AN ACT TO INCREASE ACCESSIBILITY OF FAMILY-TYPE HOMES FOR ADULTS IN NEW YORK STATE

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I. INTRODUCTION

This purpose of this exposition is to propose an act to increase accessibility of Family-Type Homes for Adults ("Family-Type Homes") in New York State to divert more persons away from premature institutionalization. Family-Type Homes are an alternative to facility-based care; operators provide supervision, limited care, and companionship for disabled persons under the age of 65 who are unable to live independently.[1] Today, Family-Type Homes are considered to be *invisible* and inaccessible due to absent incentivization at the administrative level.[2] Family-Type Homes do not receive direct funding through New York State's Medicaid budget; further, the current Supplemental Security Income ("SSI") reimbursement level is unviable for Family-Type Homes and related domiciliary-care programs to be sustained.[3] Administering Family-Type Homes with greater Medicaid funding and increased SSI reimbursements would foster greater program feasibility and systems-wide impact for persons with disabilities. Implementation of this proposal shall help to alleviate the present day, statewide shortage of appropriate-level care services.

Persons with physical, mental, and/or age-related disabilities share constitutional rights to non-discriminatory and non-isolating habilitation, freedom from harm, and *access* to adequate treatment — "through the least restrictive means." [4] Family-Type Homes were designed and implemented in support of these ideals. Accordingly, the human component of Family-Type Homes, the intent, shall be acknowledged before the regulatory schema herein.

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[1] New York State Office for the Aging, Livable New York Resource Manual, § III.1.q (2012).

[2] Id. at § III.1.p.

[3] Id. at § III.1.p.

[4] Pennhurst State School & Hosp. v. Halderman, 465 U.S. 89 (1979).

As promulgated: "The legislature finds that a growing number of frail and elderly persons in this state are at risk of placement in settings that are unnecessarily costly or… institutional in character. The legislature further finds that to alleviate this risk, supportive living arrangements must be developed which… maximizes the values of independence, privacy and integration into the surrounding community." [5] Legislative intent remains to be effectuated, as detailed in the pending lawsuit: E.B. by his guardians M.B. and R.B., et al. v. Cuomo, et al.[6] On behalf of more than 2,000 disabled persons in Western New York and related areas, the Plaintiff alleges: New York State continues to violate the Americans with Disabilities Act due to its failure to establish sufficient residential-care programs.[7] Thousands of citizens continue to live in isolation at risk for harm due to a shortage of appropriate-level care services, specifically, programs under the auspices of the Office for People with Developmental Disabilities ("OPWDD") and Adult Care Facilities monitored by the New York State Department of Health ("NYS DOH").

Studies predating the twenty-first century proposed recommendations relevant to the human relationship with behavior and environment, specifically, focusing on populations of institutionalized persons. Exposés of deplorable conditions and mistreatment in state-supported hospitals and developmental centers prompted court-mandated facility closures in the years to follow (e.g. Letchworth and Willowbrook). Subsequently, talks on the subject of psychosocial well-being were authorized; snake pits were shut down.

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[5] N.Y. Soc. Serv. Law § 461-I (McKinney 1984).

[6] E.B. by his guardians M.B. and R.B., et al. v. Cuomo, et al., 1:16-cv-00735 (W.D.N.Y. 2016).

[7] E.B. by his guardians M.B. and R.B., et al. v. Cuomo, et al., 1:16-cv-00735 (W.D.N.Y. 2016).

There was a time when children and adults were isolated and routinely chained to furniture, chemically restrained and neglected without clothing or nourishment — care services once advertised as *mental hygiene*. Making an attempt to transfer thousands of persons into community settings, residential-care programs were established in New York State after then-Governor Mario Cuomo prioritized the closure of Willowbrook by a 1987 deadline.[8] Evidence of inhumanity was irrefutable and elucidated: "Certain persons who have spent a long time in general hospitals describe them as places where a human being becomes a 'number', a 'bed', a 'diagnosis'…where the patients' rights are turned into privileges, his family into visitors, and where the outside world becomes increasingly remote."[9] Perseverance sparked human unity and succeeding departures from overcrowded wards.

New York's present-day shortage of residential-care programs remains confounding in view of the nation's glaring history. Rulemakings and decades of psychiatric research caution against the adverse effects of premature institutionalization; respective authorities promote residential care. Impact litigation across state lines, mirroring New York State Association for Retarded Children, Inc. v. Carey, led to the closure of institutions and promoted the 1990 enactment of the Americans with Disabilities Act.[10] This reform was "remarkable and far reaching" legislative progress.[11] However, New York continues to find its regulations in non-compliance with the Americans with Disabilities Act.[12] Disabled persons share a right to non-

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[8] David Rothman & Sheila Rothman, The Willowbrook Wars: Bringing the Mentally Disabled into the Community 367 (2005).

