

Housing for Individuals with Intellectual and Developmental Disabilities: Promising Practices Moving Forward

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Introduction

The advent of the Civil Rights Era in the 1960s brought increased sensitivity to the indignities and discrimination faced by Americans with intellectual and developmental disabilities (IDD). Legislation of that era contributed to the increased integration of this population into the workforce. Similarly, it reduced the physical separation of the IDD population, with emphasis on small-scale housing options that maximized freedom of consumer choice in lifestyle and independent living.

Ensuing decades have brought marginal progress in furthering independent living for those with IDD. A major contributor to the lack of progress is the earnings dynamics of Americans with disabilities. The National Disability Institute² notes that one in nine Americans aged 18-65 has a disability that precludes them from working. Sixty-two percent of those with disability are out of the labor force, compared to 20 percent without it. Unsurprisingly, this leads to a much higher level of poverty: 27% versus 12%. Significantly lower educational levels are a major contributor to these disparities.

Public assistance for this group is limited. In a seminal report, *A Place in the World: Fueling Housing and Community Options for Adults with Autism and Neurodiversities: The Universal Language for a Guided Narrative to Research, Develop and Achieve Supportive Housing Solutions,* FirstPlace and Arizona State University estimate that the national average of annual income per client, across all sources, is \$9,156.³ This income, typically comprised of Social Security and Supplemental Security Income Benefits, is too low for an efficiency apartment in most urban areas. Furthermore, Medicaid, the principal funding source for services and support for people with IDD, "typically does not allow funds to be used for rent for other community-based housing related-costs." Limited public funding, coupled with legal restraints on its use, contribute to the significant under-provision of housing for the IDD population, resulting in long waiting lists and increased risk for institutionalization or homelessness. FirstPlace and Arizona State estimate 431,000 neurodiverse residents live in Florida, with 21,000 on the Medicaid waiver, and another 21,000 on the waiting list.

The Jorge M. Perez Metropolitan Center documented the shortage of affordable housing alternatives for Florida's IDD population in its 2017 report, *Assessment of the Needs and Services to Individuals with Neurodevelopmental Disabilities.* While Florida has several examples of innovative housing developments for IDD residents the reality mirrors the broader nationwide pattern. Seventy-six percent⁵ of Florida's IDD population remains homebound with parents or relatives. This connotes and denotes limited freedom of housing. Thus, housing becomes a barrier to growth for the IDD population rather than a fulcrum for its social integration.

Housing for the neurodiverse population costs more than its traditional counterparts. The base case calls for more space in general to accommodate larger entrances, entrance ramps, and other spatial modifications for kitchens and bathrooms. However, housing for IDD clients requires further enhancements to foster livability and comfort. The IDD population is typically hyper-sensitive to light and smell. This requires softer lighting and advanced Heating, Ventilation, and Air Conditioning (HVAC) modalities. IDD residents require a quiet space (or

⁶ Nagib, W. & Williams, A. (2017). Toward an Autism-friendly Home Environment. Housing Studies, 32 (2): 140-167.



¹ Intellectual and developmental disabilities or IDD will be used to describe specific disabilities, as defined by the National Institute of Health within this definition- About Intellectual and Developmental Disabilities (IDDs) | NICHD - Eunice Kennedy Shriver National Institute of Child Health and Human Development (nih.gov); any other terms, such as neurodiverse, autism, or developmental disabilities are used within the context of the State or organizations referenced too.

² Goodman, N., Morris, M., & Boston, K. (2022). Financial Inequality: Disability, Race, and Poverty in America, 1. National Disability Institute.

³ Resnik, D. D., & Kameka Galloway, D. (Eds.). (2020). A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities. Phoenix, AZ: First Place AZ; Madison House Autism Foundation; the Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy, 19.

⁴ American Association of Intellectual and Developmental Disabilities and the Arc. Joint Position Statement of the ASIDD and the Arc. Washington, DC, September 2012, Page 3.

⁵ Frank, H. A., Ilcheva, M., Walker, M., & Boza, D. (2017). Assessment of the Needs and Services to Individuals with Neurodevelopmental Disabilities. Miami, FL: FIU Metropolitan Center, 18.

room) for privacy and downtime. Plumbing and appliances on sensors facilitate ease of use and safety. Outlays vary considerably by location and size, but incremental costs of \$20,000 to \$60,000 should be expected.

Higher housing costs are exacerbated by the higher imputed living costs faced by households with at least one member facing disabilities. These costs impact both the disabled and other family members. A recent study by the National Disability Institute estimated that "households containing an adult with a disability that limits their work requires, on average, 28 percent more income or an additional \$17,690 to obtain the same standard of living as a similar household without a disability." ⁹ Some indirect costs include family members taking leave or lowerpaid jobs to care for the disabled. Other direct costs include increased costs of housing due to larger required sizes and automotive costs (greater wear and tear due to medical visits or food shopping). While authors believe their estimates are at the lower bound of imputed costs in states such as Florida, without Medicaid expansion, adding these imputed costs raises the overall poverty rate of the disabled from 24% to 35%. ¹⁰

A combination of low earnings, limited government support, and high housing costs limit affordable housing options for the neurodiverse in Florida and nationwide. Nonetheless, there are points of light on the housing front for adults with IDD. In the next section of the paper, we highlight the concept of "Promising Practices" that afford housing choice that maximizes quality of life while remaining affordable. While there are no "one-best-way approaches," blended financial models for both capital and operating expenses foster innovative small- to mid-size residential settings that ameliorate the limited independence experienced by many adults along the spectrum. These "Promising Practices" developments are domiciled in Florida and elsewhere in the U.S. We will highlight a representative set of examples to illustrate potential approaches for broader implementation throughout Florida. After this overview of "Promising Practices," we will drill down to the status of housing options for the IDD population within the Sunshine State. This assessment will focus on the currently deployed finance options, with innovative approaches that bolster the housing supply and consumer choice.

After examining Florida's practices, we look to Arizona, Tennessee, and Texas for further examples of "Promising Practices." We examine these states to provide an "apples-to-apples" comparison with Florida on two critical policy levers. First, like Florida, these states do not have a personal income tax. Empirical evidence suggests states without a personal income tax spend less per capita on Health, Education, and Welfare. ¹¹ Equally important, Florida, Arizona, Tennessee, and Texas, have not expanded Medicaid under the Affordable Care Act, which provides coverage for most adults to 138% of the Federal poverty level (currently \$20,783). ¹² Arizona, Tennessee, and Texas benchmark Florida on these two parameters and have implemented "Promising Practices" in the IDD housing realm. Therefore, they provide useful comparisons for Florida policymakers seeking guidance for innovative IDD housing initiatives in-state.

In the final section of the paper, we provide policy recommendations that could provide incentives for the design, development, and operation of safe and affordable IDD housing options. As noted earlier, there is no established paradigm to bolster housing supply in this policy space. However, comparative analysis provides important common elements of funding and policy that augment housing for adults with IDD.

¹² Kaiser Family Foundation. (2024). Status of Medicaid Expansion Decision: Interactive Map. https://www.kff.org/affordable-care-act/issue-brief/status-of-state-medicaid-expansion-decisions-interactive-map/



⁷ Andrea Garner, Pippa Burns, Lucy Carolan, and Zac Pearson. (2024). Good Business: Creating an Autism-Friendly Community Using the Service Principles. *Disability & Society* 39 (3): 696-719.

⁸ True Cost Guide. (n.d.). Disability Accommodation Cost Guide.

⁹ Goodman, N., Morris, M., & Morris, Z. (2020). The Extra Costs of Living with Disability in the U.S.–Resetting the Policy Table. *National Disability Institute*. 1.

¹⁰ Ibid., Page 7.

¹¹ Moore, T. (2024). Pros and Cons of Having a State Income Tax. San Francisco, CA: https://www.sofi.com/learn/content/pros-and-cons-of-no-state-income-tax/

Promising Practices

For this analysis, promising practices consist of development types, management models, and funding mechanisms conducive to the provision of housing for adults with IDD, including single and family households. What follows is not encyclopedic. It is instead a distillation of salient points reported in the literature, intended to inform discussion of future programs in Florida.

Practice One: There are Promising Practices, Not Best Practices- In their assessment of the housing for the neurodiverse population, The Ray Graham Association, Clearbrook, and Aspire note that "Some of the 'best' practices in housing and support options for people IDD does not yet transfer easily to large-scale system change. The challenge of moving from typical practice toward best practice and then taking best practice to scale remains." From the authors' vantage, this relates to several factors. The first is the Federal system upon which the United States was founded. Different locales may have different funding sources. Medicaid waivers encourage programmatic experimentation to differ across states. Mission and vision for differing clientele will lead to different outcomes. The upshot: Progress in developing housing for the IDD population is prismatic rather than paradigmatic with a heavy dose of pragmatism that encourages maximum self-direction of lifestyle.

