, and other state agencies.

Additionally, the Department should implement an auditing system to verify the mental health census reported by adult homes. The proposed regulation requires adult home operators to self-report “a weekly roster of residents who are persons with serious mental illness” to the Department. We recommend that the regulation provide for a periodic independent audit and review of the censuses provided to the Department.

F. The Regulation Should Include Provisions for Due Process

The Department should institute administrative procedures to ensure due process for any resident who is denied a housing option because he or she is not defined as having a “serious mental illness,” as well as for any resident who is denied placement in the alternative community setting of his or her choice.

G. The Definition of “Transitional” Adult Homes Should Mirror the Historical Definition of “Impacted” Adult Homes

Transitional Adult Homes Should Include Homes In Which at Least 25% OR 25 Residents Have A Mental Illness

The proposed regulation defines “transitional” adult homes as homes with a certified capacity of 80 or more beds in which 25 percent or more of the resident population are persons with serious mental illness.

This proposed definition is inconsistent with the description of “impacted” adult homes found in Mental Hygiene Law §§ 45.09(a) and 45.10(a). Historically, “impacted” adult homes means homes of any size “in which at least twenty-five percent or twenty-five residents, whichever is less, have [a mental illness].” (emphasis added).

The language in this regulation should mirror the language in the Mental Hygiene Law. Adopting a more narrow definition will cause many people with mental illness to remain segregated in institutional adult homes.

The proposed regulation limits the percentage of residents with serious mental illness in certain adult homes to less than 25 percent of the resident population. Although this would significantly lower the population of people with mental illness in some homes, it permits larger homes to retain a significant number of individuals with mental illness. For example:

Home	Certified Capacity	Maximum Number of Residents with Mental Illness Allowed Under Proposed Regulation
Harbor Terrace Adult Home	427	106
Queens Adult Care Center	361	90
Elm York Home	286	71
Kings Adult Care Center	220	54
Brooklyn Adult Care Center	216	53
Garden of Eden	202	50
Lakeside Manor	200	49

Under the proposed regulation, significant numbers of individuals with serious mental illness would remain in settings which “are not specifically designed to serve people with serious mental illness; are not under the license and control of OMH; do not foster independent living due to institutional practices such as congregate meals or ritualized medication administration; and do not provide specifically designed rehabilitation programs linked to community work settings.”⁴ These individuals will continue living in a setting which is not clinically appropriate simply because they happen to live in a very large home. The regulation should, therefore, limit the number of people with mental illness in these homes to 24 percent or 24 residents, whichever is less.

Transitional Adult Homes Should Include All Adult Homes, Regardless of Capacity

This danger of individuals being confined to clinically inappropriate settings is compounded by the fact that the proposed regulation would apply only to adult homes with a capacity of 80 or more beds. The proposed regulation limits the definition of “transitional” adult homes to homes “with a certified capacity of eighty or more.” This proposed definition is inconsistent with the description of “impacted” adult homes, which includes homes of all sizes. Under the proposed regulation, homes with less than 80 beds are excluded, even if those homes have a high population of people with mental illness.

Adult homes with 79 beds, or even 30 beds, still are institutions: they house “a significant number of individuals with serious mental illness[,]...are not specifically designed to serve people with serious mental illness; are not under the license and control of OMH; do not foster independent living due to institutional practices such as congregate meals or ritualized

⁴ See Regulatory Impact Statement, Proposed Rule Making: Amendment of Section 486.7 of Part 486 and Part 487 of Title 18 NYCRR, issued August 8, 2012 (“certain housing settings in which there are a significant number of individuals with serious mental illness are not conducive to the recovery or rehabilitation of the residents. This is particularly so when the settings: are not specifically designed to serve people with serious mental illness; are not under the license and control of OMH; do not foster independent living due to institutional practices such as congregate meals or ritualized medication administration; and do not provide specifically designed rehabilitation programs linked to community work settings.”)

medication administration; and do not provide specifically designed rehabilitation programs linked to community work settings.” For example, the vast majority of the impacted homes in Nassau and Suffolk counties have a capacity of less than 80 beds, and yet house a large population of people with mental illness.