[9] Henri F. Ellenberger, *Behavior Under Involuntary Confinement*, *in* Behavior and Environment: The Use of Space by Animals and Men 188, 192 (Aristide H. Esser ed., 1971).

[10] New York State Ass'n for Retarded Children, Inc. v. Carey, 596 F.2d 27 (2d Cir. 1979).

[11] Lynda E. Frost & Richard J. Bonnie, The Evolution of Mental Health Law 13 (2001).

[12] N.Y. Sess. Law News, Legis. Memo, Ch. 259 (McKinney 2018).

isolating habilitation; however, the great majority of disabled persons in New York State remain institutionalized or isolated in settings without adequate supports. Many persons live at risk of injuring themselves and/or caregivers who wait for state assistance. Parallel to accessibility concerns, a complex regulatory schema persists.

II. CURRENT REGULATORY STANDARDS

A. Legislative Intent to Establish Family-Type Homes

The instauration of Family-Type Homes, described in the rules of the Department of Social Services, intended to: "avoid compelling individuals to either enter nursing homes unnecessarily or continue living independently while foregoing the care they need."[13] Family-Type Homes are Adult Care Facilities; however, they are not administered like most others. Family-Type Homes are the sole Adult Care Facility program administered by the Office of Children and Family Services ("OCFS") without regular health-department oversight. In response to state and federal court mandates to implement community-based and appropriate-level care services, the legislature discovered intent for Family-Type Homes. That being said, decades later, an unheeded shortage of residential-care services continues to plague the citizens of New York State.

Unlike operators of Family-Type Homes, Adult Care Facility programs including Enriched Housing and Adult Homes receive direct Medicaid funding and greater SSI reimbursement rates. These programs house persons over the age of 65 and often circumvent intended bed capacities, serving residents in numbers exceeding 100-200 persons,

[13] N.Y. Reg. Text, Update Standards for Adult Homes and Standards for Enriched Housing Programs, 494409 (2018).

quietly evading regulatory requirements to remain *non-institutional in character*. Family-Type Homes are small-group settings where operators serve four or fewer residents. Operators do not receive direct Medicaid funding for equipment, home modifications or startup efforts. Operators are not licensed by NYS DOH and receive nominal SSI reimbursements, only. The disparate absence of funding causes Family-Type Homes to remain inaccessible and, in many communities, obsolete. Absent heath-department licensure, operators are barred from accepting many applicants who present low-level care needs that could feasibly be accommodated in home-type settings. Legislative intent for aging-in-place initiatives has not been effectuated in the context of Family-Type Homes. Applicants are commonly denied services based on disparate admission standards codified into the program.

B. Staffing and Licensure

In New York State, Family-Type Home operators are not required to obtain specialized training.[14] Mental health conditions have grown in prevalence among residents in Skilled-Nursing and Adult Care Facilities, and the majority of these conditions require specialized care. That being said, skilled services are often reserved for *well-behaved* residents who could otherwise be discharged into the community if an appropriate-level placement existed. This reality underscores a systems-wide issue: "Growth in the elderly population means a direct increase in age-related diseases such as dementia and poor mental health... and serious constraints on the quality of life among elderly individuals."[15] Family-Type Homes would allow more persons to be diverted away from inappropriate institutionalization, while increasing the availability of skilled-nursing beds for persons in need.

[14] New York State Office for the Aging, supra note 1, at § III.1.q.

[15] Shubhangi R. Parkar, *Elderly Mental Health: Needs,* Mens Sana Monographs 13,1 (2015).

Inadequate training, short staffing, and unspecialized care are direct causes of harm to long-term care residents.[16] Often, staff are not prepared or equipped to care for residents who present complex care needs associated with mental health conditions. Disabled persons *not* requiring professional supervision should be diverted away from institutions and into residential-care settings. Greater collaborations between operators and regional care-services agencies should be implemented to develop training and health licensure. This would allow Skilled-Nursing Facilities to concentrate their efforts on higher-needs populations. By heightening staffing standards in institutional and residential-care settings, disabled persons would enjoy greater access to appropriate-level care services to meet their individualized needs.

C. Operating Standards and Sources of Funding

In New York, admission standards for Family-Type Homes are more exclusionary than related programs across the nation. Under current regulations, a prospective applicant is denied housing if said applicant: is bedfast; requires the assistance of another person to walk; requires the assistance of another person to navigate stairs; has chronic issues with incontinence; or requires medication regiment monitoring.[17]

Prior to 2018 *Emergency Rulemakings*, Family-Type Homes were required to reject applicants on the sole basis of being non-ambulatory and requiring a wheelchair. For decades, this rule harmed disabled citizens. Admission standards were modified to read: "An operator shall not exclude an individual on the sole basis that such individual is a person who primarily uses a wheelchair for mobility, and shall… admit such individuals, consistent with the Americans with Disabilities Act... 42 U.S.C. 12101... and the provisions of

[16] N.Y. Sen. Bill 1032, Safe Staffing for Quality Care Act (2019).

