



Building an Intentional Community in Delaware

An Affordable Housing Option for Adults with Intellectual and Developmental Disabilities (IDD)

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“The ache for home lives in all of us, the safe place where we can go as we are and not be questioned.” -Maya Angelou

Abstract

Of all populations living in the United States, the prospect of achieving "The American Dream" is the most illusory for people with intellectual and developmental disabilities (IDD).

Current headlines are painful reminders that people with IDD, rather than being embraced by their community, are frequent targets for physical and emotional abuse. The overwhelming majority live below the poverty level, unable to access stable housing and suitable employment. Yet governmental policies and regulations significantly and improperly restrict long-term services and supports (LTSS) and housing options—prohibiting many people with IDD from living in the communities of their choice.

Across the country, there are over 5 million citizens with IDD—more than five times the population of Delaware.¹

Although many are eligible for Medicaid, appropriate support is currently available for only a small group of those with IDD. The US largely relies upon an uncompensated workforce to care for those with IDD: family caregivers— who themselves are aging. Too many people and their families live with the reality that only a life-threatening crisis, such as death of a caregiver, will permit them to

access Medicaid funded supports needed to live independently in a home of their own.

The LTSS system in the US is in a constant state of emergency response and its repair will not be easy. Individuals with IDD are voiceless victims as their parents pass away. During the most confusing and vulnerable time in their lives, they are left at the mercy of state Medicaid authorities with scarce resources available to help them transition to a new living environment.

During a crisis response, individuals with IDD are often forced into “the next empty bed”, which may be hundreds of miles away from their community, with people they have never met, and in a more restrictive setting than necessary.

With a shrinking governmental funding stream, management by crisis is neither a long-term nor short-term answer to the dilemma of how to care for a quickly growing population of adults with IDD.

Many people with IDD may be unable to fully advocate for themselves because they lack intellectual capacity and depend on others such as their family members and/or guardians to care for them. While other minorities, such as LGBTQ, African-American, or Women, can use the very attribute that excludes them (i.e. being gay, black, female, etc.) as a platform for recognition and inclusion, lack of intellectual capacity limits many in the IDD community from doing so. What is perhaps most unfair, is that the voices of caregivers and guardians are marginalized

¹ Braddock, David, Richard Hemp, Mary C. Rizzolo, Emily Shea Tanis, Laura Haffer, and Jiang Wu. *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. Publication. 10th ed. Washington D.C.: American Association on Intellectual and Developmental Disabilities, 2015. Print. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado in collaboration with the Department of Disability and Human Development, University of Illinois at Chicago (“SOS Report”)

and/or ignored by policymakers, even after they have spared the state and federal governments untold billions in caregiving expenses.

The CMS (Center for Medicare and Medicaid Services) 2014 Home and Community Based Services (“HCBS”) “final rule” and subsequent guidance have harshly and inappropriately limited choice in housing and employment settings for those with IDD. CMS has arbitrarily defined “community” to remove innovative and cost efficient residential programs from the menu of options.

Imagine for a moment that the right to receive Social Security *retirement* benefits is now contingent upon the location of one’s residence. Imagine that neighborhoods, including age 55 and over communities, retirement homes or senior high rise apartments were deemed “inappropriate” by the Social Security Administration. In that case, residents would lose their funding if they chose to live with their peers. For seniors, this is an absurd, dystopian scenario which violates their Constitutional rights, yet this type of government overreach is what the IDD community faces today.

Moreover, the Supreme Court’s landmark decision in Olmstead v L.C., 527 U.S. 581 (1999), has been misinterpreted by policymakers to restrict, rather than secure, appropriate housing options. Micaela Connery, a Harvard researcher who authored a recent white paper on disability housing, noted in her discussion after visiting various residential options, “Many of the national advocates and policy leaders I met with were critical of any environment that seemed to “congregate” people with disabilities. While community integration and continuing de-institutionalization must be supported and encouraged, individuals’ desires to live with other people with disabilities must also be

acknowledged and valued. A careful balance must be struck between these two goals: integration and choice.”²

Any “one size fits all” solution to this national crisis ignores the diversity of the IDD population. All choices that improve one’s quality of life should be available to those with IDD. This report will serve as the introduction to a national conversation about the housing and LTSS crisis citizens with IDD and their families face. It is a conversation with those who are often given no voice. It is a conversation long overdue.

² Connery, Micaela. Disability Housing: What’s happening? What’s challenging? What’s needed? Joint Center for Housing Studies of Harvard University. President and Fellows of Harvard College, Apr. 2016. Web. 2 Dec. 2016. <http://www.jchs.harvard.edu/sites/jchs.harvard.edu/files/connery_disabilityhousing_april2016_v2.pdf>.



I. The Proposed Homes For Life (HFL) Intentional Community

1. Introduction

To date, HFL Foundation has designed, built and furnished twenty-five homes and purchased two condominiums where 104 adults with IDD now have a permanent and affordable “home for life.” HFL’s vision for the future is to design and build a person-centered, innovative, nurturing, safe and affordable planned/intentional community for persons with IDD who might choose such an environment to build friendships and relationships with others like themselves as well as their neurotypical neighbors.

IDD encompasses a broad range of conditions such as autism, down syndrome, and disabilities caused by birth trauma, etc. But they also share common features, namely significant limitations both in intellectual capacity (reasoning, learning, problem solving) and in adaptive behavior, which are the social and practical skills needed for adult living. On one end of the disability spectrum are severely disabled individuals, unable to perform the most basic functions of self-care (such as getting dressed, verbal expressive

communication, meal preparation, brushing teeth, toileting, etc.). On the other end are adults able to function with minimal supervision and limited support. This report focuses on a solution for those with an intellectual disability which puts them at higher risk of physical and sexual abuse, neglect and exploitation as they attempt to live a meaningful life.

The number of adults with IDD dependent upon their families is growing at an alarmingly rapid rate. Today we know that many people with IDD are not thriving, but are falling through society’s cracks. Unemployment and poverty are unfortunately the norm. Many people with IDD are without access to critical services and supports.

A 2016 RespectAbility report reflects that 40% of people in prison self-report at least one disability. Furthermore, of the **751,346**

incarcerated, **504,204** report an intellectual or cognitive disability.³

While society works to remove people from “institutions” on the one hand, the systemic failures are simply funneling them into an actual institution with far more negative ramifications for the individuals and for society. Prison should not be a substitute for appropriate affordable housing for a person with IDD.

The US educational system has invested billions of dollars teaching students with IDD the skills they need to be independent. By not providing the necessary supports or adequate housing opportunities after age 21, the system too often fails these most vulnerable citizens.

2. Definition of an Intentional/Planned Community

What is “community”? The answer to this question is being sought by other populations who are concerned about affordable housing, access to meaningful relationships and increasing their natural support systems. Millennials, seniors, and new families are all seeking more than just a house they can afford, but also neighbors they can rely upon for support and share in life’s joys and sorrows. Brian Bethune’s article, The End of Neighbors⁴, garnered national media attention across multiple target audiences with coverage by *The Today Show*⁵, *TIME Magazine*⁶, and *AOL*⁷. He reported **50% of all**

³ RespectAbility, Disability and Criminal Justice Reform: Keys to Justice (2016).

