Accommodative Residence Suites
for Older Adults and Persons with Disabilities

Multi-Disciplinary Collaborative Non-proprietary Proposal

Executive Summary IV
September 11, 2024

This proposal seeks to achieve a better quality of life and **reduce dependency on governmental benefits** for people with disabilities regardless of type or age of onset.

ACCOMMODATIVE RESIDENCE SUITES: Small community-based barrier free shared residences with private suites for people with disabilities and their spouse, child, or caregiver that facilitate appropriate person directed services, preserve personal relationships and assets, as well as provide a home environment from which a person will never need to transfer through end-of-life with better quality of life.

GOAL: Developing a versatile model that provides accommodative person-centric housing of choice which preserves relationships and can be developed in any urban or rural area. These "condos on steroids" can be either "stand alone" or as part of complexes, whether conversion, renovation or new build. The model could be developed by local builders, non-profits or private equity with licensed care support services provided through private sources or existing federal, state and community-based programs.

PURPOSE: To **c**onvert, renovate or construct small community-based condominium-style residences of 6-8 suites surrounding a central area consisting of large central kitchen, community dining, and socialization areas. The suites could be privately owned, rented, Supported, or Subsidized. with spouses, child or caregiver remaining together. The residence would provide shared non-licensed care services, food, utilities, common area housekeeping and maintenance. Shared exterior areas would be designed to facilitate progressive cognitive disorders (ex. dementia) with natural barriers rather than locks and walls.

Medicaid/OPWDD/Mental Health services for licensed care would be administered consistent with current regulation long term care and nursing home avoidance programs while also being flexible to changing methods of delivery.

Public resources are preserved by avoiding dependency while promoting personal decisional and financial independence with improved quality of life, social equity, and food security. There are further anticipated benefits for Value Based Care and better discharge outcomes due to the supported home environment.

ASSUMPTIONS: *For the purpose of discussion, the following maxims are presumed:*

1. Everyone over the course of their life will live with a disability challenge either personally or through direct involvement with a person with a disability.

2. A person with a disability should be able to direct the needed supports and services in the most integrated setting and with the least restrictive living environment.

3. Many people live in homes that are isolated, unsafe, unhealthy and cannot structurally accommodate disabilities or service needs.

4. Two people typically live more inexpensively than one. Shared residences can provide amenities at lower costs than multiple private residences.

5. There is a critical need for community based accommodative housing that facilitates appropriate service delivery for persons with acute and chronic needs, whether cognitive or functional.

6. The lack of accommodative and affordable housing is an elemental common denominator for *all* persons and families challenged by a disability. These could be developmental (0-21); work-life (18-65); or older adult (65+).

7. Preserving relationships with spouse, child or caregiver and remaining in the local community improves physical and mental health, quality of life and preventing the dangers of isolation.

8. There should be a better quality of life for people and their families addressing the challenges of living with disabilities. People with disabilities should be able to live in places of choice with those they choose to live with.

9. People with chronic or progressive disabilities many times are architecturally evicted from their homes due to stairs, small bathrooms, kitchens with hazards, inaccessible utilities, closets and cabinets. Others are unable to afford the costs of maintaining a private residence as a safe and healthy environment.

10. The financial logistics of maintaining a private home can exceed personal resources.

11. Many people who become disabled in private residences are unable to utilize or access former living areas and become confined.

12. The ability to reduce living costs increases the likelihood of avoiding or reducing benefit dependency.

13. There is a lack of private barrier-free housing choices should a person need to leave their home and fewer still if they seek to live with their spouse, child or caregiver.

14. The segmentation of disability by type or age of onset is largely immaterial in providing supports and services for cognitive and functional needs.

15. The silos created by segmentation cause barriers to a person-centric continuum of care as a result of disparate eligibility criteria, benefits and financial resource preservation.

16. Symmetrical Supports and services should not be disparate amongst people with the same or similar challenges based upon a classification of disability.

17. It is economically challenging to provide more than 12 hours of care services for chronic and progressive disabilities in private homes.

18. Shared overnight supports can provide appropriate care of multiple people and remain person centered.

19. Shared residences, services and supports are more economically efficient than custodial care in nursing homes or a solo private residence.