[17] N.Y. Comp. Codes R. & Regs. 18, supra note 14, at § 489.7.

this section."[18] This amendment was deemed an emergency under New York's Administrative Procedure Act because the blanket denial of wheelchair-bound persons is/was: "detrimental to the health and general welfare of individuals… eligible for admission to adult care facilities."[19]

Prospective operators of Family-Type Homes are faced with financial obstacles while participants are faced with stringent admission barriers. Operators receive SSI reimbursements at Level 1 with no additional Medicaid funding.[20] That being said, providers in larger-model Adult Care Facilities (e.g. Enriched Housing) receive direct Medicaid reimbursements for care services provided *plus* SSI reimbursements at Level 3 for living costs.[21] Level 3 reimbursements are considered insufficient for Enriched Housing providers; Level 1 in the context of Family-Type Homes is equally unviable.[22] Operators who aspire to establish Family-Type Homes receive no direct funding for startup efforts; they are barred from deriving any source of income from occupations inside the home. Family-Type Homes, in many ways, are impractical from the operator perspective. Institutional Medicaid is the most commonly funded care option in New York State; in effect, residential-care programs including Family-Type Homes have failed to be administered in the face of legislative priority, albeit dismal.

Care providers in Family-Type Homes navigate cryptic criteria which does not easily translate to program fruition. Operators must: live in the home; provide 24-hour supervision

[18] N.Y. Comp. Codes R. & Regs. 18, § 489.7 (2020).

[19] N.Y. Reg. Text, supra note 11, at 494409.

[20] N.Y. Comp. Codes R. & Regs. 18, § 352.8 (2016).

[21] Id. at § 352.8.

[22] New York State Office for the Aging, supra note 2, at § III.1.p.

for residents; designate a substitute caretaker; "demonstrate sufficient income, not derived solely from income from the residents;" and "not be otherwise employed in or outside the home unless the operator can demonstrate substitute provision for the care and maintenance of the residents and receives prior written approval from the local department of social services."[23] Requiring operators to show sufficient income with no state funding offered to assist with startup efforts is problematic. Substandard nursing homes with patterns of neglect are encouraged to derive their operating funds, almost entirely, from Medicaid and private-insurance reimbursements. Nationwide, long-term care facilities fail to exhibit sustainable revenues aside from reimbursements; glaring deficits and conflicting interests are presented during annual surveys. It is unjust that persons under the age of 65 who are eligible for Medicaid, often, are unable to choose Family-Type Homes. Level 1 SSI coverage is unsustainable for operators; thus, few programs exist. Without direct Medicaid funding, potential care providers and disabled persons are unduly disadvantaged.

Family-Type Home operators: "do not need specialized education or experience."[24] Prospective operators may apply through their local Department of Social Services. When a natural person receives an operating certificate, said person may provide care to related persons, "provided that the relationship between the operator and resident is not that of spouse, in-law, child or step-child."[25] Improved technologies and modes of communication have been implemented to ensure that aging and disabled persons receive advocacy services while promoting dignity in community-based settings.

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[23] N.Y. Comp. Codes R. & Regs. 18, § 489.3 (1985).

[24] N.Y. Office of Children and Family Services, Pub. 1327 (2015).

[25] St. Healthcare L. Libr., Soc. Serv. § 461-B Provisions Related to Establishment of Adult Care Facilities, 7649826 (2015).

D. Modes of Resident Advocacy

Family-Type Homes are monitored by New York's Justice Center for the Protection of People with Special Needs. When a complaint is raised to the Justice Center by a participant or third-party, the Justice Center notifies OCFS who shares the responsibility to investigate the report. Additionally, the Bureau of Adult Services coordinates with OCFS to determine the acceptance and/or denial of persons applying to become an operator.

The New York State Long-Term Care Ombudsman Program is another advocacy resource for persons in Family-Type Homes. Rulemakings of the New York State Office for the Aging indicate an increased designation of ombudsmen in rural areas and Family-Type Homes to uphold residents' rights and quality care.[26] Operators of Family-Type Homes are mandated reporters of abuse and neglect concerns. Recently-adopted proposals intend to: "relieve the necessity for multiple reports; thus, reducing the issues that can arise when multiple reports are being made… lessening the potential of employees who are needed to provide care to vulnerable persons being required to spend significant time away from these duties in order to make reports that have already been reported."[27] Heightened visitation and education services, in person and through the use of adaptive technology, may encourage prospective participants and caregivers.