⁴ Bethune, Brian. "The end of neighbours." *Maclean's*, N.p., 8 Aug. 2014. Web; <http://www.macleans.ca/society/the-end-of-neighbours/>

⁵ <http://www.today.com/video/today/55849781#55849781>

⁶ <http://time.com/3101555/why-people-dont-know-who-their-neighbors-are-anymore-and-other-fascinating-news-on-the-web/>

Americans do not know their neighbors’ names, demonstrating the need to create spaces and opportunities for all people to foster more human connections. Isolation is not limited to those with IDD. As statistics demonstrate, neighborhoods today are not cultivating community relationships as they did in decades past. Therefore, it is logical to conclude that the suburban sprawl and busy urban epicenters may be too distracted to consider, let alone care for, their neurodiverse or aging neighbors.

Since the end of WWII, homes in neighborhoods have been built with convenience of a vehicle driver in mind. Neighbors drive down wide asphalt streets, into their garage, close the door, and have little to no soft social interactions with those who live next door. Many intentional communities, however, focus on the person, not the auto. According to the Fellowship for Intentional Communities:

"An ‘intentional community’ is a group of people who have chosen to live together with a common purpose, working cooperatively to create a lifestyle that reflects their shared core values. The people may live together on a piece of rural land, in a suburban home, or in an urban neighborhood, and they may share a single residence or live in a cluster of dwellings.

This definition spans a wide variety of groups, including (but not limited to) communes, student cooperatives, land co-ops, cohousing groups, monasteries and ashrams, and farming collectives. Although quite diverse in philosophy and lifestyle, each of these groups places a high priority on fostering a sense of

⁷ "Why Americans don't know their neighbors anymore." Aol. N.p., 12 Aug. 14. Web. 29 Jan. 2017; <http://www.aol.com/article/2014/08/12/why-dont-americans-know-their-neighbors-anymore/20945813/>

community—a feeling of belonging and mutual support that is increasingly hard to find in mainstream Western society.”⁸

Susan Pinker, author of *The Village Effect*, says that “face-to-face contact matters: tight bonds of friendship and love heal us, help children learn, extend our lives and make us happy.”⁹ This may be why intentional communities create spaces for spontaneous social interaction through a Common House with community mailboxes, a laundry room, game room, art studio or library as well as a community kitchen to share common meals a few times a week. Relational community is paramount to one’s feeling of value and belonging.

HFL recognizes the need for affordable, accessible housing in an intentional community. Funding from the HCBS waiver program is strictly for LTSS and is not permitted to be used for rent. The majority of adults with IDD are not employed or do not earn a living wage to be able to rent or purchase their own home. In Delaware, the average rent for a one-bedroom apartment was \$927 per month – or 127% of the national average monthly SSI income.¹⁰ A renter earning \$8.25 per hour would need to work **86 hours per week** to afford a one-bedroom rental home at the Fair Market Rent.

Although policy is creating barriers to building an intentional community for those with IDD in Delaware, the issues of inequality, government overreach, violations of human

dignity and civil rights has prompted HFL to move forward.

3. The Pros

HFL is a 501(c)(3) foundation, with no paid staff, dedicated to building safe and affordable homes for people with IDD. To date, HFL has raised nearly ten million dollars to build and furnish 25 neighborhood homes and purchase two condos for adults with IDD. This resulted in a public-private partnership with the State of Delaware. HFL built the debt free homes making the “rents” affordable. The State, using HCBS waivers, subsidized the necessary individualized supports.

HFL’s goals are simple – to ensure that a person with IDD has the right to choose where and with whom they desire to live.

HFL has currently raised \$2,500,000 towards the \$8,000,000 goal to build this community. HFL’s track record of developing quality homes through private donations makes HFL an ideal candidate for continued public-private partnerships.

4. The Challenges

HFL is realistic and understands that the financial and political climate has changed dramatically since fundraising first began 25 years ago. However, there are 11,000 persons with IDD living at home in Delaware, 3,000 of whom are living with caregivers over the age of 60.¹¹ This represents a looming crisis and will require innovative ideas as these citizens leave their parental homes.

In the past, MBNA and its CEO Charlie Cawley embraced the HFL’s housing concept, were major funders and offered full-time jobs with benefits to over 300 adults with IDD. MBNA was purchased by Bank of America in 2005

⁸ Kozeny, Geoph. "Intentional Communities: Lifestyles Based on Ideals." Fellowship for Intentional Community. N.p., n.d. Web. 24 Jan. 2017. <<http://www.ic.org/wiki/intentional-communities-lifestyles-based-ideals/>>. Another version of this this article has been published in Claude Whitmyer’s book, *In the Company of Others* (Jeremy Tarcher, San Francisco, 1993).

⁹ Pinker, Susan. *The village effect: how face-to-face contact can make us healthier, happier, and smarter*. New York: Spiegel & Grau, 2014. Print.

¹⁰ *Out of Reach 2016: No Refuge for Low Income Renters*. National Low Income Housing Coalition, 2016. Web. 24 Jan. 2017. <<http://nlihc.org/oor/delaware>>.

¹¹ SOS Report at 6. State Profiles for I/DD Spending During Fiscal Years 1977-2013. Web. 24 Jan. 2017. <<http://www.stateofthestates.org/index.php/intellectualdevelopmental-disabilities/state-profiles>>.

which has its corporate headquarters in Charlotte, NC. Because of downsizing, many of the donors to HFL, especially the former senior MBNA executives, have since relocated from the Delaware community.

Since the economic downturn of 2008 the State of Delaware has been hit hard:

- Chrysler and General Motors have left the state resulting in thousands of job losses
- The banking industry downsized resulting in thousands of lost jobs
- DuPont merged with Dow Chemical, resulting in thousands of additional job losses including hundreds of scientists
- AstraZeneca, headquartered in Wilmington, Delaware also downsized resulting in nearly 1,500 job losses
- Delaware casinos, a source of revenue for many years, have been struggling due to the competition from nearby states
- State revenue from escheatment has dropped precipitously

In addition, official guidance from CMS has hindered efforts to design and build innovative living communities for those with IDD. Medicaid, a major financial backbone for those with IDD, is under significant strain.

5. HFL's Plan

1. Garner local support from elected officials, the community and those with IDD who are clamoring for innovative housing opportunities. Reignite the public-private partnership that allowed for the success of HFL.
2. Work cooperatively with organizations and policymakers nationwide to overturn unreasonable policies and guidance.
3. Identify a five-acre site in Delaware with convenient access to employment, transportation, shopping and entertainment facilities.
4. Raise an additional \$5,000,000+ by asking potential donors to pledge their gifts to HFL.
5. Build an intentional community in Delaware to provide safe and affordable housing for at least 30 individuals with IDD.

II. National Background

1. Whose Voice? Whose Choice?

Recent articles have highlighted the fact that individuals with IDD have little functional choice over their own housing and LTSS options: “Who Decides Where Autistic Adults Live”¹², “The Federal Government’s Quiet War Against Adults with Autism”¹³; “You Can Choose Where You Want to Live Unless You Have Autism”¹⁴; “Luke’s Best Chance: One Man’s Fight for His Autistic Son”¹⁵; “Why the Next “Empty Bed” Isn’t Enough for Adults with Disabilities”.¹⁶ As local communities seek solutions to address the national housing and support crisis, they are confronted with barriers in policy and outdated ideology.

This tension is becoming more apparent as value-systems and measures of quality are being challenged by advocates with differing perspectives. For example, grassroots efforts across the nation value the creation of accessible housing and amenities that would foster integration and better access to the community.