Practice Two: Cafeteria-Style Choices Pervade Choice of Domicile and Service Delivery- Choices abound in this policy space. This is consistent with the belief that neurodiverse individuals deserve the same housing choices as the population at large. Individuals may choose to live by themselves or with family, roommates, or in a group setting. Domiciles could be houses, intermediate care facilities, condominiums, shared living arrangements, group homes, or state-operated facilities. Ownership is also varied—it can be self- or family-owned. It could also be co-owned with roommates, or a landlord that could be a public or nonprofit agency, housing corporation, or state agency.

Service choice also allows for multiple options. It can be directed by the client, their family, an agency, or the state. Assistance can be technology-supported or centered around family or friends. It may also entail neighbors, roommates, or paid staff. The support can be case-managed, part-time, or full-time. Its funding is also varied, including self-funding, family, or the government (programs and entitlement). ¹⁴

Practice Three: Planning for New Facilities Necessitates Simultaneous Consideration of Capital and Operating Expenses- A salient finding of the FirstPlace/Arizona State University study, A Place in the World: Funding Housing and Community Options for Adults with Autism and Other Neurodiversities is the tendency to separate capital and operating expenses for housing in this policy arena. This has caused operational challenges in some IDD facilities a few years after opening and may reflect three factors. The first is poor capital budgeting practice, typically in the state and local sectors which separate annual operating and multi-year capital budgets. This practice may lead to the construction of capital facilities with limited regard for their impact on an organization's operating budget. A second factor reflects the realities of housing construction for the neurodiverse population. Organizations responsible for its construction and those responsible for facility maintenance and client support services are likely to have different domiciles. Moreover, these organizations may have different eligibility requirements and funding structures. These factors contribute to the difficulty in linking capital and operating outlays in this policy arena. These factors contributor to the potential impaired capital-operating linkages is the likely

¹⁷ ECONorthwest. (2020). Housing Needs for Individuals with Intellectual and Developmental Disabilities. Portland, OR., Page xi.



¹³ Housing and Support Options for People with Intellectual and Developmental Disabilities. (2014). The Ray Graham Association, Clearbrook, and Aspire, Page 2.

¹⁴ Ibid.

¹⁵ Resnik, D. D., & Kameka Galloway, D. (Eds.). (2020). A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities. Phoenix, AZ: First Place AZ; Madison House Autism Foundation; the Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy.

¹⁶ Beverly S. Bunch, B. S. (2016) Capital Budgeting Strategies in Good Times...and Bad. *Illinois Municipal Policy Journal*, 1 (1): 51-65.

inclusion of low- and moderate-income earners. Policymakers have known for a half-century that home maintenance for owners and renters in these categories can be challenging. The use of multiple funding sources for capital and operating funds augurs for careful long-term planning to ensure their appendage.

Practice Four: Smaller Settings are Becoming More Prevalent- The deinstitutionalization process that commenced in the 1960s has led to continued downsizing in the modal size of new housing for the neurodiverse. Graham Association, Clearbrook, and Aspire note a "movement away from group homes of 6-8 individuals with 1-3 persons, each with his/her own bedroom. The shared living model often promotes a smaller, individualized setting and is prevalent in many states." While there is no unambiguous linkage between residential setting and clinical psychological outcomes when controlling for numerous factors, it appears that policymakers are opting to provide smaller and more individualized dwelling types to facilitate consumer choice. Ultimately, several factors, including the ability to live independently, the type of assistance needed daily, and the ability to afford one option over another, will impinge on the choice of dwelling type. Those with greater independence may be better suited to smaller residences.

However, the switch to smaller domiciles will add costs. In the Metropolitan Center's 2017 study on Florida's neurodiverse population, we reported that supported living at home averaged per capita \$15,241. In settings with six or fewer, per capita costs were \$44,392, and in ICFs or similar settings with seven or more people, the per capita cost was \$97,141.²¹ Providing support outside of the home adds considerable incremental cost. In context, providing smaller, more individualized housing settings bolsters client choice and expands the continuum of care. However empirical research in the Florida setting that illuminates the possible linkages between residential settings and psychological outcomes (e.g., the Adaptive Behavior Scale) may better facilitate client and family choices, consistent with cost and service provision (quantity and quality). ²²

Practice Five: Smart Housing and Technology Innovation Are Significant Innovations in the IDD Space-Technology support may improve the quality of life and independence of the neurodiverse population while reducing the need for paid and unpaid support. ²³ In general, the implementation of smart housing for the IDD is in urban and more affluent communities. The focus tends to be on innovations that improve residents' sense of safety, privacy, and well-being. "Smart" control of cooking, cleaning, and entertainment focusing on home appliances, is central. Visual and audio signalization are also present. ²⁴

LADD in Cincinnati has developed an innovative program that puts adaptive technology to use by implementing virtual report support structures. The YouTube video associated with this link demonstrates how these are implemented in a cost-effective manner that fosters greater independence for clients and residents.²⁵

The Florida Alliance for Assistive Services and Technologies (FAAST) in Tallahassee provides multiple services to the disabled to foster their independence and successful functioning in daily lives. These services include the

²⁵ Gaffney, N. (2020). LADD Launches First-of-its-kind Smart Living Pilot To Increase Independence, Support More People With Disabilities. LADD.



¹⁸ U.S. Department of Housing and Urban Development. (1974). Housing in the Seventies: A Report of the National Housing Policy Review. Washington, DC: U.S. Department of Housing and Urban Development.

¹⁹ The Ray Graham Association, Clearbrook, and Aspire. (2014). Housing and Support Options for People with Intellectual and Developmental Disabilities. Chicago, IL: The Coleman Foundation, Page 13.

²⁰ Raynes, N. V. & Sumpton, R. C. (1987). Differences in the Quality of Residential Provision for Mentally Handicapped People. Psychological Medicine, 17 (4): 999-1008.

²¹ Frank, H. A., Ilcheva, M., Walker, M., & Boza, D. (2017). Assessment of the Needs and Services to Individuals with Neurodevelopmental Disabilities. Miami, FL: FIU Metropolitan Center, Page 20.

²² Mansell, J., Ashman, B., MacDonald, S. and Beadle-Brown, J. (2002). Residential Care in the Community for Adults with Intellectual Disability, Needs Characteristics, and Services. Journal of Intellectual Disability Research, 46 (8): 625-633.

²³ Ray Graham Association, Clearbrook, and Aspire. (2014). Housing and Support Options for People with Intellectual and Developmental Disabilities. Chicago, IL: The Coleman Foundation.

²⁴ Lindsay, S., Fuentes, K., Ragunatha, S., Li, Y., & Ross, T. (2024). <u>Accessible Independent Housing for People with Disabilities: A Scoping Review of Promising Practices, Policies, and Interventions</u>. PLOS ONE.

lending of assistive devices to the disabled. They also provide loans for the purchase of assistive technologies. In 2020, FAAST provided almost 16,000 assistive technologies and thousands of training events, virtually and face-to-face.²⁶ FAASt's operations are a reminder of the significance of assistive technology in the daily lives of the disabled. The diffusion of this technology to the IDD is essential to improving their quality of life.

Practice Six: Building IDD-Dedicated Housing Is Likely to Require Proactive Anti-NIMBYism- Fair Housing legislation, specifically, the Civil Rights Act of 1968 that endeavored to curb long-time discrimination in housing, has been "on the books" for a half-century. Nonetheless, housing discrimination persists. In their report, Making Every Neighborhood a Place of Opportunity, the National Fair Housing Alliance (NFHA) reported a significant longterm increase in fair housing complaints, increasing from 16,962 in 1996 to 28,843 in 2017. Of the approximately 20,000 complaints that went to the U.S. Department of Housing and Urban Development, Disability (62%) effectively swamped Race (24%), National Origin (10%) Family Size (9%), Religion (3%) and Other (1%).²⁷

The NFHA notes that most of the disability-related complaints were based on unwillingness to make accommodations in multi-family dwellings. However, the high proportion of disability-related filings which are likely to be rooted in physical challenges, suggests that longstanding stigmas and stereotypes are likely to draw "Not-In-My-Backyard" sentiment in the context of housing for the neurodiverse population. Legislation such as the Americans for Disability Act or the Fair Housing Act will not dampen all discrimination against this group. The authors hypothesize that an embedded "Promising Practice" in this policy space is the willingness and ability to deal proactively with community leaders and elected officials in efforts to develop IDD-related housing.

Lessons learned from the affordable housing realm suggest several key strategies for fighting NIMBYism in the housing realm. First and foremost, informal meetings with opponents are a better venue than public hearings to assuage community concerns. Fact-based discourse matters. Building goodwill with opponents and listening to their objections are great lubricants. So is a thorough knowledge of potential planning and zoning roadblocks. Educating public officials is crucial. 28

While stigma against those with IDD remains, Jansen-van-Vuuren and Aldersey present evidence that it is abating worldwide. The assessment notes the importance of culture in stigmatization. From their vantage, "The predominant Western focus on independence and productivity can perpetuate stigma and exclusion for people with IDD, and it will be important for anti-stigma work moving forward to reconceptualize community so that it can become a place where people with IDD are accepted and belong regardless of their ability and contribution."29 This connotes that proponents of IDD-centered housing are social educators charged with reshaping longstanding social norms about the disabled and their relationship to the surrounding community.