E. Noncompliance with Federal Regulations

At the federal level, home and community-based care services for disabled adults are defined to include: "training…in managing the individual" and "nursing care services."[28]

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[26] NY Reg. Text, Administration of the Long Term Care Ombudsman Program, 471203 (2018).

[27] NY Reg. Text, Duty of Mandated Reporters to Report Incidents Involving Vulnerable Persons, 467272 (2017).

[28] 42 U.S.C.A. § 1396t (1999).

Operators of Family-Type Homes in New York State do not receive formal training; they do not provide nursing-care services to residents. This undermines federal guidance outlined in the proclamation of grants to states to mitigate unnecessary institutionalization of disabled persons through residential-care services.

New York State has recognized: "Foster family care for elderly or disabled persons is one community-based program which the legislature believes should be encouraged."[29] However, there are gaps between aspirational intent and the services rendered in Family-Type Homes. This is apparent by the low number of residents served; in 2016, there were 328 licensed operators with a statewide capacity of 1,084 persons.[30] Comparatively, there were 103,696 persons living in New York State's long-term care facilities and nursing homes.[31]

III. PROPOSED ACT TO INCREASE ACCESSIBILITY OF FAMILY-TYPE HOMES

A. Shortage of Residential-Care Programs: Family-Type Homes as a Solution

Incentivizing Family-Type Homes through increased Medicaid and SSI reimbursement rates, implementing health-department licensure and amending admission standards would make Family-Type Homes more accessible. In effect, this would help resolve New York's statewide shortage of residential-care programs in efforts to divert more persons away from premature institutionalization. Comparable programs in other states offer comprehensive care services, and the positive fiscal implications are measurable. Principally, Family-Type Homes provide a dignifying option for appropriate-level care services.

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[29] N.Y. Soc. Serv. Law § 364-h (McKinney 1985).

[30] N.Y. Office of Children and Family Services, Annual Report (2016).

[31] Kaiser Family Foundation, State Health Facts: Total Number of Residents in Certified Nursing Facilities (2016).

Health and wellbeing are directly associated with physical environment. In the context of institutionalized persons: "exchanges occur within a physical environment and involve active use of that environment to cope with and structure their social relationships."[32] Family-Type Homes promote care in a dignifying and home-type atmosphere. Implementing a greater number of Family-Type Homes, separate and apart from institutions, would satisfy statutory directives while providing an option with increased autonomy.

As alleged in E.B. by his guardians M.B. and R.B., et al. v. Cuomo, et al., the New York State Governor and Commissioner of OPWDD are: "continuing to fail to plan for and provide sufficient services, including supported community residential opportunities, necessary to prevent the unjustified isolation" of disabled persons.[33] It is further alleged: New York State's failure to administer residential-care programs "in compliance with their Federal and... state law obligations impedes the aforementioned adults from participating in community life, including everyday social contacts with persons other than family members."[34]

Family-Type Homes were established to serve disabled persons under the age of 65, including persons with developmental disabilities who do not require professional monitoring. That being said, Family-Type Homes are not widely implemented despite their potential for effectiveness. New York State *must* implement a sufficient number of appropriate-level care services for persons with disabilities to mitigate the harmful effects of premature and isolating institutionalization; Family-Type Homes present a solution.

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[32] Irwin Altman, *Ecological Aspects of Interpersonal Functioning*, *in* Behavior and Environment: The Use of Space by Animals and Men 188, 291 (Aristide H. Esser ed., 1971).

[33] E.B. by his guardians M.B. and R.B., et al. v. Cuomo, et al., supra note 6, at 1:16-cv-00735, Mem. of Law.

[34] Id. at 1:16-cv-00735, Mem. of Law.

New York State has neglected its *parens patriae* duty to provide adequate services: "in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[35] OCFS reports that Family-Type Homes serve less than 1% of disabled persons.[36] Restrictive institutions remain the most prevalent option among convalescent-care facilities. New York's failure to establish sufficient OPWDD group homes and comparable Family-Type Homes administered by OCFS prevents thousands of disabled persons from achieving community integration. "This matter's urgency is a function of both the severity of the crisis for those individuals affected by it and its increased prevalence."[37] Following the closure of New York's state-supported institutions – asylums and almshouses alike – disabled persons and their caregivers have struggled to solidify community-based alternatives.

The shortage of residential-care programs, specifically Family-Type Homes, prevents many disabled persons from engaging with a "range of people interested in their welfare" and causes undue isolation.[38] Disabled persons who were once committed to deplorable institutions were eventually joined as a special class – the *Willowbrook Class*. These persons were guaranteed protections and opportunities for community integration. That being said, there has been a resurgence of "low legislative priority" for present-day disabled persons who should be afforded the same opportunity for community-based care services under the law.[39]

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[35] Id. at 1:16-cv-00735, Complaint.