Planned recreational opportunities, social enterprises, and needed community spaces would benefit both the needs of specific individuals as well as the local area. In many communities, counties, faith-based, and local not-for-profit have stepped in to support these efforts financially and through volunteer efforts. Designed and informed by local individuals with IDD, these intentional community projects relieve states of financial and legal obligations and offer residents a safety net of friendship and employment opportunities.

On the other hand, those who are opposed to the development of intentional communities claim that they are neo-institutions being developed to “segregate” and isolate individuals with IDD. They claim that a residence developed to offer housing and amenities centered around people with disabilities is a negative trajectory as it sets them apart from the general population. Critics claim that neurodiverse intentional communities are not normal or typical neighborhoods and therefore do not support efforts to increase integration into the broader community.

There are strong opinions about where and with whom individuals with IDD should and will live. Over nearly two decades, Olmstead has fueled efforts by advocates, federal and state agencies to prevent people with disabilities from being forcefully institutionalized against their wishes and to help them gain full access to the greater community. There is no disagreement that this is a necessary and welcome development. At the same time, however, any regulations or policies based on an interpretation of Olmstead which creates barriers to opportunities for people with IDD should be questioned. The market place of consumer options for service delivery is circumscribed by

¹² Lutz, Amy S.F. "Who Decides Where Autistic Adults Live?" *The Atlantic*. Atlantic Media Company, 25 May 2015. Web. 25 Jan. 2017.

<<http://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults-live/393455/>>.

¹³ Escher, Jill. "The Federal Government's Quiet War Against Adults with Autism." *Autism Society San Francisco Bay Area*. Autism Society San Francisco Bay Area, 19 Apr. 2016. Web. 25 Jan. 2017. <<http://www.sfautismsociety.org/blog/the-federal-governments-quiet-war-against-adults-with-autism>>.

¹⁴ Escher, Jill. "You Can Choose Where You Want to Live... Unless You Have Autism." *Autism Society San Francisco Bay Area*. Autism Society San Francisco Bay Area, 21 Sept. 2016. Web. 25 Jan. 2017. <<http://www.sfautismsociety.org/blog/you-can-choose-where-you-want-to-live-unless-you-have-autism>>.

¹⁵ Solotaroff, Paul. "Luke's Best Chance: One Man's Fight for His Autistic Son." *Rolling Stone*. Rolling Stone, 27 July 2016. Web. 25 Jan. 2017.

<<http://www.rollingstone.com/culture/features/luke-s-best-chance-one-mans-fight-for-his-autistic-son-w431012>>.

¹⁶ Kameka, Desiree M. "Why the Next “Empty Bed” Isn’t Enough for Adults with Disabilities." *Autism Housing Network*. Madison House Autism Foundation, 13 Apr. 2016. Web. 25 Jan. 2017.

federal and state regulations dictating Medicaid reimbursement rates. Without access to a variety of home and service delivery options, individuals with IDD do not have authentic choices, but simply the option provided by the state.

2. Prejudice from Without— And Within

Sometimes the more things change, the more they stay the same. Those with IDD have long suffered from the dictum that neurotypicals know what’s best for them. The rise of the self-advocacy movement has helped give a voice for what they actually want, but has for those with the most severe intellectual disabilities doubled back to the same nodding authority – “We Know What’s Best for You.” “Enlightened” bureaucrats are bolstered by “self advocates” who are often articulate, quite independent and may have college or even advanced degrees. The bureaucratic and philosophical arguments do not align with the reality of today’s economic and social environments to address the needs of people who have high support needs and lack even basic self-care skills.

Consequently, having been excluded from governmental appointments and the national policy dialogue, the voiceless and those who actually care for them—family members, support professionals, guardians— have been organizing. This is happening locally, in grassroots organizations such as Families Speaking Up in Delaware, advocating for state-wide system change. This is also happening nationally, such as the Coalition for Community Choice (CCC), which seeks to advance policy that increases options and decreases barriers for people with IDD.

In some circles, voices of loved ones and guardians on behalf of those who cannot speak, or lack capacity, are peremptorily dismissed. Such opinions are deemed worthless, as guardianship for those who lack

capacity is attacked as unnecessary. In the view of some self-advocates, group homes should be closed; sheltered workshops should be closed; and intentional communities should not be built.¹⁷ For many voiceless people, the chant of “nothing about us without us” has been as empty and paternalistic as the decades of disability policy that preceded it.

If the ADA has any meaning, at the very least it should protect all persons with disabilities— and should not be permitted to be used as a weapon by some against others, less abled than they.

This report concludes that in the end, no one can walk in the shoes of anyone else; therefore the rights and choices of all people must be respected. In order for person-centered support to have any meaning, a full range of actual choices, consistent with well-settled law, must be available. In the arena of disability policy, this means funded choices. The need for well-considered public-private partnerships is all the more evident in a time when Medicaid budgets are stretched and vulnerable lives are already unnecessarily challenged by additional governmental burdens.

¹⁷ Autistic Self Advocacy Network. 2015 Annual Report. N.p.: *Autistic Self Advocacy Network*, n.d. Autistic Self Advocacy Network. Web. 25 Jan. 2017. <<https://autisticadvocacy.org/wp-content/uploads/2015/12/ASAN-2015-Annual-Report.pdf>>.

Ideologues have long argued that their insistence on full inclusion for all people in all environments is based on decades of research. Yet the studies they cite in their articles and briefs do not support this conclusion. Some compare outcomes for intellectually and developmentally disabled adults who moved from giant institutions into community settings – effectively using snakepits like Pennhurst and Willowbrook as a baseline to which integrated housing is compared, even though nobody in this debate is arguing for a return to such facilities. Other studies fail to distinguish among different types of larger settings, such as clustered housing, intentional communities, and state-run, residential campuses. Those researchers that did examine the differences among these models actually found that intentional communities and supported, clustered housing out-performed dispersed settings on several important indicators, particularly in the social connectedness of residents (findings not mentioned by inclusion zealots like the Autistic Self Advocacy Network (ASAN), the American Association of University Centers on Disabilities (AUCD) and the American Association on Intellectual and Developmental Disabilities (AAIDD) in their briefs on integrated settings). Finally, many studies purporting to tie better outcomes to smaller settings fail to consider residents’ level of impairment. One thing research has consistently shown is that higher degrees of intellectual disability, lower levels of adaptive functioning and increased amounts of challenging behavior are all strongly correlated with low levels of choice-making and overall poorer outcomes, no matter the residential setting.

Lutz, Amy S.F., summarizing, "Ideology, Not Data: Studies Fail to Create the Case Against Intentional Communities." Psychology Today. Sussex Publishers, LLC, 22 Jan. 2017. Web. 25 Jan. 2017.
(See Appendix)

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McConkey, R. "Variations in the Social Inclusion of People with Intellectual Disabilities in Supported Living Schemes and Residential Settings." Journal of Intellectual Disability Research, 2007, Vol. 51, part 3, 207-217.

Today I read of the devastation left by tornados in the Midwest. As so often the case and so baffling is that while one house is obliterated, the house next to it is relatively unscathed, only missing some siding or a roof. Man cannot yet explain why disaster chooses to land in some homes but bypasses others. Wouldn't we be appalled, however, if someone who was fortunate enough to sidestep such a loss—perhaps only suffering only damage to their shingles-- said to a grieving family, who lost their home..."Look, you're not really suffering- a tornado isn't that bad..."