These "Promising Promising" practices frame an approach for moving away from a home-centered model for adults with IDD. This model is framed in experiences in Florida and elsewhere. It is more descriptive than prescriptive. However, the case studies in the following sections lend credence to their applicability in contemporary social settings. Our discussion is, by design, at the 30,000-foot level. We do not discuss clinical interventions that may foster greater independence away from home. As noted earlier, we do not consider how residential type serves to mediate these interventions. As noted in this paper's conclusion, this is one of many empirical questions that require attention in the IDD space. Meanwhile, we turn to "Promising Practice" housing developments that serve as models for the Sunshine State.

²⁹ Jansen-van-Vuuren, J. and Aldersey, H. M. (2020). Stigma, Acceptance and Belonging for People with IDD Across Culture. Current Developmental Disorders Reports, 7: 162-172, Pages 178-179.



²⁶ Florida Alliance for Assistive Services & Technology. (2024). *Training and public awareness*. FAAST, Inc.

²⁷ National Fair Housing Coalition. (2018). Making Every Neighborhood a Place of Opportunity: 2018 Fair Housing Trends Report. Washington, DC: NFHC, Pages-52-54.

²⁸ Jamie Ross, J. & Glazer, K. (2022). Overcoming NIMBY Opposition to Affordable Housing. Washington, DC: National Low Income Housing

The Florida Scene

Existing Programs in Florida

In Florida, the housing needs of individuals with IDD have historically been addressed using the same or similar mechanisms as other vulnerable populations such as individuals with physical disabilities or individuals experiencing homelessness. This can be explained, in part, by the shared challenges of providing permanent supportive housing (PSH). Permanently supportive units are unique in that they combine subsidized housing with effective access to supportive services inherent to residency. This approach to addressing housing insecurity along with the needs of individuals with disabilities has proliferated across the state over the last decade. Significantly, it has allowed for developer flexibility in size, scale, and services while still providing access to blended financial models.

In 2024, Governor Ron DeSantis increased funding to address the needs of adults with IDD by allocating \$2.2 billion to the Agency for Persons with Disabilities. While the bulk of this funding will go towards the improvement of existing service delivery programs such as the iBudget Waiver program, \$241 million has been directed for use in enhancing service delivery "through targeted projects and infrastructure improvements."

The Florida Housing Finance Corporation (Florida Housing) was created by the state legislature more than 40 years ago to assist in providing a range of affordable housing opportunities for residents. Florida Housing's multifamily development programs include State Apartment Incentive Loan (SAIL), Multifamily Mortgage Revenue Bonds (MMRB), Florida Affordable Housing Guarantee (Guarantee Program), HOME Investment Partnerships, Elderly Housing Community Loan (EHCL), Low-Income Housing Tax Credit (LIHTC) program, Grants to Serve Persons with Developmental Disabilities, and National Housing Trust Fund. The Florida Legislature has appropriated funding for a competitive grant program for housing developments designed and constructed to serve persons with developmental disabilities, as defined in section 393.063, Florida Statutes. Developments eligible for these grants include community residential homes (CRHs), as defined in section 419.001, Florida Statutes, and licensed by the Florida Agency for Persons with Disabilities; individual support units; and apartment properties that provide permanent supportive housing units. Funds may be used to renovate existing CRHs or build new properties.

The Low-Income Housing Tax Credit program (HC program) has been used to finance permanent supportive housing projects throughout the State of Florida. Special Compass Living Ltd. was successful in obtaining an HC allocation for Compass Place in Pembroke Pines. The HC program provides for-profit and nonprofit organizations with a dollar-for-dollar reduction in federal tax liability in exchange for providing equity financing for the rehabilitation (with or without acquisition) or new construction of low and very low-income rental housing units. An HC allocation to development can be used for 10 consecutive years once the development is placed in service and is designed to subsidize either 30 percent (the 4 percent tax credit) or 70 percent (the 9 percent tax credit) of the low-income unit costs in development. Qualifying buildings include gardens, high-rises, townhouses, duplexes/quads, or mid-rises with an elevator. The program can be used in conjunction with the HOME Investment Partnerships program, the State Apartment Incentive Loan program, the Predevelopment Loan program, or the Multifamily Mortgage Revenue Bonds program.

Each HC program development must set aside a minimum percentage of the total units for eligible low or very low-income residents for the duration of the compliance period, which is a minimum of 30 years with the option to apply for a Qualified Contract after the 14th year unless this option is waived by the Applicant in the Application, or according to requirements in a competitive solicitation. Applicants must commit to one of the following set aside commitments: (i) at least 20 percent of the housing units set aside for households earning less than 50 percent or less of the area median income (AMI), (ii) 40 percent of the units set aside for households earning less



than 60 percent or less of the AMI, or (iii) 40 percent of the units for households whose earnings may range from 20% to 80% of the AMI provided the average on the income designations within that range do not exceed 60% of the AMI. Because of the competition among developers seeking an allocation of tax credits from Florida Housing, most developers commit to providing deeper set-asides and for longer periods than the minimums described above as required by IRS Code (Source: Florida Housing).

Successful financing awardees of Florida Housing's various programs, including the HC program, represent some of the best examples of innovative housing developments for adults with IDD in the state. The following is a summary of recent developments that have received Florida Housing financing:

FHFC RFA -102 Program: SAIL Financing for Smaller Permanent Supportive Housing Developments for Persons with Special Needs

The 102 Program is one of FHFA's oldest grant programs, having now been offered annually for over a decade. The Finance Corporation has adjusted its terms and purview over the years to better meet the funding needs of developers targeting specific segments of Florida's residents. Over the years, the grant has focused on multifamily housing, supportive housing, and low-income housing. For the past several years, however, the 102 Program has been specifically focused on "Financing for Smaller Permanent Supportive Housing Developments

with Special Needs." ³⁰ Awarded developments are required to set aside upwards of 70 percent of their total units for Permanent Supportive Housing for Persons with Special Needs, as defined by statute. The program has resulted in hundreds of new units created and allocated towards individuals with IDD, among other disabilities.

RFA – 102, Median Development Cost Per Unit: \$274,688

Name	County	Total Development Costs	Units Produced	Avg. Cost Per Unit				
2021								
Whispering Pines	Pinellas	\$4,796,585	20	\$239,829.25				
Founders Point	Pinellas	\$3,747,465	15	\$249,831.00				
Scholars' Village	Broward	\$6,601,864	24	\$275,077.67				
Dillingham Apartments	Osceola	\$7,234,640	30	\$241,154.67				
Village at River City	Duval	\$6,075,193	30	\$202,506.43				
2022								
Founders Point	Pinellas	\$4,114,500	15	\$274,300.00				
Space Coast Commons	Brevard	\$6,339,536	30	\$211,317.87				
HOMES Inc., Scholars Village LLC	Broward	\$7,954,264	30	\$265,142.13				
2023								
Eleven44	Miami-Dade	\$10,692,14 3						
The Egret	Miami-Dade	\$4,410,942	10	\$441,094.20				
Vincentian Villas	Charlotte	\$9,926,802	30	\$330,893.40				
2024								
The Point	Pinellas	\$6,323,409	17	\$371,965.24				
The Egret	Miami-Dade	\$4,838,446	34,838,446 10					
Vincentian Villas	Charlotte	\$6,607,351	15	\$440,490.07				

Source: FL Housing Finance Corporation RFA Applications Data. September 2024

³⁰ Request for Applications 2024-102, <u>SAIL and Home-ARP Financing for Smaller Developments for Persons with Special Needs</u>. Florida Housing Finance Corporation.



FHFC RFA -106 Program: Financing to Develop Housing for Persons with Disabling Conditions/Developmental Disabilities

Similar to the 102 program, the RFA-106 program targets adults and families with a defined condition. However, these awards do not come from the SAIL funds, the developments are typically much larger, and there is no requirement for units to be set aside for households belonging to certain income ranges.