[36] N.Y. Office of Children and Family Services, supra note 28, at Annual Report.

[37] Elder Law Journal, Helping Them Rest In Peace: Confronting The Hidden Crisis Facing Aging Parents of Disabled Children, 10 Elder L.J. § 393 (2002).

[38] David J. Rothman & Sheila M. Rothman, supra note 5, at 232 (2005).

[39] Elder Law Journal, supra note 35, at 10 Elder L.J. § 393.

Deficient legislative priority relevant to residential-care programs for the disabled stems from a longstanding excuse: complexity of the issue. As discussed in Klostermann v. Cuomo: "The mentally ill…are entitled to a declaration of their rights as against the State. Their claims do not present a nonjusticiable controversy merely because the activity contemplated on the State's part may be complex and rife with the exercise of discretion."[40] As it pertains to residential care, disabled persons are burdened to ask courts, yet again, "only that the program be effected in the manner that it was legislated ."[41] For decades, New York State has failed to implement a sufficient number of supportive residential-care programs for disabled persons.

In 1986, the Office of Mental Retardation and Developmental Disabilities, now OPWDD, predicted: "Given the deinstitutionalization efforts currently underway… it is quite conceivable that many of this nation's public institutions for mentally retarded persons will eventually evolve into geriatric care facilities."[42] Within a decade of this predication, several of New York State's formerly-supported institutions were completely abandoned, left to rot physically. The number of geriatric care facilities serving disabled persons has increased, but not through a process of repurposing former asylums. Dispiriting waiting lists and dismal funding, both, prevent deinstitutionalization from becoming a systems-wide reality.

New York State has not implemented a sufficient number of Family-Type Homes to support the growing number of disabled individuals who are eligible to receive care in the community. A streamlined approach should be taken to link Family-Type Homes with care-services agencies. Absent health licensure, operators are barred from offering care beyond

[40] Klostermann v. Cuomo, 61 N.Y.2d 525 (1984).

[41] Id. at 61 N.Y.2d 525.

[42] Matthew P. Janicki, *Some Comments on Aging and a Need for Research*, *in* Mental Retardation: Research, Education, and Technology Transfer 261, 262 (Henryk M. Wisniewski & Donald A. Snider eds., 1986).

basic supervision; in effect, many applicants with low-level care needs are automatically denied admission — encouraging persons to enter institutions prematurely. It is often the case that feasible collaborations with care-services agencies are not established. Operators may provide care for physically, developmentally, and/or mentally disabled persons; though, this program functions separately from group homes and family care under the auspices of OPWDD. Today, program placement depends on availability rather than individual care needs, choice or preference. New York State must acknowledge and act on its unsatisfied directives in order to develop an infrastructure for residential care. Disabled persons in long-term care facilities should only be in such a placement if their complex medical needs and/or physical limitations require skilled services — "so inherently complex that it can be safely and effectively performed only by, or under the supervision of, professional or technical personnel."[43] Disabled citizens should not be institutionalized due to low-level care needs that could be accommodated, feasibly, in a residential setting.

Alternatively, when persons achieve rehabilitation goals following *necessary* placement in a long-term care facility, options should be available to assist with reintegration back into the community. Instead, there are national trends of prolonged institutionalization and inadequate discharge planning, alternatively known as Medicaid fraud. Aside from Family-Type Homes, many residential-care programs are still found to be institutional in character; some function as *individualized* units in congregations of 100-200 residents; others are corporate-run adult homes without ambience. Family-Type Homes have not been incentivized due to the purported complexity of rendering individualized services.

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[43] 42 C.F.R. § 409.32 (1994).

Questions are raised pertaining to the feasibility of in-home care services, satellite nurses, resources and overall staffing. Operators of Family-Type Homes are encouraged to transport residents to medical care providers in the same way that many family members do for one another. Under the Rehabilitation Act of 1973: "Individuals with disabilities cannot be excluded from a community residential service program solely by reason of their disabilities, even if the disabilities are multiple and severe."[44] Disabled persons should not be confined to institutions as a result of an insufficient number of residential-care programs. Family-Type Homes were established to provide care and shelter for variously disabled persons under the Rehabilitation Act in efforts to mitigate "unnecessarily segregated services."[45] Operators are not required to "commingle the elderly and individuals with physical disabilities with the intellectually challenged," but the option is available in Family-Type Homes.[46] As a result, participants may live in diverse environments with opportunities for enriched socialization and development.