Yet, some members of the Autism Community think nothing of telling my family we are not suffering, my brother is not suffering because they have an amazing quality of life and are able to tour the country telling others like them— "Autism is great"! I can honestly say, I am glad they just lost a shingle. But I am sad my brother, and others like him, have had parts of their lives and dreams destroyed by a disabling kind of autism. I would not wish that tornado of profound and severe Autism on anyone. I would not want anyone to feel the fear and sadness every time I think of my non-verbal stimming brother's inability to let me know if he is in pain, being abused or is simply lonely. Standing in the ruins, feeling my brother's ache and looking up at your mostly intact house-I am allowed to say "In my house, Autism is a disaster."

-Laurie Schraml, Sibling/Advocate, Daughter of Autism Advocacy Pioneer, Phoenix, AZ



Andrew and Ben Swanson

I am the proud parent of 28-year-old identical twin boys: Andrew, an adult with autism and Ben, who is neurotypical (i.e. he has strictly typical neurology). When diagnosed at age 2, my husband and I embarked on a pathway of extensive therapies to help Andrew meet the same developmental milestones as Ben. As years passed, we started to accept Andrew's limitations and at age 12 made the extremely painful decision to remove him from inclusionary academics into a functional life skills program. Although we felt as if we had given up on Andrew, once he was in this environment with true peers and given the necessary supports for success in the classroom, he flourished and became a content and happy young boy. It became clear that this choice was Andrew's and helping him make correct choices meant accepting the realities of his disability.

I have parented identical twin boys whose abilities to live freely in the community of their choice as adults are literally worlds apart. Andrew lives with us while Ben lives and works in China. I would give all that I own to have Andrew capable of this life. But, I have had to accept this reality: he will need help for even the simplest of daily tasks for the rest of his life. Despite what I want for him, I can no more change his intellectual capabilities than a parent of a paralyzed child can ask that child to get up out of their wheelchair and walk.

I now embark on the next milestone in Andrew's life. As I help Andrew find an appropriate living situation outside our home there is yet another reality: a divide among people and families of those with disabilities on how to define community. Does community mean full inclusion or can community be an intentional community living beside peers all of whom require some type of daily support? Some say full inclusion is the only choice and for those who can advocate for themselves and whose needs are best served with full inclusion this choice should be afforded them. Andrew's choice was made years ago and his is an intentional community. He is at his best when he is with his peers and his greatest independence comes only with the necessary supports that allow him to do the things he wants. Just as I discovered years ago, it is in the true acceptance of a person's disability that their true ability is achieved. I will continue to advocate and fight for my son's right for what I know to be his choice. This is not because of fear or for ease of my own life. I am his mother. This is what I know.

-Pat Swanson, Mother, Advocate, Nurse, Wilmington, DE

3. The Past is Prologue

In the past century individuals with all disabilities in the United States were often hidden away. In more recent times, they were routinely institutionalized, denied education and subject to discrimination in employment, housing, transportation and many other aspects of daily life. But advocates, self-advocates and supportive family members have been tenacious in their efforts to bring about change, and much progress has been achieved.

The Medicaid funds are generally recognized as the “lion’s share” of lifetime support due to the costs of ongoing support for persons with IDD.

The IDD population, by virtue of their disabilities, requires much assistance. Governmental assistance has followed a number of paths and programs over the decades as people with IDD have struggled to find their ways into the “least restrictive, most appropriate” residential setting. There are various governmental programs and funding streams, but none are more important than Social Security and Medicaid. Supplemental Security Income (“SSI”) and Social Security Disability Insurance (“SSDI”) represent a cash subsidy that may be applied towards essentials, such as food, clothing and housing. Medicaid dollars are used for ongoing care of the person: the necessary supports to facilitate daily living. **The Medicaid funds are generally recognized as the “lion’s share” of lifetime support due to the costs of ongoing support for persons with IDD.**

a) Road to Current Services

As stated on the Medicaid website, “Medicaid, an entitlement program authorized by Title XIX of the Social Security Act was signed into law in 1965 by President Lyndon B. Johnson and was designed to help states meet the costs of health care for low-income and medically needy populations including those with

disabilities. All states, the District of Columbia, and the U.S. territories have Medicaid programs and although the Federal government establishes certain parameters for all states to follow, each state administers their Medicaid program differently, resulting in variations in Medicaid coverage across the country.”¹⁸

When first enacted, Medicaid’s main purpose was to cover primary and acute health care services, such as doctor visits and hospital stays. Individuals with any disability who needed LTSS had no other choice but to be

admitted to a skilled nursing facility (SNF). In 1971, section 1905(d) of the Social Security Act offered another option that specialized in the LTSS of individuals with IDD by creating what is now referred to as Intermediate Care Facilities for individuals with IDD (ICF-ID). This allowed any state-run institutional setting with 4 or more beds who agreed to convert to ICF-ID to receive matching federal funds. Obligatory compliance with new federal regulations created a market for privately run ICF-ID’s.

Even with the establishment of multiple service delivery options, individuals with IDD were still forced into institutional facilities in order to access services and did not have access to LTSS to live in the greater community. As a result of tremendous advocacy efforts, in 1981 Congress authorized the HCBS waiver.¹⁹ This literally “waived” the requirement of access to Medicaid funding in

¹⁸ "Program History." *Medicaid.gov*. Centers for Medicare & Medicaid Services, n.d. Web. 25 Jan. 2017. <<https://www.medicaid.gov/about-us/program-history/index.html>>.

¹⁹ "Medicaid: A Timeline of Key Developments." *Kaiser Family Foundation*. The Henry J. Kaiser Family Foundation, n.d. Web. 28 Jan. 2017. <<https://kaiserfamilyfoundation.files.wordpress.com/2008/04/5-02-13-medicaid-timeline.pdf>>.

an institutional setting, providing individuals with disabilities the option to receive LTSS in the community — whether it be in their family home, a group home, an adult foster home or in their own home.

HCBS waiver is the single most important public benefit available to individuals with IDD in order to maintain access to their community.

In 2000, for the first time since the 1981 implementation of the waiver program, total HCBS waiver funding surpassed ICF-ID funding. In 2014, 53% of all Medicaid long term care spending was on HCBS.²⁰ The HCBS waiver is the single most important public benefit available to individuals with IDD in order to maintain access to their community.

States are responsible for developing waivers to meet the needs of specific populations and their projected needs (e.g. HIV patients, traumatic brain injury, elder care, IDD, etc.) A determination of disability, however, is only the first step in securing public assistance for LTSS. Significantly, not everyone with an IDD qualifies for Medicaid. Because Medicaid is administered jointly by the federal and state governments, every state sets its own eligibility requirements to qualify for support services as well as determines the support services available in various HCBS waiver options in that specific state.²¹

A state may implement an infinite amount of HCBS waivers as long as they are approved by

the Centers for Medicaid & Medicare Services (CMS); funding costs are shared in varying negotiated proportions by the state and federal governments. Currently, there are more than 300 HCBS Section 1915(c) waiver programs active nationwide.²²

State HCBS Waiver programs must:

- Demonstrate that providing waiver services won't cost more than providing services in an institution;
- Ensure the protection of peoples' health and welfare;
- Provide adequate and reasonable provider standards to meet the needs of the target population; and
- Ensure that services follow an individualized and person-centered plan of care.²³

HCBS funding can be used in home settings that are either "consumer-controlled" or "provider-controlled."