RFA – 106, Median Development Cost Per Unit: \$393,738.09

Name	County	Total Development Costs	Units Produced	Marked for Disabling Conditions or Developmental Disabilities	Avg. Cost Per Unit			
2021								
Southwest Hammocks	Broward	\$30,282,480	100	Disabling	\$302,824.80			
Baytown Apartments	Hillsborough	\$9,805,701	30	Disabling	\$326,856.70			
2022								
Brentwood Village	Volusia	\$19,803,861	64	Disabling	\$309,435.33			
2023								
Orchid Place	Brevard	\$26,523,215	70	Disabling	\$378,903.07			
Blue Coral Apartments	Lee	\$25,680,061	72	Disabling	\$356,667.51			
The Vistas	Orange	\$29,799,185	64	Disabling	\$465,612.27			
Brentwood Village	Volusia	\$22,049,333	56	Disabling	\$393,738.09			
Notre Communaute	Miami-Dade	\$35,606,903	75	Disabling	\$474,758.71			
Lepley Road Apartments	Escambia	\$24,400,683	70	Disabling	\$348,581.19			
Sulzbacher Enterprise Village	Duval	\$29,330,569	100	Disabling	\$293,305.69			
Gardens at Casa Familia	Miami-Dade	\$27,992,502	50	Developmental	\$559,850.04			
2024								
Orchid Place	Brevard	\$25,232,781	60	Developmental	\$420,546.35			
Legacy Village	Manatee	\$25,793,094	60	Developmental	\$429,884.90			
The Franklin	Hillsborough	\$32,780,233	80	Disabling	\$409,752.91			
The Residences	Lee	\$28,290,483	60	Developmental	\$471,508.05			
Willow Way Village	Okaloosa	\$25,890,073	72	Disabling	\$359,584.35			
Special Compass Living	Broward	\$34,211,737	60	Developmental	\$570,195.62			

Source: FL Housing Finance Corporation RFA Applications Data. September 2024

Ongoing High Utilizer Pilot program

FHFC has recently launched its **High Utilizer and Services Pilot** which seeks to contribute \$40 million in funding, to monitor and evaluate three developments over the next three years. This pilot is aimed at providing Permanent Supportive Housing for high utilizers of behavioral health services or individuals who are a high priority for diversion from an institutional setting. 20 percent (or a minimum of 15) of all units developed as part of this project will house "High Utilizers." While these "High Utilizers" are selected from Managing Entities that belong to the state healthcare system, these projects may provide important insights into future innovations in this space.³¹

³¹ Florida Alliance for Assistive Services & Technology. (2024). *Training and public awareness*. FAAST, Inc. https://faast.org/services/public-awareness-training/



The three proposed developments, set to be online by 2025 are:

- Village at Cedar Hills in Duval County
 - 90 Total Units
 - o Housing Provider: Ability Housing, Inc.
 - Managing Entity Partner: Lutheran Services of Florida, Inc.
- Apollo Gardens in Brevard County
 - 84 Total Units
 - o Housing Provider: Carrfour Supportive Housing
 - Managing Entity Partner: Central Florida Cares Health System
- Jersey Commons in Polk County
 - o 68 Total Units
 - Housing Provider: Blue Sky Communities; Community Assisted and Supported Living; Tri-County Human Services
 - o Managing Entity Partner: Central Florida Behavioral Health Network

Nonprofit Programs

The Arc, Jacksonville: The Arc Jacksonville, founded in 1965 by "local parents and citizens who shared a common vision," is a nonprofit organization that provides a range of services and programs to individuals of all abilities. The nonprofit strives to help individuals with IDD "achieve their full potential and... participate in community life".

Across its 15 different programs and services, the organization serves over 500 individuals daily and actively employs 135 staff members. These include adult training, mental health services, community clubs, employment opportunities, and housing.

The Arc Jacksonville addresses the housing needs of adults with IDD via three unique residential programs. The Housing Referrals program assists households with IDD earning extremely low income (ELI) attain affordable rental housing. The program works with housing providers across Duval County to refer eligible individuals. Eligibility for housing referrals is based on the following: proof of disability, income requirements, and "[having] community-based supports based on needs in place". The Community Homes program is a set of five group homes that house a total of 44 residents. Each group home is tailored to meet the needs of its cohort of residents in a communal setting, while still providing private bedrooms and the comfort of a true home. 32



The Arc Jacksonville Village program is the flagship of the organization's multiple residential options. The Village provides affordable, independent, apartment-style living for individuals with intellectual and developmental disabilities. The community houses about 121 residents across its 97 affordable one- and two-bedroom rental apartments and offers over 1,300 activities for residents at its campuses. By providing a unique mix of autonomy and community living, households and residents can structure their lives as they see fit, while ideally leveraging The Arc's many resources and on-site services. For example, while the community offers game rooms, fitness areas, complimentary wi-fi, and organized activities, The Arc also "recognizes and supports its residents' right to freely gain access to the greater community". Additionally, residents are encouraged to develop their social relationships, seek employment, and build natural supports.

³² The Arc Jacksonville. (n.d.). Who we are. https://arcjacksonville.org/who-we-are/.



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Housing units at The Village have individual bedrooms and bathrooms, kitchen/dining areas, washer/dryer, and emergency/fire suppression systems. Residents have the option of a 1-1 apartment for themselves or a 2-2 apartment to be shared with a roommate. 25 percent of all units are ADA-compliant, while the rest are wheelchair accessible. Eligibility for these units is based on the following criteria: 18 years or older, less than a \$29.4k annual salary (including benefits), proof of sufficient resources to pay rent, utilities, food, etc., a co-signer if required, and abstention from illegal drug use or criminal behaviors.

- Target Market: Individuals with intellectual and developmental disabilities, low-income residents
- Resident Support Needs: Drop-in support
- Property Relationship to LTSS: Consumer-controlled setting
- Funding Options: Private pay, Medicaid HCBS waiver

According to IRS reporting, The Arc earned \$9,129,064 in revenue in FY2022; the large majority of this (\$5,380,5433) came from program service fees. Importantly, the next two largest sources of revenue were contract revenue (\$1,275,329) and government revenue (local, state, and federal) (\$1,194,130). While the funding stack is diverse, with significant donor contributions and auxiliary revenue streams, The Arc relies on meaningful government funds and likely gains access to these funds through its various alignments with targeted priorities such as low-income, elderly, and IDD needs.



Promising Practices Examples

Florida has several options and funding opportunities for those with intellectual and developmental disabilities. However, we seek an "apples-to-apples" comparison to examine innovations in housing provision for the neurodiverse. In this section of the paper, we examine state-lead and nonprofit programs in Arizona, Texas, and Tennessee as benchmarks. As stated, these are states with no income tax and Medicaid Expansion, suggesting, according to empirical evidence, these states spend less per capita on Health, Education, and Welfare due to the lack of personal income tax. ³³ Therefore, they provide useful comparisons for Florida policymakers seeking guidance for innovative IDD housing initiatives in-state.

Arizona

In Arizona, state-supported housing for individuals with developmental disabilities (IDD) is provided by the Division of Developmental Disabilities (DDD) in the Arizona Department of Economic Security.³⁴ Grants through HUD's Section 811 Project Rental Assistance (PRA) are the leading source of funding for the Affordable Housing opportunities that DDD can access for members. In FY13, \$2.94 million was utilized to construct 55 Units, and another 50 units were added with \$3 million in funding in FY19.

As of April 2023, DDD served more than 51,130 Arizonans with disabilities such as Autism, Cerebral Palsy, Epilepsy, Cognitive/Intellectual Disability, and Down Syndrome. In all three programs, members pay 30% of their total household income for rent, with specific income eligibility requirements depending on the type of program and housing location, ranging from \$18,310 to \$37,400 for a 2-person household, and \$\$23,030-\$42,100 for a 3-person household. The Division refers the members directly to the opportunity instead of a public waitlist.

Arizona's three state-funded programs include:

Coffelt-Lamoreaux Apartment Homes: This apartment home community is in Phoenix and includes 301 total units available in one-, two-, and three-bedroom floorplans. Through a partnership with the Housing Authority of Maricopa County (HAMC), thirty (30) of the 301 units were made available for qualified DDD members. The total development cost for the public housing development was \$46,128,109. This 301-unit, 38-acre public housing development was originally built for returning Korean War veterans and migrant farmhands and now houses low-income individuals, families, seniors, and people with disabilities in the Phoenix area. The HAMC had originally planned to demolish and dispose of the Coffelt development due to its physical decay and lack of federal resources. Coffelt underwent a 'gut rehabilitation'. Coffelt was the first project in Arizona to ever be awarded a Rental Assistance Demonstration (RAD) Program funding from HUD and has since been added to the National Register of Historic Places.

Voucher Program: Vouchers are set aside for DDD referrals. DDD Collects all documents and submits a complete referral packet to HAMC for housing in the area served by the Housing Authority of Maricopa County or within the City of Tucson.

811 PRA Grant: Through a joint effort, two grants were awarded to ADOH to pay approximately \$6 million in rental subsidies in several properties across the state. New units will be open in the cities of Phoenix, Tucson, and Page in 2024-2025.

According to DDD, from 2017 to April 2023 the Division has saved in service costs by members making progressive moves into the community from group homes and developmental homes.