20. Demographics demonstrate an increasing need for non-government supported housing ownership which preserves personal financial and decisional independence.

21. Medicaid needs to reduce costs and obtain better value for funds spent.

22. Value Based Care is beneficial to both the person and costs for services to which that person is entitled.

PROPOSAL: A small condominium residence with 6-8 privately occupied suites. The Suites could be privately owned, rented, Subsidized or Supported. Notwithstanding, this proposal is focused upon lower- and middle-income individuals though subsidized and supported models are also possible.

The residences would provide non-licensed care services including meal preparation, common services, security, housekeeping and exterior area maintenance. The residents can live with spouse, child, or care giver through end of life without ever having to transfer. Residents would receive appropriate person-centered licensed care consistent with existing long-term care and nursing home avoidance programs.

The condo/coop residence allows shared equity, expenses, governance, and long-term operation. As the residence could be in any small town or urban neighborhood, access and contributions from family and friends can be maximized. Additionally, existing community-based service programs are being expanded and modified for integration of care, activities of daily living and normative activities-those things that make life worth living.

Private home ownership is an "exempt" asset typically not counted towards financial eligibility for community-based benefit programs for individuals otherwise eligible for custodial care facilities. Consequently, people preserve financial assets and equity which can be used for housing expenses and support without them being lost to Medicaid, subsequent poverty and government dependency.

Medicaid savings could occur though small economies of scale in service delivery of licensed care, blended care and non-care services, including the ability to handle multiple "overnight" care residents while retaining the assistance of spouse, child or caregiver if available. Better medical outcomes after hospitalizations are expected as an individual is discharged to a supportive, safe, and

healthy environment. Additionally, there is better value for dollars spent comparing residential "home" services cost/care hours versus nursing home costs/care hours.

A better quality of life including behavioral health is achieved through maintaining personal relationships with family, friends and community. Potential trauma and negative behaviors resulting from currently required transfers from home to Assisted Living or Nursing Homes are reduced and persons confronting cognitive deficits can remain in a home they own which accommodates the often-increasing challenges. Residences will allow a spouse, child or caregiver to also have a supportive environment, whether disabled or non-disabled. Beyond respite care, the co-resident has non-care environmental supports which also facilitate their personal independence.

COMPOSITION: The condo residences, either stand alone or clustered, would consist of suites directly opening to common interior areas with secure exterior areas directly accessible from interior common areas. Suites would be of universal barrier-free design with private bedroom, accommodative bath, sitting area, and hazard-free kitchen. The suites could have 2 bedrooms such that a parent, child, or caregiver could co-reside. Exterior spaces would be of memory care design and include porches and patios, grass and gardens, playgrounds and walkways with familiar and natural barriers rather than doors, walls, or and "lock in" barriers.

The Proposal is loosely based upon the Green House Project (GHP) and The Eden Alternative Care Models concepts as a demonstration of the design with achievable small economy of scale with person-centric and directed integrated service delivery. This Proposal is based upon private ownership or rental with personal responsibility for monthly expenses such that dependency upon government benefits is avoided or minimized. A stand-alone individual residential unit could be economically viable in any urban or rural environment. The residences could also be clustered with enclosed courtyards or co-located with other types of housing for integrated and socially diverse communities, including affordable housing or universal housing that supports diverse needs.

OWNERSHIP OPTION: Residents retain all exclusive occupancy rights and responsibilities typical of condo/coop ownership for their individual suite. At any time, the resident can sell their interest as is typical of any condominium interest, though one of the purchasers would need to be otherwise eligible for congregate care. Notwithstanding, while the equity may be accessed for any purpose, sufficient balances must be preserved to provide an uninterrupted monthly income stream together potentially with others (ex. SSI, SSDI, pension, 401(k) etc.) to provide for long-term financial independence. This is the same for any privately owned or rented premises in the community.