In a provider-controlled setting, the home and one's support services are inextricably tied. If the relationship begins to strain, it is the individual with IDD that must move from the home to access support services from a different provider. In many circumstances, the individual with IDD can be asked to leave upon the provider's request regardless of how the person with IDD feels about the decision.

²⁰ United States Of America. Centers for Medicare & Medicaid Services. U.S. Department of Health and Human Services. *Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2014: Managed LTSS Reached 15 Percent of LTSS Spending*. By Steve Eiken, Kate Sredl, Brian Burwell, and Paul Saucier. Princeton: Mathematica Policy Research, Inc., 2016. Print.

²¹ Zaharia , Ric, and Charles Moseley. *State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants*. New Brunswick: Rutgers Center for State Health Policy , 2008. Print.

²² State Waivers List. *Medicaid.gov*. N.p., n.d. Web. 25 Jan. 2017. <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/waivers_faceted.html>.

²³ "Home & Community-Based Services 1915 (c)." *Medicaid.gov*. Centers for Medicare & Medicaid Services, n.d. Web. 25 Jan. 2017. <<https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html>>.

In a consumer-owned or controlled setting, the individual with IDD rents or owns the home and they choose their LTSS provider and roommates. The funding follows the individual, not the service agency or provider. The separation of one's home from their LTSS provider allows for more housing choices and flexibility in choosing a provider. Residents cannot be asked to relocate, and more importantly, they can request that their provider or roommate vacate if the relationship is no longer supportive.

Once the government no longer required Medicaid supported services to be given in institutions, it was slowly recognized that many previously served institutionally could in reality be supported in their homes and communities, preserving their independence and bonds to family and friends, at a cost much less than institutional care.

b) Who is Being Served?

The Developmentally Disabled Assistance and Bill of Rights Act and the Rehabilitation Act of 1973 was inadequate to secure opportunities and access to community living for citizens with disabilities. It was not until 1990 with the passing of the Americans with Disabilities Act (ADA) that the nation first addressed in comprehensive legislation a civil rights law

Some regard the passing of the HCBS waiver program as the immediate impetus for the passing of the Americans with Disabilities Act of 1990 (ADA) and the disability rights movements today.

prohibiting discrimination in employment, public services, public accommodations, and telecommunications on the basis of disability.²⁴ It is critical to recognize that

²⁴ Americans With Disabilities Act of 1990. 42 U.S.C. §12101 et seq., (2006), as amended by ADA Amendments Act of 2008 (P.L. 110-325) (2009)

disability under the ADA encompasses ALL types of disabilities, including conditions that affect the general population, such as migraines, vision and hearing impairments and mobility disorders, as long as it substantially limits one or more "major life activities." 42 U.S.C. §12102.

The Developmental Disabilities Assistance and Bill of Rights Act was amended in 2000 ("DD Act") to define "developmental disability" as a severe, chronic disability of an individual that:

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

- (I) Self-care.
- (II) Receptive and expressive language.
- (III) Learning.
- (IV) Mobility.
- (V) Self-direction.
- (VI) Capacity for independent living.
- (VII) Economic self-sufficiency; and

(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated."²⁵

Today, although estimates vary greatly, nearly 5 million US citizens have an IDD such as autism, Down Syndrome, Prader-Willi

²⁵ 42 U.S.C. § 15002(8)(2006).

Syndrome, fetal alcohol syndrome, and other disorders that occur during the developmental period (birth to age 18).²⁶ The abilities of these individuals range from those who can live alone with drop-in supports to those needing 24x7 assistance to ensure they do not injure themselves or others; all have some level of impairment that prohibits them from navigating the many intricacies of planning and executing daily life activities independently.

People with IDD accounted for 41% of HCBS waiver enrollment in 2012, but 72% of spending on waiver services was devoted to this population

As there is significant diversity within the population of citizens with IDD, the right to a home and supports in the community that are equally diverse must be determined by a realistic assessment of an individual's physical, medical and intellectual abilities and lifestyle preferences. This much is clear, however: there exists within the population of those adults with IDD a significant sub population of people with moderate to profound intellectual impairments. "People with IDD accounted for 41% of HCBS waiver enrollment in 2012, but 72% of spending on waiver services was devoted to this population, again reflecting their more intensive need for LTSS relative to other groups."²⁷ Although comprehensive data

²⁶ Braddock, David, Richard Hemp, Mary C. Rizzolo, Emily Shea Tanis, Laura Haffer, and Jiang Wu. *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. Publication. 10th ed. Washington D.C.: American Association on Intellectual and Developmental Disabilities, 2015. Print. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado in collaboration with the Department of Disability and Human Development, University of Illinois at Chicago

²⁷ Ng, Terence, Charlene Harrington, MaryBeth Musumeci, and Petry Ubri. *Medicaid Home and Community-Based Services Programs: 2013 Data Update*. Rep. Washington D.C.: The Kaiser Commission on Medicaid and the Uninsured, 2016. Print.

is lacking, there are some snapshots of the IDD population currently spending Medicaid dollars for LTSS, and their needs are significant:

1. Approximately 40% require support to assist in the management of disruptive behaviors;²⁸
2. Approximately 50% take medication for psychiatric issues;²⁹ and
3. 50% are assessed to have IDD impairments ranging from moderate to profound.³⁰

In order to understand the residential needs and preferences of autistic adults, Autism Speaks surveyed family caregivers to better understand the hours of support needed for individuals on the autism spectrum. Over 77% of autistic adults need at least a few hours of daily supports. Approximately 35% require 24x7 support.³¹

The services needed for independent living will range not only in type but in duration and cost. While person centered planning is a giant step forward³², it in itself does not remove the

²⁸ Human Services Research Institute (HSRI), The National Association of State Directors of Developmental Disabilities Services (NASDDDS). *National Core Indicators*. N.p., n.d. Web. 26 Jan. 2017. <<http://www.nationalcoreindicators.org/charts/>>.

²⁹The proportion of people who currently take medications to treat mood disorders, anxiety and/or psychotic disorders: 49%; The proportion of people who currently take medications to treat behavior problems: 26%. Ibid.

³⁰Level of ID: 5% n/a, 36% Mild, 28% Moderate, 12% Severe, 10% Profound, 9% unspecified/unknown. Moreover, the proportion of people who have participated in a self-advocacy group meeting, conference, or event is only 27%. Ibid.

³¹ *National Housing and Residential Supports Survey*. Executive Summary. Washington D.C.: Autism Speaks, 2013. Print. Partnered with SIS International Research to develop and execute the survey.

³² The CMS HCBS Final Rule requires a specific set of person-centered planning procedures and documentation to ensure every person who uses a HCBS waiver has a leadership role in the development of their individualized person-centered plan. The intent is that HCBS supports will follow the trajectory as stated in this plan. Cornell University's Employment and

many barriers that disabled individuals with IDD face. Without funding for systemic supports needed, this vulnerable group of citizens will never be fully integrated into the greater community.

c) The Promise of Olmstead

Of most significance to the future of LTSS for individuals with IDD was the 1999 Supreme Court's opinion in Olmstead.

(2) the affected persons do not oppose community-based treatment; and

(3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.