B. Positive Fiscal Implications

Though Family-Type Homes are administered differently throughout the nation, there is a wide understanding: Residential-care programs are a cost-effective alternative to Institutional Medicaid. Through demonstration projects and diversion phases, greater community integration may be achieved. In 2008, the State of Tennessee proposed an expansion of its cost-effective residential alternatives to institutionalization, including group adult foster care.[47]

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[44] Americans with Disab.: Pract. & Compliance Manual, *Section 504: Nondiscrimination under Federal Programs or Activities*, § 1:167 (2019).

[45] Id. at § 1:171.

[46] Id. at § 1:171.

[47] St. Healthcare L. Libr., Plan to Expand Cost-Effective Community-Based Residential Alternatives to Institutional Care, P 71-5-1411 (2018).

In Florida, the Adult Foster Home Program is one of the leading residential-care programs available to disabled adults who require housing and assistance with activities of daily living. In 1991, approximately 6,000 persons utilized Adult Congregate Living and Adult Foster Care programs in the State of Florida, and that number has grown.[48] Additionally, "Foster Care…developed in Oregon provides services to 6,000 elderly clients with disability levels similar to many nursing home clients, and the program ties reimbursement to service packages."[49] New Jersey's legislature found Adult Family Care to be a cost-effective means of providing care services to elderly and disabled persons with dignity in home-type settings.[50] Many states recognize: To achieve a greater number of residential-care programs, and accessibility, there is a "need to adjust the fiscal relationship between community and institutional programs by funding a shift from institutional to community-based long-term care programs."[51]

Creating a cost-effective, community-based infrastructure for residential care is an unfulfilled aspiration in New York, and it remains the subject of perpetual litigation. Other states have effectuated diversion plans to shift persons away from institutionalization. These models should be followed in New York to expand Family-Type Homes; this could be achieved through demonstration projects to reallocate existing Medicaid funds over time. As it stands, the dismal funding for Family-Type Homes is a barrier for persons in search of appropriate-level care services.

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[48] Larry Polivka, *In Florida the Future Is Now: Aging Issues and Policies in the 1990s*, 18 Fla. St. U. L. Rev. 401 (1991).

[49] Id. at 18 Fla. St. U. L. Rev. 401.

[50] St. Healthcare L. Libr., Findings, Declarations Relative to Adult Family Care, P 26:2Y-2 (2018).

[51] Larry Polivka, supra note 41, at 18 Fla. St. U. L. Rev. 401.

The maximum monthly benefit for operators of Family-Type Homes varies between downstate and other regions of New York. In any event, the monthly SSI reimbursement is far less than the average Medicaid or private-pay reimbursement in a Skilled-Nursing Facility. In the counties of New York, Nassau, Rockland, Suffolk and Westchester, the monthly Level 1 SSI reimbursement is $1,037.48 per participant; operators in other regions of New York State receive $999.48 monthly per resident.[52] According to NYS DOH, the average reimbursement rate for a Skilled-Nursing Facility in New York City is $149,028, annually.[53] Medicaid, separate from SSI, reimburses long-term care facilities at a national average of $206 per day ($6,180 per month per resident).[54] Many persons who are currently forced to reside in nursing homes could receive appropriate-level, cost-effective care in the community if a sufficient number of residential programs were made available. Access to residential care would help to mitigate inappropriate institutionalization of persons statewide; this reduction would lessen New York State's exorbitant spending on Institutional Medicaid that far exceeds residential care.

C. Diverting Residents Away from Institutional Neglect and Abuse

The greatest cost of institutionalizing disabled persons is the risk for harm at the expense of the resident body. No survey report can truly narrate the conditions inside the walls of our present-day institutions (monitored by NYS DOH and the Centers for Medicare and Medicaid Services). Taxpayers fund Medicaid reimbursements for nursing homes *plus* the costs associated with poor care, abuse and mistreatment.

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[52] New York State Office of Temporary and Disability Assistance, SSI and SSP Benefit Levels Chart effective January 1, 2019 (2018).

[53] New York State Department of Health, Estimated Average New York State Nursing Home Rates (2019).

[54] Liz Liberman, *Medicaid Reimbursement Rates Draw Attention*, National Investment Center (2018).

It should be known: "Adverse events in long term care facilities, which occur, largely, due to inadequate treatment, care, and understaffing, cause preventable harm to residents and approximately $2.8 billion per year in costs."[55] Residential care including Family-Type Homes should be promoted to help mitigate the physical and financial costs attributed to inappropriate institutionalization.