The ownership interest preserves resources and liquidity consistent with eligibility requirements of Home and Community Based Services (HCBS) waivers and programs including Community Medicaid, Managed Long Term Care Programs (MLTCP), Program of

All-inclusive Care for the Elderly (PACE) as well as the Office of People with Developmental Disability (OPWDD) managed care. The residences could be simple or complex, and the purchase funds preserved can be used for non-Medicaid services and a source of funds for monthly expenses. People who are house rich and cash poor will be able to preserve their resources and provide for their future needs. Conversely, people with strong income but no residence can invest in an exempt asset and utilize monthly income for their expenses while preserving assets consistent with exemptions.

Residents would be responsible for their monthly expenses, the same as if they were living in a private residence**.** Monthly expenses will vary the same as any retirement community, condo/coop, or homeowners' association. The condo plan and resident governance would determine the extent of amenities or services that would be shared.

SERVICE DELIVERY: There are many existing and developing community-based programs that provide nursing home avoidance services for chronic and acute disabilities including Community Medicaid, HCBS, PACE, 1115 Waivers, Mental Health, Developmental Disability, Traumatic Brain Injury and Self-Directed or Consumer Directed Care. The common purposes and goals are to promote the best quality of life, self-facilitation, and least restrictive living environments (Olmstead). This Proposal seeks to minimize the government being responsible for housing and care which ultimately are Nursing Homes, Group Homes and Assisted Living. Isolation in a facility and transfer trauma typically compound negative behaviors. An intersectional, intergenerational, blended care service model is achievable. Notwithstanding the disparate programs. However, there are opportunities to provide more equitable blended care through program coordination or integration.

Community-based service delivery occurs primarily through a combination and coordination of licensed/non-licensed caregivers, family, and community support. Most individuals have Managed Long Term Care Plans (MLTCP) which develop the care plans and largely subcontract for the delivery of services by licensed caregivers. A significant challenge is 24-hour care, particularly "overnights", though minimal care is necessary during those times. Significant "personal care" needs are guidance, prompting, companion care and supervision for which training, but not licensing, is necessary. Often, these are the contributions sought from family and community which require substantial coordination and are met with vacillating results.

Self-Directed or Consumer Directed budgets can be maximized thorough shared services which can remain individualized.

There are voids in service delivery. For persons living home, long term care services under MLTCPs **do not** cover supervision, companion care or prompting which are the basic needs of many persons with dementia or those with IDD, TBI and other cognitive challenges. Conversely, nursing home minimum staffing requirements per 24-hour day cannot realistically provide appropriate dementia care and assistance. The Proposal helps bridge this gap by providing access to these non-licensed care supports or allowing cost-saving shared licensed services.

The Proposal anticipates better medical outcomes following hospitalizations as discharge would occur to an appropriate environment that facilitates necessary follow-up care, assistance and proper nutrition. Consequently, better value-based outcomes increase quality of life and reduce medical costs.

COMMUNITY BASED SUPPORTS and SERVICES (CBS): Currently there are broad community supports and services for persons with disabilities across a wide spectrum, though unfortunately there are disparities based upon the type of disability. These include behavioral health services, peer counseling, faith-based services, visiting care and "push-in" services as well as socialization programs that provide greater access both to and by residents. There are significant disparities in eligibility, services and benefits primarily dictated by budgetary funding sources or grants. Segmentation by disability type or age of onset dictates which silo will provide services or oversight. Consequently, there exists administrative redundancy and inefficiencies.

CBS are provided through county departments of social service, not for profits, religious groups, fraternal organizations and veterans associations as examples. Other CBS programs are directed toward particular types of disabilities, such as cancers, dementias, TBI, DD, IDD, dystrophies or sclerosis. Services include push-in medical services, meals on wheels, engagement, as well as oversight or intervention against abuse or neglect. The panoply of available programs are substantial though access becomes a challenge in navigation or multiple applications.

There are existing community-based nursing home/group home avoidance programs for Developmental Disability, Mental Health, TBI as well as supported housing or transitional housing. While the proposed residences are versatile to these needs, similar CBS networks can be utilized for an expansion of care, oversight, supports and services without increasing resident costs by utilizing existing programs and benefits.