³⁴ Arizona Department of Economic Security, (2024). Developmental Disabilities. https://des.az.gov/ddd



³³ Moore, T. (2024). Pros and Cons of Having a State Income Tax. San Francisco, CA: https://www.sofi.com/learn/content/pros-and-cons-of-no-state-income-tax/

Arizona has an estimated 157,500 individuals with IDD. 35 To meet the need, Arizona also has several examples of non-state IDD housing or *promising practices*.

First Place AZ: The \$19.7 million cost of the 55-unit rental facility was funded from New Markets Tax Credits (NMTC - 16% of funding), a private sector loan (38%), and a capital campaign (46%). In addition to construction (\$15.4 million) and land purchase (\$1.5 million), the comprehensive capital campaign funded start-up operations and program development (\$2.8 million). After a 2014 land purchase and a multi-year campaign, in 2018, Clearinghouse CDFI provided \$8 million of NMTC allocation for construction. US Bank was the investor.

- Target Market: Neurodiverse adults and adults with autism
- Resident Support Needs: No support needed, drop-in support, low to moderate support.
- Property Relationship to LTSS: Consumer-controlled setting
- Funding Options: Private pay and Medicaid HCBS waiver

First Place-Phoenix services include lifeskills training (transportation navigation, meal planning, and instruction, social integration), workplace & vocational support (support developing careerreadiness skills, such as arriving on time, packing a lunch, dressing appropriately), community life (daily social activities and events, such as Social Saturdays, special quests, dances; local outings), and Health & fitness activities (meditation, yoga, Zumba, sports, pool activities).2 The facility is not for those who need intensive support. Individuals who are qualified through the Arizona Dept. of Economic Security DDD and



Source: First Place Phoenix

ALTCS can apply for public funding to help cover the cost of enrollment in the Transition Academy and pay for rent and amenities with private pay.

A First Place has been a registered nonprofit since 2015. According to its 2022 990 IRS Form, First Place had a total of \$6,135,757 in revenue, a significant drop from its 2021 revenue (\$7,150,509). Of the 2022 revenue, \$0 was given from government grants or contributions. The largest revenue generators for First Place were program service revenues and all other contributions and grants.

³⁵ Resnik, D. D., & Kameka Galloway, D. (Eds.). (2020). A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities. Phoenix, AZ: First Place AZ; Madison House Autism Foundation; the Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy.



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Luna Azul is a gated "pocket neighborhood" of homeowners for adults with intellectual, developmental, and acquired disabilities. Luna's business model merges home ownership with access to customizable services for residents – even allowing them the freedom to have a housemate.

The neighborhood is comprised of two- and three-bedroom cottage-style homes, 1,100-to 2,000 square feet, with 24/7 onsite staffing. In 2020, the first homes sold at a range of low-\$400,000 to high-\$500,000. The neighborhood has 32 homes.



Texas

Approximately 688,000 individuals in Texas have an intellectual or developmental disability, increasing the need for social assistance and resources.³⁶ Texas has several options specifically for housing assistance ranging from private to public and from state to local.

Housing Finance Corporations: Housing assistance through housing finance corporations in Texas is operated by a network of Housing Finance Corporations at the county and municipal level, including the Austin Housing Finance Corporation, the Southeast Texas Housing Finance Corporation, and the Dallas Housing Finance Corporation. However, at the state level, one nonprofit, the Texas State Affordable Housing Corporation, exists as a "self-sustaining nonprofit housing organization" that believes "every Texan deserves the opportunity to live in safe, decent, and affordable housing." Upon review, the Texas State Affordable Housing Corporation does not explicitly assist those with disabilities. Their programming refers those with disabilities to the Texas Department of Housing and Community Affairs.

Texas HOME, Project Access, and Section 811: The Texas Department of Housing and Community Affairs lists several "tools for serving people with disabilities" as resources for developers and administrators interested in opportunities for funding to support those with disabilities. First, the Texas HOME Program Rental subsidies allocate 5 percent to assist persons with disabilities for up to 24 months. Project Access "utilizes Section 8 Housing Choice Vouchers administered by TDHCA to assist low-income persons with disabilities in transitioning from institutions into the community by providing access to affordable housing." Finally, the Section 8111 Project Rental Assistance Demonstration Program allows persons with disabilities to gain and increase their independence by offering rental assistance for those with extremely low income linked with the need for long-term services. As an interagency cooperative, this program ensures that those with disabilities continue to receive the needed services while maintaining safe and affordable housing. However, while all these programs seek to offer assistance to those with disabilities, none of these programs are directly targeting those with intellectual or developmental disabilities. Furthermore, some of these programs have strict funding limitations, restricting the reach of their assistance. For example, the Section 811 Program Rental Assistance Demonstration Program serves approximately 385 individuals in seven metropolitan statistical areas.

³⁹ Texas Department of Housing and Community Affairs. (n.d.). Project Access.



³⁶ Resnik, D. D., & Kameka Galloway, D. (Eds.). (2020). A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities. Phoenix, AZ: First Place AZ; Madison House Autism Foundation; the Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy.

³⁷ Texas State Affordable Housing Corporation. (2024). Texas Supportive Housing Institute. TSAHC.

³⁸ Texas Department of Housing and Community Affairs. (2024). Tools for Serving People with Disabilities.

State Supported Living Centers: The Texas State Supported Living Centers (SSLCs) is a network of thirteen group homes for those with intellectual and developmental disabilities "who are medically fragile, have behavioral challenges, or have mental health issues." ⁴⁰ SSLCs provide 24-hour residential-based services, including behavioral treatment, nursing, dental, and psychiatric care. The campus-based settings accommodate between 60 to 460 people per site. The thirteen sites assisted 2,515 residents in the 2023-2024 fiscal year and are estimated to support 2,437 residents in 2024-2025. ⁴¹ The average monthly cost for a resident staying at either a state-supported living center or a state center, which may include mental health state hospitals, was \$26,293 in 2023-2024. The current maximum daily cost to serve an individual at one of the thirteen SSLC campuses is \$1,305.78. However, not every resident will pay the maximum, depending on their assistance and needs. Each SSLC is a certified Intermediate Care Facility for Individuals with Intellectual Disabilities, meaning the facilities are a Medicaid-funded federal and state service. "Approximately 60 percent of SSLC operating funds... come from the federal government, and 40 percent from state general revenue and third-party revenue sources." ⁴²

According to the 2024-2025 Texas General Appropriations Act, the Health and Human Services Commission, under the Department of State Health Services, was allocated \$793,530,359 in the 2023-2024 year which ends on August 31st and will be appropriated \$791,462,594 in the following fiscal year. Financing for the Texas Health and Human Services Commission derives from dedicated general revenue funds, federal funds, and other/miscellaneous funds. The largest contributor to the general funds dedicated to the Health and Human Services Commission is the general revenue match for Medicaid, at \$12,905,277,156 in 2023-2024. \$352,186 was appropriated in 2023-2024 for capital projects and facility repairs and both SSLCs and state hospitals. This amount will be replicated in the following year. \$500,000 was appropriated in 2023-2024 and will be dedicated again in 2024-2025 for SSLC infrastructure maintenance to support electronic health records. Further allocations were made for SSLC staff salary increases and staffing capacity. Unfortunately, this revenue does not and will not meet the total need for capital improvements.

Texas has the highest institutionalized population of those with IDD, subsequently resulting in Texas having the highest number of SSLCs. However, despite the accessibility and ability to help meet the needs of Texas, the severe downfall of these programs exists. According to the State Supported Living Center Long Range Planning Report, published in August 2024, the network of SSLCs has 55 ongoing maintenance and capital projects which total approximately \$128 million. If the funding or the progress for these projects were to be deferred, the overall sustainability and quality of these programs would be detrimental. Furthermore, the thirteen SSLCs have requested funding for 189 projects with costs that exceed \$485 million. Given this funding was evenly distributed, each SSLC requires an estimated \$37.7 million. The aging structure is a major issue with the current stock of residential units at the SSLCs. The Texas Health and Specialty Care System argues that the conditions will continue to worsen due to the lack of ongoing investment.

While state-supported examples exist in Texas, there are hundreds of options for individuals with IDD, ranging from state support to private care. *Two promising practice examples include 29 Acres and Marbridge.*

Marbridge: The Marbridge Campus is in Manchaca, Texas, and houses 275 adult residents. ⁴⁴ These residents work and live at the campus and are given "unparalleled opportunities to learn, experience, and achieve a whole new life." ⁴⁵ There are three residential options at Marbridge, the Village, the Ranch, and the Villa. The Village supports semi-independent and independent living. The residences are structured with three two-bedroom suites

⁴⁵ Marbridge. (n.d.). Home.



⁴⁰ Texas Health and Human Services. (n.d.). State Supported Living Centers.

⁴¹ Texas Fiscal Years run September 1st to August 31st.