"The identification of unjustified segregation as discrimination reflects two evident

The Olmstead decision arose from the advocacy of two Georgia women, Lois Curtis and Elaine Wilson. They both lived with mental illness and developmental disabilities and were voluntarily admitted to a psychiatric unit in the State-run Georgia Regional Hospital. When treatment completed, mental health professionals approved the women's return to their community, but the state refused to provide the essential life supports needed for them to do so. They remained institutionalized for years and finally filed suit under the ADA. On June 22, 1999, the United States Supreme Court held in Olmstead v. L.C. that these two women were unjustifiably segregated against their will and that the state of Georgia discriminated against them by refusing to provide community-based services, thus forcing them to remain institutionalized.

The Supreme Court in Olmstead determined under Title II of the ADA that "unnecessary institutional segregation constitutes discrimination per se, which cannot be justified by a lack of funding."³³ In other words, Georgia could not justify involuntary institutionalization by withholding essential community-based services to persons with disabilities when:

(1) such services are appropriate;

judgments: Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life, cf., e.g., Allen v. Wright, 468 U.S. 737, 755; and institutional confinement severely diminishes individuals' everyday life activities."³⁴

The Supreme Court clearly intended to preserve the rights of persons with IDD to access a range of support service options appropriate to their needs, including institutional placement if and where the needs of an individual so required. Justice Ginsburg's opinion states, "We emphasize that nothing in the ADA or its implementing regulations condones termination of

Disabilities Institute describes person-centered planning as "... a process-oriented approach to empowering people with disability labels. It focuses on the people and their needs by putting them in charge of defining the direction for their lives, not on the systems that may or may not be available to serve them. This ultimately leads to greater inclusion as valued members of both community and society."
<http://www.personcenteredplanning.org/>

³³ OLMSTEAD v. L. C., 527 U.S. 581 (1999). *Cornell University Law School*. Legal Information Institute, n.d. Web. 26 Jan. 2017. <<https://www.law.cornell.edu/supct/html/98-536.ZS.html>>.

³⁴ OLMSTEAD v. L. C., 527 U.S. 581 (1999). *Cornell University Law School*. Legal Information Institute, n.d. Web. 26 Jan. 2017. <<https://www.law.cornell.edu/supct/html/98-536.ZS.html>>.

institutional settings for persons unable to handle or benefit from community settings.” A plurality of Justices noted:

“No placement outside the institution may ever be appropriate . . . ‘Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times-perhaps in the short run, perhaps in the long run-for the risks and exposure of the less protective environment of community settings’ for these persons, ‘institutional settings are needed and must remain available’” (quoting Amicus Curiae Brief for the American Psychiatric Association, et al).³⁵

“As already observed by the majority, the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... ‘Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution’ Similarly, Justice Kennedy states in concurrence that:

“It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision... In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the

³⁵ Opinion of the Court: OLMSTEAD v. L. C., 527 U.S. 581 (1999) Cornell University Law School. Legal Information Institute, n.d. Web. 26 Jan. 2017. <<https://www.law.cornell.edu/supct/html/98-536.ZO.html>>.

services and attention necessary for their condition.”³⁶

d) Barriers to Community Living

Despite the promise of Olmstead, there remain a number of significant barriers to successful community inclusion, largely stemming from the financial hardships people with IDD suffer.

1) HCBS Waivers Are Very Difficult to Obtain in A World of Shrinking Resources

Unavailability of HCBS supports and services that they provide are the greatest limitation and barrier to the potential of our citizens with IDD. 86% of individuals with IDD do not have access to an HCBS waiver.³⁷ For those fortunate enough to receive waiver services, these supports range from comprehensive, giving access to independent community living, to limited assistance for families in supporting their loved one in the family home. **Only 11% of the total population of individuals with IDD have access to an HCBS waiver that covers the comprehensive support needed to live in a home other than their family home.**³⁸ Even if a person can clearly articulate their independent living goals and necessary support staff to access their

³⁶ Kennedy, J., concurring in judgment OLMSTEAD v. L. C., 527 U.S. 581 (1999) Cornell University Law School. Legal Information Institute, n.d. Web. 26 Jan. 2017. <<https://www.law.cornell.edu/supct/html/98-536.ZS.html>>.

³⁷ Braddock, David, Richard Hemp, Mary C. Rizzolo, Emily Shea Tanis, Laura Haffer, and Jiang Wu. *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. Publication. 10th ed. Washington D.C.: American Association on Intellectual and Developmental Disabilities, 2015. Print. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado in collaboration with the Department of Disability and Human Development, University of Illinois at Chicago

³⁸ Braddock, Et al. "PERSONS SERVED BY SETTING: FY 2000-2013." *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. 10th ed. N.p.: American Association on Intellectual and Developmental Disabilities, n.d. N. pag. *The State of the States in Developmental Disabilities: University of Colorado*. Web. 26 Jan. 2017. <<http://www.stateofthestates.org/documents/UnitedStates.pdf>>.

Jorge was lucky enough to get a Housing Choice Voucher and move into his very own apartment. He quickly became friends with a young woman next door who drove a white corvette with red leather interior. They liked to talk about sports cars. One day she asked him if he would like to trade his car for her sports car. Very excited, he said he would love to. She said that since she was a friend, she would do all the paperwork for him. The next day, he signed a Bill of Sale to purchase her 1984 Corvette by trade of his 2011 F-150 truck his father left him when he passed away. The actual value of his truck was around \$18,000, and the value of his new corvette was less than \$5,000. When he arrived at the bowling alley to show off his new sports car to his bowling club team, one of the members told him the difference in value of the two cars. Furious, he left to approach his neighbor about the trade. He confronted her and was beaten up by her boyfriend and his friends while she watched. Needless to say, he was afraid to leave his apartment anytime he saw that F-150 in the parking lot.

community, without funding to hire adequate support help, implementation of their person-centered plan is impossible.³⁹

2) Nationally There Is a Lack of Affordable, Accessible Housing

Even with HCBS waiver supports, one cannot live in the community if one cannot afford a home. For decades, access to community living for persons with IDD has been associated with provider-owned and controlled homes, widely known as group homes. As a result, affordable housing systems have not been developed to meet the growing needs of the IDD population. Despite President Obama's Executive Order 13548 - Increasing Federal Employment of People with Disabilities⁴⁰, individuals with disabilities continue to have the significantly higher rates of unemployment.⁴¹

³⁹ See Appendix-- Barriers to Community Living

⁴⁰ 75 Fed. Reg. 146 (July 30, 2010); <https://www.gpo.gov/fdsys/pkg/FR-2010-07-30/pdf/2010-18988.pdf>

⁴¹ Bureau of Labor and Statistics, Table A-6. Employment status of the civilian population by sex, age, and disability status, not seasonally adjusted. Comparing 2015 and 2016 year-end. < <https://www.bls.gov/news.release/empstat.t06.htm>

When specifically addressing employment of individuals with IDD, the unemployment rate skyrockets to 80% despite 49% stating they would like to work. For those who work in the community, 78% earn less than \$600 a month.⁴² Citizens with IDD have the highest rate of unemployment, and thus the highest poverty rates as well. This group of vulnerable citizens is within the population considered "worst-case needs", a growing population whose primary sources of income is often only SSI (max. \$733 a month) or SSDI (avg. \$832 a month).⁴³

Furthermore, the nature of one's IDD may render a certain type of housing inaccessible. An adult on the autism spectrum with heightened sensory perception may experience extreme pain or anxiety at the sound of honking cars or sirens of first

⁴² Human Services Research Institute (HSRI), The National Association of State Directors of Developmental Disabilities Services (NASDDDS). National Core Indicators. N.p., n.d. Web. 26 Jan. 2017. <<http://www.nationalcoreindicators.org/charts/>>.