Limiting application of the regulation to adult homes with 80 or more beds would lead to illogical and arbitrary results. For example, under the proposed regulation, an adult home with a capacity of 80 beds that has 21 residents with mental illness would be classified as a transitional adult home, but an adult home with a capacity of 79 beds that houses 79 residents with mental illness would not be classified as a transitional adult home. An adult home that has 79 beds that are all filled with people with mental illness is not more “conducive to the recovery or rehabilitation of the residents” than an adult home with 80 beds that has 21 residents with mental illness. The regulation must be amended to fix this innumeracy.

All adult home residents should be given the opportunity to live in a setting that is conducive to their recovery and rehabilitation, regardless of the size of the facility they happen to live in. The proposed regulation should not draw an arbitrary line at homes with a certified capacity of 80 beds, thereby excluding hundreds, if not thousands, of people who continue to be unnecessarily segregated in institutionalized settings.

Transitional Adult Homes Should Define Mental Illness More Broadly

The proposed regulation includes persons with “serious mental illness” in the mental health census. This is defined as persons who “(1) meet criteria established by the commissioner of mental health, which shall be persons who have a designated diagnosis of mental illness under the [(DSM-IV-TR)] and whose severity and duration of mental illness results in substantial functional disability or (2) are receiving or have received within the past five years services from a mental hygiene provider which is licensed, operated or funded by the Office of Mental Health.”

Using this definition, the proposed regulation is in danger of creating a system that excludes many people with disabilities who are stuck in the adult home system. These are people who came to live in an adult home many years ago after a hospitalization, are in recovery and, therefore, do not receive mental health services, but nonetheless live in the adult home. Additionally, this definition excludes people who have a psychiatric history but are receiving services in another system, such as substance abuse services or services through the Office for People with Developmental Disabilities.

Under the traditional definition of “impacted” adult homes, the mental health census includes “persons who have at any time received or are receiving services from a mental hygiene provider which is licensed, operated or funded by the office of mental health, or the office of mental retardation and development disabilities.” This broader definition would capture a number of individuals who meet the criteria to receive increased services and oversight

established by the Mental Hygiene Law, but who would not meet the more narrow definition of “persons with serious mental illness” outlined in the proposed regulation.

H. The Regulation Should Remove “Senior Housing” from the Definition of “Alternative Community Setting”

The proposed regulation lists “senior housing” as a type of “alternative community setting.” It is unclear what type of housing this refers to. On its website, the New York City Department of the Aging includes many adult homes under its list of “senior housing.”⁵ We recommend that the term “senior housing” be removed from the proposed regulation.

I. Transitional Adult Homes Should Not Be Licensed as Assisted Living Residences, Enhanced Assisted Living Residences, or Special Needs Assisted Living Residences

An Assisted Living Residence (ALR), Enhanced Assisted Living Residence (EALR), and Special Needs Assisted Living Residence (SNALR) are three types of regulated facilities which provide housing and services to people who are elderly or have disabilities. 10 NYCRR § 1001.2. The Department provides a process by which adult homes may apply to become licensed as ALRs, EALRs, and SNALRs and provide services to people with a higher level of medical need.

We recommend that the Department include a provision in the proposed regulation precluding transitional adult homes from obtaining licenses to become ALRs, EALRs, and SNALRs. We have grave concerns that these facilities – many of which have a long history of providing substandard care – will become the easy referral for people who have disabilities or are elderly and who, if not for the difficulty of accessing personal care or home health services, could continue to live in their apartments or other independent living settings more integrated in the community. The inclusion of such a provision will help prevent unnecessary institutionalization for thousands of New Yorkers who are elderly or have disabilities.

For over thirty years, government investigations, news reports, and judicial decisions have documented the deep-rooted problems of resident neglect and abuse in impacted adult homes. The Department consistently has cited many of these facilities for abusive practices and poor conditions. Without a provision specifically preventing these same facilities from being licensed as ALRs, EALRs, and SNALRs, this regulation will create a new system that continues to warehouse vulnerable populations.

Conclusion

Thank you for the opportunity to comment on the proposed regulation. It is our hope that this regulation marks the beginning of a system where people with disabilities will have the opportunity to live in the most integrated setting appropriate to their needs.

⁵ <https://a069-webapps12.nyc.gov/egovt/housing/index.cfm>

Respectfully submitted,

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