⁴² State Supported Living Center Long-Range Planning Report. (2024). Texas Health and Human Services. (texas.gov)

⁴³ General Appropriation Act for the 2024-25 Biennium. (2024). *The State of Texas*. (texas.gov)

⁴⁴ First Place Global Leadership Institute, Madison House Autism Foundation, Arizona State University. (2020). APITW-Report-2021-04.13.21.pdf (autismhousingnetwork.org)

in a single-family home, with a shared living, dining, kitchen, and laundry area. The homes have instructors who provide training on independent living skills including shopping and cooking. The Ranch at Marbridge offers private and shared accommodation in one of the lodges or a dorm setting, with several communal areas and staffing that are available 24/7 to help with daily activities. Finally, the Villa offers around-the-clock skilled nursing in shared bedrooms and offers activities, health and fitness activities, and community spaces.⁴⁶

In a snapshot, the pillars for the long-term services and support at Marbridge are as follows:

- Target Market: Adults with intellectual and developmental disabilities, neurodiverse residents, and adults with intense medical conditions and needs.
- Resident Support Needs: Drop-in support, low to moderate support, 24/7 support, or daily medical support.
- Property Relationship to LTSS: Provider-controlled setting
- Funding Options: Private pay and Dual eligible Medicare-Medicaid

Marbridge offers a care continuum and allows families to develop an Individual Program Plan for each resident to focus on their specific needs, skills, and goals. However, there are eligibility requirements. The residents must be 18 years or older and must have a primary diagnosis of developmental delay or cognitive challenge, including Autism Spectrum Disorder, Down Syndrome, or Williams Syndrome. Marbridge offers independent and semi-independent living; therefore, residents at the Village or Ranch must be able to ambulate and transfer independently. Residents at The Villa must need physical assistance with regular daily activities (bathing, toileting, and hygiene care). Residents with differing diagnoses such as cerebral palsy may also meet the eligibility requirement for this residential option.



Marbridge has been a registered 501(c)3 organization since 2011, and in the 2023 fiscal year, it received the majority (\$13,997,836) of its total \$19,900,665 revenue from tuition and fees.⁴⁷ While the organization had not released its IRS 990 form for the 2023 fiscal year, the 2022 IRS 990 forms indicated that the organization received \$336,160 in government grants (contributions). As the 2022 revenue was \$22,446,270, the governmental contributions were marginal to the total generated revenue. The remaining funding sources, aside from programmatic service revenues and government grants, came from "all other contributions, gifts, grants, and similar amounts not included." This "other" category does not include federated campaigns, membership dues, fundraising events, or related organizations. According to the 990 form, these line-item sources for revenue were all marked with \$0. Therefore, while Marbridge has stacked funding opportunities, the revenue derives from private gifts, governmental grants, and tuition/fees.

⁴⁶ First Place Global Leadership Institute, Madison House Autism Foundation, Arizona State University. (2020). APITW-Report-2021-04.13.21.pdf (autismhousingnetwork.org)





29 Acres: The mission of the nonprofit 29 Acres was cited as "to help ensure that people living with autism have community and a safe place to live and where opportunity and happiness are the standard." ⁴⁸ 29 Acres is a dual-component long-term residential service provider. The two components are a real-estate LLC (the planned living community) and a separate direct support agency. The 10-home campus houses 40 residents in Crossroads, Texas. The non-profit provides daily community activities, while the residents choose their direct support provider. All residences are shared, ranging from townhomes to single-family homes. Residents can connect with the surrounding communities through public transportation and vehicles owned by 29 Acres. 29 Acres offers transportation to the surrounding communities to encourage individuals to connect with social, educational, and employment opportunities.

In a snapshot, the pillars for the long-term services and support at 29 Acres are as follows:

- Target Market: Neurodiverse adults
- Resident Support Needs: Drop-in support, low to moderate support, 24/7 support, or daily medical support.
- Property Relationship to LTSS: Consumer-controlled setting.
- Funding Options: Private pay, private insurance for behavioral therapy, and Medicaid or the HCBS Waiver.

29 Acres was founded in 2015 by a group of families who shared the need to find quality, safe, and supportive housing for those aging out of the school system. Its nonprofit status allows for more data from its 990-form like Marbridge. 29 Acres had a \$5,890,483 revenue in 2022. According to their 990 form, 29 Acres did not receive any government grants or contributions. The primary source of its revenue was tuition, fees, and miscellaneous income. The tuition for the living community includes all utilities and amenities. Amenities include the clubhouse, gym, pool, weekly individual well-being visits by staff, group transportation to surrounding areas, and covered internet and cable. However, "for those residents who need additional direct support, this can be secured through the agency of your choice using public and/or private funding." 49

Tennessee

Tennessee is home to approximately 160,000 individuals with developmental disabilities (IDD), but only about 9%, or 15,000 people, receive long-term support for their daily needs. This leaves the majority of people with IDD dependent on family members for care. The annual healthcare cost for individuals with disabilities in the state is estimated at \$17.8 billion, accounting for up to 38% of Tennessee's healthcare spending, or about \$13,925 per person with a disability.

Tennessee addresses housing needs for *individuals with mental health challenges, including those with intellectual and developmental disabilities, through various initiatives.* One of the most prominent is the **Creating Homes Initiative** (CHI), which was launched in 2000 by the Tennessee Department of Mental Health and Substance Abuse Services (TDMHSAS). The initiative was established to develop affordable, safe, and permanent housing for those with mental illness, including IDD. CHI employs several strategies to ensure success: providing a framework and incentives, leveraging full-time Regional Housing Facilitators to identify housing needs, and partnering with local agencies to develop housing. Emphasizing independent living and homeownership, CHI has helped create over 36,000 new housing opportunities by leveraging more than \$1.3 billion as of FY23. Housing is owned and operated by local mental health providers or affordable housing agencies, ensuring a variety of living arrangements from supervised facilities to independent homeownership.⁵⁰

Community Supportive Housing: Another key program, Community Supportive Housing (CSH), offers flexible funding to support housing for adults with mental illness and co-occurring disorders. This program contracts

⁵⁰ Gobin, N. (n.d.). TDMHSAS Supportive Housing Programs. Department of Mental Health and Substance Abuse Services. PowerPoint Presentation (thda.org)



⁴⁸ First Place Global Leadership Institute, Madison House Autism Foundation, Arizona State University. (2020). APITW-Report-2021-04.13.21.pdf (autismhousingnetwork.org)

^{49 29} Acres. (n.d.) Pricing and Floor Plans.

agencies to provide on-site supervision and other supportive services, helping individuals live independently. The funds also help cover other program costs, such as utilities, food, and transportation. CSH provides a safety net for individuals who require ongoing support but are not eligible for other sources of funding beyond resident rent.

Licensed Supportive Living facilities in 11 counties can apply for financial assistance (\$2/day per eligible resident) to maintain the availability of housing options for those with mental illness or co-occurring disorders. This funding helps ensure these housing opportunities remain financially viable, especially for those who receive limited support outside of resident fees. The program, mandated by Tennessee law, receives a designated annual legislative appropriation.

Tennessee's 1915(c) waiver programs, managed by TennCare, the state's Medicaid program, provide an alternative to institutional care for people with intellectual disabilities. These Home and Community-Based Services (HCBS) include several types of residential support.⁵¹:

- Family Model Residential Support: Living in the home of a trained caregiver who is not a family member.
- **Residential Habilitation**: Support in a shared living arrangement, with up to three roommates, to help individuals live independently and engage with the community.
- **Supported Living**: Similar to Residential Habilitation but typically for smaller living arrangements with up to two roommates.

In 2023, TennCare's total expenditure was \$16,184,591,000, with \$622,011,000 allocated for mental health services and \$370,121,000 dedicated to intellectual disability services. ⁵² TennCare's Division of Long-Term Services and Supports (LTSS) oversees the administrative management of the 1915(c) waiver programs, while the Disability and Aging division (DDA) is the state agency contracted by TennCare to handle the day-to-day operations of these programs. Out of the 415 DDA providers in Tennessee, 46 agencies offer Residential Habilitation, 120 provide Family Model Residential Supports, and 192 provide Supported Living services.

Additionally, the Tennessee Local Development Authority (TLDA) offers financing assistance for nonprofit organizations building facilities for mental health, developmental disabilities, and substance abuse services. By providing bond and note financing to local governments, TLDA plays a critical role in expanding housing options for vulnerable populations across the state.

Gloriana and BrightStone: In Tennessee, innovative housing solutions for individuals with IDD have faced legal hurdles, despite promising new models that aim to enhance quality of life. Two nonprofit organizations, Gloriana and BrightStone, were at the forefront of offering these new housing options. However, their efforts were initially hindered by state regulations enforced by the Tennessee Department of Intellectual and Developmental Disabilities (DIDD). Specifically, the DIDD code required a 500-yard separation between buildings housing IDD residents and limited occupancy to no more than four people per building, rules that would prevent these initiatives from proceeding.