LICENSING and INSPECTIONS:

When a person lives in a private residence, licensing is related to care giving of medical/ ADL needs. Whether a person remains home is dependent on structural barriers (stairs, small bathrooms) and whether the environment is safe for a resident but otherwise a person's home is unregulated and provides maximum personal independence.

When a person can no longer live in a private residence, they "go" to a building in which the operator is licensed to provide care. Licensing regulations also relate to providing a barrier-free physical environment. Consequently, regulations are directed towards licensed care assuming the living environment being barrier free. The concept separates the building from licensed care such that residents continue dominion and control over their environment while care continues under existing programs.

Existing regulations are directed at a variety of custodial care residences where varying degrees of supports are offered with a person's eligibility based upon the ability to perform Activities of Daily Living (ADL) and the obligation of the residence to provide for those needs. Senior Housing, Adult Home, Group Homes, Assisted Living and Nursing Home require a person to transfer from one to the other as their ADL needs progress and exceed the facility's ability to provide the care under licensing requirements. Spouses, children and caregivers are typically separated at the Assisted Living stage. Regardless of moniker, the demarcation line is always when licensed/nursing care is required due to escalating needs and what supportive care may be available. The Custodial Care facility is responsible for providing for all needs, including care and non-care services.

The Proposed Suite Residence would be providing non-care supports and services little different than those provided in many retirement communities, existing condo/coop residential buildings, or clubs with common food service, security, and interior/exterior area maintenance.

The residence facilitates shared Self-Directed or Consumer-Directed programs. All direct care services requiring licensing would be provided through existing licensed MLTCP, HCBS, OPWDD and the emerging Program of All-inclusive Care for the Elderly (PACE). Consequently, existing regulations already encompass care plan development, management, and service delivery.

The best defense against abuse and neglect is the involvement of family and community. Isolation rarely benefits either the person or the caregiver. The Proposal promotes personal independence by the person controlling their environment and maintaining access to family, friends and community while also living in a supportive community that is not dominated by only disabled people and caregivers.

BROAD APPLICATION: While most beneficial in providing an immediately implementable residential alternative for older adults, the residences can be utilized for transitional supportive residences or allow people with particular types of disabilities being able to share resources and services specific to their needs and desired supportive amenities by choice. Additionally, parents of adult children with developmental or work-life disabilities will be able to live with or provide for their future, comfortable that each of their long-term needs will be met without either becoming institutionalized.

Notably, a residence could be built as part of any non-profit, recreational or faith community insuring people stay in the community or with a group with whom they want to associate, such as veterans. People can choose where and with whom they want to live.

CONCLUSION: The proposal provides an opportunity for individuals with disabilities regardless of type or age of onset, whether living in rural or urban settings, to enjoy an appropriate living environment with improved quality of life while having their support

and care needs met. Most importantly they will preserve their assets and continue to reside in the community with their spouse, child or caregiver and never have to move.

A goal is to provide a free market alternative to custodial care that could be built and operated on a local level independent of the need for government or large-scale investment. Notwithstanding, development or conversion of complexes can also integrate with other types of affordable housing or independent living options. These residences can exist in any small community without being limited to a particular group or type of disability.

Lastly, Medicaid will save resources through custodial care avoidance and better value for dollars spent.

Respectfully submitted,

Joseph J. Ranni, Esq.
Lead Collaborator

A Note About the Proposal Development and Collaboration

This proposal has been a four (4) year pro bono multi-disciplinary collaboration among legal, government, elder, disability, health industry and residential care professionals brought together through personal and professional direct involvement during the pandemic and the need for systemic response. All have acted in their individual capacities and no association or organization endorsement is represented.

Special thanks are extended to the Interdisciplinary Public Health and Palliative Care Certificate Program, Finger Lakes Geriatric Education Center at University of Rochester Medical Center.

Joseph J. Ranni is an attorney in private practice for thirty-seven (37) years concentrating in Disability, Elder and Civil Rights law and litigation who has acted pro bono as Lead Collaborator. He is Past Board Chairman of the non-profit Independent Living Inc. which provides community supports and services for people with disabilities in the Hudson Valley. He is a Certified Dementia Practitioner. He is active in several bar associations and committees addressing disability, health policy and long-term care reform.