The Office of the Medicaid Inspector General is "responsible for preventing, detecting and investigating Medicaid fraud."[56] Long-term care facilities circumvent these efforts through acts of evasion, often, in an attempt to conceal operating costs and padded reimbursement rates. When a facility fills 100-200 beds, it becomes increasingly difficult to monitor the legitimacy of individual reimbursement practices. Continuously, facilities are cited for reporting higher-level care needs than what residents require. In the context of Family-Type Homes, there is a clear and known SSI benefit for operators to receive with no room to inflate the reimbursement. The small number of residents in each home helps maintain individualized reimbursement practices with reduced fraud. While long-term care facilities have fought to prevent the Medicaid Inspector General from conducting audits of patient review instruments, operators of Family-Type Homes are hopeful to receive any direct Medicaid funding.[57] The duties of the Medicaid Inspector General include: investigation of Medicaid fraud; referrals for criminal prosecution; and recovering "improperly expended medical assistance funds."[58] Family-Type Homes would be advantaged if Medicaid funding was allocated to the program — a practical consideration.

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[55] United States Dept. of Health and Human Services, Office of Inspector General, General Report: Adverse Events in Skilled Nursing Facilities (2014).

[56] New York State Health Facilities Ass'n, Inc. ex rel. its member Residential Health Care Facilities v. Sheehan, 953 N.Y.S.2d 712 (N.Y. 3rd Dept. 2012).

[57] Id. at 953 N.Y.S.2d 712.

[58] N.Y. Pub. Health Law § 31 (McKinney 2006).

III. CHALLENGES TO FEASABILITY

Legislative intent supports the expansion of Family-Type Homes; however, the program has failed to be administered with a reaching impact. To ensure greater accessibility and viability for the program, misconceptions pertaining to quality-care monitoring, staff professionalism, and impacts on community character must be discussed.

A. Quality Care Monitoring

Ensuring the safety and well-being of vulnerable persons should be a top priority of New York State's enforcement and regulatory agencies. This includes the quality of life for residents living in Family-Type Homes and comparable Adult Care Facilities. Family-Type Homes lack investment at the administrative level; quality assurance presents a true area of concern. In one unfortunate case, operators of a Family-Type Home left residents in the care of a 14 year old child.[59] The same operators were subsequently charged with stealing money from two elderly residents, along with their identities, to commit fraud. OCFS closed the home in 2004, and the New York State Governor stated: "As we move toward providing more care to patients in home settings, it is absolutely essential we not allow such abuses to take place."[60]

Ensuring a thorough applicant-approval process and implementing substantive training will help reduce issues of quality care. Mistreatment of disabled persons is not a Family-Type Home issue; it is a systems-wide issue. Quantified, the percentage of abuse and neglect cases substantiated from institutions far exceeds reports from Family-Type Homes. "Systematic reviews and meta-analyses of recent studies on elder abuse in both institutional and community

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[59] Andrews Nursing Home Litig. Rep., NY Care Home Owners Charged With Stealing From Elderly Residents, at 10 No. 3 ANNHLTGR 8 (2007).

[60] Id. at 10 No. 3 ANNHLTGR 8.

settings… suggests that the rates of abuse are much higher in institutions than in community settings."[61] In either setting, dutiful advocacy and monitoring is crucial. In New York State, residents in Adult Care Facilities, including Family-Type Homes, engage with the Long-Term Care Ombudsman Program. Ombudspersons are state-certified, trained volunteers who advocate for residents in areas of dignity and quality of life. Family-Type Homes are monitored by OCFS and the Justice Center; until recently, they did not interact with the Long-Term Care Ombudsman Program. Under recently adopted proposals, ombudspersons shall have a greater presence in Family-Type Homes and long-term care facilities in rural locations.[62] The Justice Center, Bureau of Adult Service, OCFS, and the Long-Term Care Ombudsman Program are all effective modes of resident advocacy to promote the wellbeing of vulnerable persons.

B. Accessibility and Impact on Community Character

State agencies often face backlash at the municipal level when attempting to establish residential-care programs for disabled persons. That being said, courts have found most community concerns to be, repeatedly, "speculative and undocumented."[63] Residential-care programs do not adversely "alter the character" of communities; rather, these programs promote diversified integration.[64] The process under New York State Mental Hygiene Law, authorizing the establishment of residential-care programs, is challenged by critics as an "unconstitutional delegation of power."[65] In the case of Incorporated Village of Old Field v.

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[61] World Health Organization, Fact Sheet: Elder Abuse (2018).

[62] NY Reg. Text, supra note 25, at 471203.

[63] Town of Oyster Bay v. Maul, 647 N.Y.S.2d 242 (N.Y. 2nd Dept. 1996).

[64] N.Y. Mental Hyg. Law § 41.34 (McKinney 2011).

[65] Incorporated Village of Old Field v. Introne, 430 N.Y.S.2d 192 (N.Y. Sup. Ct. 1980).

Introne, issues raised by the municipality in opposition to the establishment of community services for the disabled were found to have been raised "without merit."[66] Necessary residential-care programs must be implemented to promote greater participation in housing and community life for disabled citizens.