Gloriana proposed building residential homes within an existing senior living community, creating an intergenerational, inter-ability environment. This would allow aging caregivers and their adult children with IDD to live together in three homes, each designed with four suites, providing private bedrooms and shared bathrooms. BrightStone, meanwhile, raised over \$20 million through community donations to develop a 140-acre property that already includes two homes, with plans for 11 more. These 7-bedroom homes would offer residents a range of amenities including a learning center, equestrian facilities, a fishing pond, and opportunities for community engagement both on and off the property. BrightStone's model promotes a level of integration and quality of life

⁵² Tennessee State Government. (2023). Annual Comprehensive Financial Report. ACFR_fy23.pdf (tn.gov)



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⁵¹ Division of TennCare. (n.d.). 1915(c) HCBS Waivers. 1915cBenefitTable.pdf (tn.gov)

not typically available under Tennessee's current living options of Community Living Support through the state's HCBS waiver.

To enable these programs to move forward, Tennessee legislators introduced HB2497, a bill that sought to waive the restrictive DIDD code for these two completely self-funded specific nonprofit initiatives. Despite opposition from the Tennessee Disability Coalition (TDC), the bill passed both the House and Senate with strong support. As a result, individuals with IDD in Tennessee will soon have access to more diverse and integrated housing choices, marking a significant victory for disability housing in the state⁵³.

Through these comprehensive programs, Tennessee strives to offer a range of housing solutions for individuals with mental health challenges and developmental disabilities, ensuring more people have access to safe, affordable, and supportive living environments. Two promising practice examples include Pacesetters and Sunshine Services.

Pacesetters: Founded in 1971 by community members and families, Pacesetters began as an adult activities center focused on improving the lives of individuals with developmental disabilities. Over the years, it has grown into one of Tennessee's largest providers of day and residential services for the IDD community. As of 2022, Pacesetters operates in five counties within the Upper Cumberland Region, offering services through the 1915c Waiver, CHOICES, and the Employment and Community First Choices (ECF) Waiver. The organization also received Quality Assurance Accreditation from The Council on Quality and Leadership (CQL) in 2022.

Pacesetters provides a range of residential services, including Residential Habilitation (agency-owned homes with 2-3 residents), Supported Living (homes or apartments with 1-3 residents), Medical Supported Living (homes for residents requiring medical care), Semi-Independent Living (individual homes with intermittent support), Respite care, and Personal Assistance. With 34 sites across five counties, Pacesetters supports around 97 individuals with residential services, offering up to 24-hour supervision and assistance with daily living tasks. These services allow individuals to live independently in a home in the community, rather than in institutional settings.

According to its IRS 990 form, in fiscal year 2023, Pacesetters generated 97% of its total revenue of \$12,200,316 from government grants, amounting to \$11,829,240. In contrast, only 2.5% (\$307,971) came from program services, which include client fees, food stamps, and other revenue sources. This marks a shift from fiscal year 2022, when 95% (\$11,333,681) of the organization's total revenue of \$11,880,092 came from program services, while just 4.4% (\$518,800) was derived from contributions and grants. Additionally, Pacesetters holds an annual golf tournament as a key fundraising event, partnering with private companies such as Swallows Insurance, First National Bank of Tennessee, Honda Cookeville, McGriff, and Coca-Cola.

Sunshine Services (formerly Arc Knox): Established in 1953, Sunshine Services is a nonprofit dedicated to supporting Knoxville area individuals with intellectual and developmental disabilities. The organization offers two key residential programs: Beta Homes and the Independent Living Program (ILP).

The Beta Homes program provides housing for adults with IDD in two 10-person homes, each offering 24/7 staff supervision. These homes not only ensure safety and security but also foster personal development and an active lifestyle. Many residents work at Sunshine Industries or participate in the Arc's Community Participation Program, which offers job training, volunteer opportunities, and leisure activities. Beta Homes are funded by a grant from the Tennessee Department of Mental Health and Substance Abuse Services.

The Independent Living Program (ILP) serves individuals capable of more independent living but who still require some assistance. ILP residents receive support with tasks like money management, medical appointments, grocery shopping, and household chores during the weekdays. While there is no supervision on weekends or

⁵³ Kancir, J. (2024). A Major Victory for Disability Housing — and Choice — in Tennessee. NCSA. (ncsautism.org)



overnight, residents can contact staff in case of emergencies. Many participants in this program are employed in the community.

The IRS 990 form indicates that in fiscal year 2023, 28.6% (\$798,883) of the agency's total revenue (\$2,789,310) came from government grants and contributions. Program service revenue, including Medicaid payments, program service fees, management fees, workshop contracts, and recreation fees, accounted for 52.5% (\$1,463,914) of total revenue. In fiscal year 2022, 16.8% (\$438,886) of the total revenue (\$2,609,363) came from government grants, while 56.1% (\$1,463,914) was derived from program services.

Other Promising Practices

The HomeChoice Second Mortgage program is a Downpayment Assistance Program for low- to moderate-income people with a disability or who have a family member with a disability living with them and qualify for the Home Advantage First Mortgage loan program. The Program offers up to \$15,000 per household in a 1.00% interest, payment deferred second mortgage. Second mortgages are due when the home is sold, if the home is refinanced, or after 30 years. If the home purchase is in a target area, the program is also open to non-first-time homebuyers. The income limits are \$147,400 for King/Snohomish County and \$115,900 for all other counties.



Implications

Federal policies mandate that communities divest from congregate and institutional settings. A commensurate investment would need to be made at the local, state, and federal levels in affordable, accessible, integrated, and inclusive housing. From the perspective of people with IDD, they have little choice in where they live because of a lack of options, and they want more opportunities to integrate into their communities. ⁵⁴ While there is valuable information provided by some organizations on housing options, ⁵⁵ the reality is a lack of affordable housing and choice for most people with IDD. The research used in the development of this report leads to several important implications related to the challenges and opportunities or promising practices that can change the tide.

There is no precise estimate of the unmet needs for IDD housing.

While there are some estimates on the size of the IDD population, there is no systemic national research effort addressing the prevalence and health status of adults with IDD. The number of individuals with disabilities and their disability types is estimated by several national surveys. However, these surveys do not ask specific IDD questions but instead use broad categories of disabilities, e.g. ambulatory, hearing, visual, etc. ⁵⁶ In the absence of nationally representative survey estimates, estimates rely on the prevalence approach to calculate the number of IDD individuals. One report estimates this population at 7.43 million, ⁵⁷ of whom 431,200 are in Florida. ⁵⁸ The National Health Interview Survey (NHIS) estimated that during 2019–2021, the prevalence of any diagnosed developmental disability in children aged 3–17 years increased from 7.40% to 8.56%. ⁵⁹ It stands to reason the number of adults will also keep rising.

The increasing number of IDD adults would also signify a growing need for support, including housing. In 2018, 51% of all adult Medicaid Waiver recipients In Florida lived with a family member. Florida provided Medicaid waiverfunded support to fewer than 200 adults with IDD ages 22 years or older per 100,000.⁶⁰ Households with a member with disabilities are almost twice as likely to pay over half their monthly income on housing than households with no disabled members (27% versus 15%).⁶¹ A household that includes a member with a disability requires \$18K more than a similar household without a disabled member. If additional costs for households with a disabled member are considered, the poverty rate in states with no Medicaid expansion increases from 24 percent to 35%. ⁶²

A successful research effort that allows for more dedicated financing and subsequent assessment of impact was completed in 2021 when the Washington State Legislature tasked the Department of Social and Health Services (DSHS), Developmental Disabilities Administration (DDA) with the responsibility of generating two reports to advise on the housing needs of people with intellectual developmental disabilities (IDD). The Housing Fund Priority Study was released in 2022 and estimated that 22% of the Washington IDD population, or 37,000, had unmet housing needs. The study also determined the ratio of IDD set aside Housing Trust Fund vs. total Housing Trust Fund, the award rate of IDD housing projects vs. general low-income housing and other projects, and the IDD unit gap.⁶³

⁶³ Washington State Department of Social and Health Services. (2022). Report to the Legislature: Housing Fund Priority Study Report.



⁵⁴ The Arc and the Council on Quality and Leadership (CQL). (2019). 2019 Housing Study.

⁵⁵ Florida Developmental Disabilities Council, Inc. (2013). Housing in Florida: A Resource Guide for Individuals with Developmental Disabilities.

⁵⁶ Susan Havercamp, Gloria Krahn, Sheryl Larson, Glenn Fujiura, Tawara Goode, Barbara Kornblau, and the National Health Surveillance for IDD Workgroup, "Identifying People With Intellectual and Developmental Disabilities in National Population Surveys," Intellectual and Developmental Disabilities 57, no. 5 (October 2019): 376–389. https://doi.org/10.1352/1934-9556-57.5.376.