⁴³ U.S. Department of Housing and Urban Development. Office of Policy Development and Research. *Worst Case Housing Needs: 2015 Report To Congress*. By Berry L. Steffen, George R. Carter, Marge Martin, Danilo Pelletiere, David A. Vandenbroucke, and Yunn-Gann David Yao. U.S. Congress, Apr. 2015. Web. 28 Jan. 2017. <https://www.huduser.gov/portal/Publications/pdf/WorstCaseNeeds_2015.pdf>.

responder vehicles. They may bolt out of the home trying to escape the sound and run into traffic because they do not understand the difference between the safe space of a sidewalk and the street. The variable and unpredictable city environment can cause severe anxiety in some individuals who will isolate themselves in their home rather than face the bombardment of sensory input of the urban epicenter.

i. Behavior Leading to Eviction

Some individuals cannot live in apartments or townhouses as the habits of their lives may be disruptive to neighbors. For example, pacing, shrieking or jumping repeatedly in their home is a necessary coping skill that unfortunately can be quite disruptive to a neighbor who lives downstairs. They could be cited and evicted for repeated noise disruptions. If a contractor must be called multiple times to repair holes in the wall as a result of an individual's meltdowns, one's lease could be terminated for destruction of property.

ii. Discrimination

For the past five years of data collection, the department of Housing and Urban Development ("HUD") Annual Report on Fair Housing finds discrimination against persons with disabilities the leading cause of complaints, tipping over half of all complaints at 59% in FY2016.⁴⁴ Higher than any other minority, discrimination against people with disabilities is a major barrier to affordable, accessible housing.

⁴⁴ U.S. Department of Housing and Urban Development. Office of Fair Housing And Equal Opportunity. *Office of Fair Housing And Equal Opportunity Annual Report to Congress: FY 2016*. U.S. Department of Housing and Urban Development, 19 Jan. 2017. Web. 28 Jan. 2017. <<https://portal.hud.gov/hudportal/documents/huddoc?id=FY2016FHEOAnnualReport.pdf>>.

iii. Predatory Relationships

Many individuals with IDD have difficulty recognizing predatory relationships of platonic or romantic nature. This type of crime occurs when an individual with IDD is manipulated, taken advantage of or coerced by someone they consider a friend or romantic partner and is more commonly known as 'mate-crime.' In a UK study carried out by the National Autistic Society in 2014, 49% said they had been abused by someone they thought of as a friend, 37% believed a friend had forced or manipulated them into doing something they did not want to, and 27% have had money or possessions stolen by a friend. In a more recent report from the Wirral Autistic Society, a staggering 80% of respondents over the age of 16 believed they had been bullied or taken advantage of by a friend and a third of adults said that they had been subject to bullying or manipulation of a sexual nature.⁴⁵

3) There is an Inadequate Workforce of Direct Support Professionals (DSP)

Imagine wholly relying on other people to help coordinate one's schedule, plan and prepare meals, attend doctors appoints, or assist in dressing and bathing. In the course of a week, over 10 sets of hands may touch someone with an IDD, 10 different voices may update them about their home life when not at work, and those 10 people have learned to understand the unique communication and preferences of those they support. What if one of those 10 people must quit? If one has a self-directed waiver, someone must recruit, interview and train the new staff person while trying to balance the staff shifts. If one lives in a provider controlled setting, the agency will take care of staffing, but the individual being

⁴⁵ Wirral Autistic Society. N.p.: Wirral Autistic Society, n.d. *Mate crime in Merseyside*. Wirral Autistic Society, July 2015. Web. 28 Jan. 2017. <<http://www.autismtogether.co.uk/wp-content/uploads/2015/07/WAS-mate-crime-report-June-2015.pdf>>.

supported will not have much authority over who is chosen. **The quality and quantity of direct support professionals may be the most important influence on community participation and the quality of life for a person with IDD.**

With a national average hourly wage of \$10.11 that has decreased over the past 10 years when adjusted for inflation, recruiting and retaining direct support professionals is challenging. **Statistics reveal that 50% of Direct Support Professionals rely on some form of public assistance and 1 in 4 live in poverty.**⁴⁶ The lack of benefits offered, little to no career advancement opportunities, and opportunities to work in less physically and emotionally demanding environments for the same pay leads to high turnover of staff. Retention of quality staff who enjoy and are passionate about supporting individuals with IDD in the community is difficult if they cannot make a living wage.⁴⁷

4) There is Limited Access to Relationships

Just because one lives in the community, one does not automatically have friends or support. One's geographic location does not inevitably create meaningful community access. The movement toward community living is based on a mistaken premise that if individuals with IDD have physical access to their community, they will form the necessary relationships to actually become part of it. In the over 35 years since HCBS waivers offered

⁴⁶ *U.S. Home Care Workers: Key Facts*. Rep. Paraprofessional Healthcare Institute, Sept. 2016. Web. 28 Jan. 2017. <<http://phinational.org/sites/phinational.org/files/phi-home-care-workers-key-facts.pdf>>.

⁴⁷ Even more of a challenge is finding service providers or direct support professionals who are committed to supporting adults with IDD who have high support needs. Adults with IDD may not be able to use the bathroom independently, may communicate through behavior that is dangerous to themselves or others, may have medical support needs, or may have socially challenging behaviors such as spontaneous undressing, fondling of oneself, or repetitive spitting.

access to community living, data shows that individuals with IDD are still lonely and do not participate in the greater community to the same extent as neurotypicals.⁴⁸ To realize the intent behind the community living movement, a culture of access must permeate the community, and that can only occur with increased access to neurodiverse relationships.

The University of Miami Center for Autism and Related Disabilities surveyed their constituents to find out what exactly were the barriers to community participation. They realized that not having a supportive companion, transportation, lack of activities and cost were the biggest barriers to participating in their community⁴⁹. Research from Drexel University found that adults on the autism spectrum are more likely than others with IDD to be disconnected from their community.⁵⁰

5) Abuse and Neglect are Continuing and Significant Problems

Unfortunately, abuse of people with IDD did not end with deinstitutionalization. **Over half of the IDD population have been victims of abuse, more than any other sub-population with disabilities, and this rate is increasing as**

⁴⁸ "NCI Charts: The proportion of people who feel lonely." National Core Indicators. N.p.: n.p., n.d. N. pag. NCI Chart Generator. Web. 28 Jan. 2017. <<http://www.nationalcoreindicators.org/charts/?i=107>>.

⁴⁹ An online survey of approximately 200 families of transition-age and adult constituents with ASD in southern Florida. 2008. Raw data. University of Miami/Nova Southeastern University Center for Autism and Related Disabilities, Miami-Dade and Broward County.

⁵⁰ Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy A. *National Autism Indicators Report: Transition into Young Adulthood*. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

reported with data from the Bureau of Justice Statistics.⁵¹

Moreover, this abuse can continue for years when the victim is an individual who does not have capacity to communicate or recognize that he or she are victims. Research shows that only 10% of alleged perpetrators are arrested.⁵²

Abuse of persons with IDD can be physical, emotional, financial, or sexual in nature. A 2012 national survey of the Disability and Abuse Project found that 63% of individuals with IDD have been victims of abuse and that 1 in 3 individuals on the autism spectrum will be the victim of abuse.