State legislatures have encouraged local governments to participate in site selection for community services for the disabled — "an apparent effort to reconcile the need of mentally ill persons for treatment in a homelike…environment, and for early integration into normal community life, with the interest of local communities in preserving the integrity of traditional, single-family residential areas."[67] OPWDD has a regulatory obligation to engage in community planning for civilly-committed persons who present the "most intensive service needs."[68] Though OPWDD and related agencies have an obligation to integrate disabled persons into community-based settings, the physical lack of residential-care programs is prohibitive.

Long-term care facilities monitored by NYS DOH are cited for improper discharge planning, in certain events, attributing to prolonged institutionalization. There must be an adequate number of residential-care programs in place for persons to be discharged to. There is hardly an infrastructure in place to support the many *thousands* of persons with disabilities who remain on waiting lists, isolated with minimal supports. The New York State Governor must allocate the funds necessary to build a dignifying future for disabled citizens.

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[66] Id. at 430 N.Y.S.2d 192.

[67] Thomas M. Fleming, *Validity, construction, and effect of statute requiring consultation with, or approval of, local governmental unit prior to locating group home, halfway house, or similar community residence for the mentally ill*, 51 A.L.R.4th 1096 (1987).

[68] Chenango County Proceedings of the Board of Supervisors 2015, Regular Monthly Meeting: Monday, February 9 (2015).

IV. CONCLUSION

In Youngberg v. Romeo, the Unites States Supreme Court held: Disabled persons have "protected liberty interests" guaranteed under the Due Process Clause of the United States Constitution.[69] However, when balanced against "relevant state interests," disabled persons struggle to live as equal citizens.[70] The aforementioned protections need to be upheld, as illustrated by decades of litigation and the present-day shortage of residential-care programs. Security is owed to persons with disabilities and their caregivers who endured years of mistreatment and neglect, while continuing to face discrimination at several intersections of daily life.

Many of the obstacles experienced by persons with disabilities are a product of a "society that places a great value on a single, appropriate, normal way of doing things" — often excluding disabled persons and their caregivers.[71] Family-Type Homes were once promoted by New York State's legislature in an attempt to mitigate isolation, but the program has not been administered effectively to fulfill its intent. Progress stagnates at the same rate that institutions are prioritized over residential-care programs in the community. The hierarchy of needs to support disabled persons living in the community includes: secure living environment; supervision of treatment; rehabilitation; and interpersonal relations.[72] This model is achievable and should be made accessible, statewide, to support the persons whose interests the program intends to serve.

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[69] Youngberg v. Romeo, 457 U.S. 307 (1982).

[70] Id. at 457 U.S. 307.

[71] Aristide H. Esser & Sylvia D. Lacey, Mental Illness: A Homecare Guide 213-214 (1989).

[72] Id. at Mental Illness: A Homecare Guide 225-226.

Diversified integration of persons in Family-Type Homes promotes interpersonal skills in a setting where residents may experience comradery. When older adults live among younger adults, a sense of guardianship is often fostered and promotes intergenerational engagement.[73] Uniquely personal and supportive bonds can be forged between residents and home operators – where aides become family and residents become friends. This program, however, remains invisible. New York State must take action to invest in an expansion of residential-care programs including Family-Type Homes. Opined in New York State Ass'n for Retarded Children, Inc. v. Carey, the New York State Governor: "has substantial flexibility in the use of transfer of money from the state treasury and is apparently not limited under New York State Finance Law § 51 in reallocating funds."[74] On April 30, 1975, a consent judgment to support persons with disabilities was approved and indicated: "affirmative intervention and programming is necessary if… capacity for growth is to be preserved, and regression prevented."[75] Defendants were subsequently enjoined from violating the same consent judgment in 1982. Decades later, persons with disabilities are unable to achieve full community integration, placed on indefinite and dispiriting waiting lists. New York State has an obligation to allocate permanent funds to establish sufficient residential-care services for its citizens. An investment today will help divert more persons away from institutional settings tomorrow, while promoting residential-care for the centuries ahead. Moving forward, away from the era of sanatoria, we must remember: "Of all the flowers, the human flower needs the sun the most."[76]

[73] Stamford Center on Longevity, Hidden In Plain Sight: How Intergenerational Relationships Can Transform Our Future 8-9 (2016).

[74] New York State Ass'n for Retarded Children, Inc. v. Carey, supra note 9, at 596 F.2d 27.

[75] New York State Ass'n for Retarded Children, Inc. v. Carey, 393 F.Supp. 715 (E.D.N.Y. 1975).

[76] Frank Ruslander, The J.N. Adam Memorial Hospital: Perrysburg, New York (1920).