⁵⁷ Larson, S.A., van der Salm, B., Pettingell, S., Sowers, M., Anderson, L.L., Neidorf, J., & Vegas, L. (2021). In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2018. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

⁵⁸ Resnik, D. D., & Kameka Galloway, D. (Eds.). (2020). A Place in the World: Fueling Housing and Community Options for Adults with Autism and Other Neurodiversities. Phoenix, AZ: First Place AZ; Madison House Autism Foundation; the Arizona Board of Regents for and on behalf of Arizona State University and its Morrison Institute for Public Policy at the Watts College of Public Service and Community Solutions.

⁵⁹ Zablotsky et al. (2023). Diagnosed Developmental Disabilities in Children Aged 3–17 Years: United States, 2019–2021. *NCHS Data Brief*, No. 473.

⁶⁰ Larson et al. (2021).

⁶¹ Trivedi, K., Meschede, T., & Gardiner, F. (2020). Unaffordable, Inadequate, and Dangerous: Housing Disparities for People with Disabilities in the U.S. Community Living Policy Center. Brandeis University, Waltham, MA.

⁶² Goodman et al. (2020). The Extra Costs of Living with a Disability in the U.S. - Resetting the Policy Table. National Disability Institute.

The construction and operations of IDD housing require a funding stack.

According to Home Advisor, building a completely accessible home costs \$100 to \$300 per square foot. Retrofitting a home for accessibility costs \$4,500 on average but costs vary largely depending on the need. According to some estimates, IDD housing may cost about 60K more than usual. However, most of the general estimates are for making the home more physically accessible, for individuals with ambulatory disabilities, rather than accounting for the auditory, visual, and other needs of individuals with IDD. ⁶⁴ For social integration and good quality of life, neurodiverse individuals often require housing with sensory-friendly and accessible qualities, relaxation and recreation spaces, transit access, and security features.

Nancy Detert Residential Community Phase II is a Florida project that would allocate up to 40% of the 38 affordable homes to be sold to the IDD-identified resident at a low cost and 0% interest. The Local Funding Initiative Request requested from the State 48% of the \$15.5M project funding, with additional funding sources from federal sources (23%), local (16%) and Other (13%). Based on the total project amount, the per-unit cost was almost \$408K.65

Capital and operating costs before construction.

In addition to capital, IDD communities require ongoing support and there has been a tendency to overlook this with an inevitable outcome—new facilities fall into disrepair within a few years of operation. This has been a longstanding issue in housing targeted to those of low and moderate-income. Projects serving individuals with IDD often face very high operating costs, such as maintenance and repair costs, insurance, or turnover costs (when tenants move out and the unit must be refreshed). 67

To avoid these outcomes, IDD housing needs to include not only appropriate housing but also account for the additional services that will provide a decent quality of life, e.g., transportation, medical services, social activities recreation, etc. Depending on the type of needs of the IDD community for whom the housing is intended, it might also include vocational, life skills, and other types of training that will enable integration within society and the labor force.

IDD communities are developed in both urban and rural settings.

The location and type of IDD housing vary significantly, and IDD communities can be found in urban suburban, and rural settings, with variations between multiunit and single-family dwellings, as shown in the *Promising Practices Examples* section. In urban and suburban settings, they may require rezoning as was the case with the Luna Azul pocket neighborhood in Arizona.⁶⁸

In their planning and pre-construction phase, IDD housing developments in urban settings encounter challenges like any other housing development, including high land values, construction cost, and the "Not in My Backyard Syndrome" (NIMBYism). According to the Florida Housing Coalition, "local zoning codes that segregate uses by housing type and require subjective standards of "compatibility" with existing surroundings set the stage for NIMBYism and segregation." ⁶⁹ The IDD community also experiences stigmatization, that might be masked as opposition to zoning changes. ⁷⁰

Service delivery models vary depending on need and location.

An IDD housing development requires simultaneous decisions on clientele, type of community, location, and service model. In addition to housing, many IDD communities, especially the renter

⁷⁰ Jansen-van Vuuren J, Aldersey HM. Stigma, Acceptance and Belonging for People with IDD Across Cultures. Current Developmental Disorders Reports. 2020;7(3):163-172. doi: 10.1007/s40474-020-00206-w.



⁶⁴ Home Advisor (accessed September 2024). https://www.homeadvisor.com/cost/disability-accommodation/

⁶⁵ The Florida Senate Local Funding Initiative Request Fiscal Year 2024-2025 (LFIR #2348). (December 2023).

⁶⁶ U.S Department of Housing and Urban Development. (1974). Housing in the Seventies A Report of the National Housing Policy Review HUD-0000968. National Housing Policy Review.

⁶⁷ ECONorthwest and Washington State Department of Social & Health Services. (2021). Housing Needs for Individuals with Intellectual and Developmental Disabilities in Washington State.

⁶⁸ Luna Azul Planned Unit Development Narrative. (November 2, 2016)

⁶⁹ Ross, Jaimie, and Kody Glazer. (2022). Overcoming NIMBY Opposition to Affordable Housing. 2022 Advocates Guide, Florida Housing Coalition.

communities, also include a variety of supportive services. One of the reasons for locating many of these communities in urban settings is to provide connectivity to the broader community and improve access to services that are not available on-site. On-site services can be extensive as in "Babe's House", a community residential home in Palm Beach County, which opened in 2022. Six male adults with autism reside in the home, with the ARC of the Treasure Coast staffing it 24/7 with professionals to meet the needs of residents. The 29-acre community in Texas is inclusive of the full spectrum and provides services depending on need, from transportation, education, employment and life skills training, and social activities.

There is a lack of research on the economic impact of the lack of IDD housing.

Advocates for more IDD assistance, including housing and wraparound services, contend that more comprehensive IDD support, including housing, would reduce the "indirect costs" of disability and produce economic benefits, as family caregivers return to the labor force, or capture otherwise foregone earnings with transition from part- to full-time employment. 73 The economic impact of unpaid caregiving on family caregivers includes (1) reductions in available financial resources of the caregiver as a consequence of out-ofpocket expenses; (2) employment-related costs for the caregiver who must reduce work hours, exit the labor force, and forego income, benefits, and career opportunities to provide care; (3) employment-related costs to the employer who must replace workers who leave the labor force or reduce hours; and (4) societal benefits that include the potential cost savings to the formal health and long-term services and supports (LTSS) systems because of the care and support provided by family caregivers. ⁷⁴ While the focus of much of the research is on older adults with significant physical and cognitive impairments (and associated behavioral symptoms), the impacts on families with IDD members are similar. 75 There are no exact estimates of the impact of lack of affordable housing choices for IDD individuals but studies have shown the impacts on families with a Down syndrome member. 76 A 2023 report estimated employment-related costs for mothers providing unpaid care at \$295,000 per person over a lifetime, based on the 2021 U.S. dollar value, and a reduction in a mother's lifetime earnings by 15 percent, also leading to a reduction in retirement income.⁷⁷

Increasing housing choices for the IDD population presents thorny challenges for policymakers. Multiple, "stacked" funding is likely necessary for its construction and sustainability. A gap exists between available housing and consumer demand but estimating that gap is difficult without further quantitative research. Building smaller residential options is a trend in this space, but adds considerable costs, as does the inclusion of state-of-the-art assistive technology. Increasing the supply of affordable housing in the IDD space is a potential positive for client choice. This begs an important question of whether increased residential options correlate to increased independence and higher quality of life for individuals with IDD.

⁷⁷ Johnson, Richard W., K. Smith, and B Butrica, Urban Institute. (2023). Lifetime Employment-Related Costs to Women of Providing Family Care. U.S. Department of Labor's Women's Bureau.



⁷¹ SouthFloridaReporter.com (2022). Babe's House – A Special Home for a Special Group of Men with Autism.

^{72 29} Acres, Our Story. https://29acres.org/about/our-story/

⁷³ Lilly, M.B., Laporte, A., & Coyte P.C. (2007). Labor Market Work and Home Care's Unpaid Caregivers: A Systematic Review of Labor Force Participation Rates, Predictors of Labor Market Withdrawal, and Hours of Work. Milbank Quarterly. 85(4): 641–690.

⁷⁴ Keating NC, Fast JE, Lero DS, Lucas SJ, Eales J. (2014). A taxonomy of the economic costs of family care to adults. The Journal of the Economics of Ageing; 3:11–20.

⁷⁵ Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, Engineering, and Medicine; Schulz R, Eden J, editors. Families Caring for an Aging America. Washington (DC): National Academies Press (US); 2016 Nov 8. 4, Economic Impact of Family Caregiving. Available from: https://www.ncbi.nlm.nih.gov/books/NBK396402/

⁷⁶ Shetty J, Shetty A, Mundkur SC, Dinesh TK, Pundir P. Economic burden on caregivers or parents with Down syndrome children-a systematic review protocol. Syst Rev. 2023 Jan 6;12(1):3. doi: 10.1186/s13643-022-02165-2. PMID: 36609318; PMCID: PMC9817293.