6) Cost Containment and Olmstead Violations

It should come as no surprise that there is not enough public funding allotted in state and federal budgets to meet the LTSS needs of everyone who has a disability of any kind. This amount was more than four times higher than average waiver spending on both aged (\$11,490) and aged or disabled (\$11,834) waiver participants.⁵³

Lack of state and federal funding results in the use of cost containment strategies such as eligibility criteria based on assessed functional limitations, finances, limiting services within waivers, spending caps, and the use of waiting

lists.⁵⁴ These cost containment strategies may be a financial reality but it is difficult to balance exactly when these strategies violate the protections of Olmstead and the ADA. The following strategies are highlighted:

i. Over-Reliance on Family Caregivers

The use of family caregiving as a cost saving mechanism cannot be overstated. Access to community living without public assistance is largely dependent on one's family for financial and direct support. Without waiver funding to provide options, many family members of individuals with IDD must retreat from the workforce once their loved one leaves the school system and loses all daytime support. **Easter Seals *Living with Disability*** study reports that 43% of adult children with disabilities stay at home all day and 90% of family caregivers report they do not receive any financial support or physical support (82%) from family and friends.⁵⁵

The Research and Training Center on Health and Intellectual Disabilities at the University of Illinois is also uncovering the racial disparities to African-American and Latino citizens with IDD and their family caregivers. Latino and African-American citizens with IDD are more likely to live with their families and parents are often involved with caring for as long as they are able. Both African-American and Latino citizens with IDD and their family caregivers are more likely to be in fair/poor health and fair/poor mental health than white citizens with IDD or their family caregivers.⁵⁶

⁵¹ The Arc's National Center on Criminal Justice and Disability (NCCJD). *Violence, Abuse and Bullying Affecting People with Intellectual/Developmental Disabilities*. Rep. Washington, D.C.: The Arc, 2015. Print.

⁵² Baladerian, Nora J., Ph.D., Thomas F. Coleman, and Jim Stream. *Abuse of People with Disabilities: Victims and Their Families Speak Out*. Rep. Spectrum Institute Disability and Abuse Project, 2013. Web. 28 Jan. 2017. <<http://disability-abuse.com/survey/survey-report.pdf>>.

⁵³ <http://files.kff.org/attachment/report-medicare-home-and-community-based-services-programs-2012-data-update>

⁵⁴ Ng, Terence, Charlene Harrington, MaryBeth Musumeci, and Petry Ubrí. *Medicaid Home and Community-Based Services Programs: 2013 Data Update*. Rep. Washington D.C.: The Kaiser Commission on Medicaid and the Uninsured, 2016. Print.

⁵⁵ *Ibid.*

⁵⁶ Magaña, Sandy, and Miguel Morales. "Racial and Ethnic Disparities Among Adults with IDD and their Family Caregivers." Research and Training Center on Health and Intellectual Disabilities. University of Illinois at Chicago. 22 Sept. 2016.

The stress of caring for some people with significant IDD can be devastating to everyone, especially so when critical supports are not provided. Sadly, that point may only be recognized when a tragedy occurs. Headlines tell of horror stories of caregivers who have taken the lives of loved ones, and themselves, when hope was gone.⁵⁷ Many times, these individuals are disconnected from their community and support networks. March 1st has been informally declared the Disability Day of Mourning. A running catalogue describes details of over 500 people with disabilities in the US who were intentionally killed by family members.⁵⁸

Supporting families to keep individuals with IDD in their family home is an important choice, but it has ceased to be a choice when it has turned into the only option for many individuals. Without access to enough LTSS to live outside of the family home, individuals with IDD may be forced to stay in family homes long after care is competent, or in extreme cases, is abusive; be forced to become a ward of the state to access supports; be shuttled into adult foster care or be admitted into an institution after a crisis intervention.

ii. The Smoke and Mirrors of the “Waiting Lists”

Being placed on a waitlist for services or accepting less than comprehensive supports is common as there is not enough funding for

Family Support Research and Training Center, University of Illinois at Chicago. Web. 28 Jan. 2017.
<http://fsrtc.ahslabs.uic.edu/wp-content/uploads/sites/9/2016/10/Racial-and-Ethnic-Disparities-Presentation_9-22-16.pdf>.

⁵⁷ Himmelman, Jeff. "Four Bodies in Elmhurst." *New York Times Magazine* 2 Dec. 2015: n. pag. Print; <https://www.nytimes.com/2015/12/06/magazine/four-bodies-in-elmhurst.html>

⁵⁸ "Category: Location: USA." Disability Day of Mourning. Disability Day of Mourning, n.d. Web. 28 Jan. 2017.
<<http://disability-memorial.org/category/location/usa>>.

everyone who qualifies to have access to the supports and services they need to live in the community.

Kaiser reports that in 2014, the average time spent on a waiting list after being found eligible is 47 months for IDD waivers, nearly 4 years⁵⁹, yet even this can be misleading. First, some states do not even maintain a “waiting list,” despite the fact that people are waiting for services. Moreover, getting “off” the waiting list does not mean that an individual gets all the services they need. For those who have access to a waiver, the amount of services afforded each person varies greatly from state to state, based on state-assessed need, access to providers who can support individuals with high behavioral or medical supports, and the waiver offerings services provided within that state. This sets up **inequality of services** among people with similar needs who may or may not have the money or knowledge to challenge eligibility or service determinations.

4. A Poor Federal Response: Regulate Away Choice and Develop Adult Foster Care

In response to the burgeoning population and the crippling of the LTSS support system, federal policymakers have adopted non-institutional strategies to address the need. However, these strategies are woefully inadequate.

a) New CMS Regulations and Guidance of HCBS Waivers

Following multiple rounds of public comment over the course of 6 years, CMS released the

⁵⁹ Henry J Kaiser Family Foundation, The Kaiser Commission on Medicaid and the Uninsured. “Medicaid Home and Community Based Services Programs: 2012 Data Update” at 11, Rep. N.p.: n.p., n.d. Print; <http://files.kff.org/attachment/report-medicaid-home-and-community-based-services-programs-2012-data-update>

federal HCBS Final Rule in January 2014. According to the Final Rule, in order for individuals with IDD to use their HCBS waiver in settings that are consumer-controlled (private-residences), the following requirements must be met as well as any additional state regulations:⁶⁰

- The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.
- The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting.
- The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board.
- Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.
- Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

⁶⁰ 42 C.F.R. § 441.301(c)(4)-(5)(2014); <https://www.medicaid.gov/medicaid/hcbs/downloads/requirements-for-home-and-community-settings.pdf>

- Facilitates individual choice regarding services and supports, and who provides them.⁶¹

States are required to revise their state regulations and ensure all settings where individuals with IDD use HCBS waivers comply with the Final Rule by March of 2019.

In March 2014, just two months after the release of the Final Rule, CMS began publishing guidance on the CMS website as the “Setting Requirements Compliance Toolkit” regarding implementation of the Final Rule.⁶² Several pieces of CMS guidance have created barriers to the expansion of housing and support opportunities as state leaders fear federal withholding of Medicaid reimbursement for being non-compliant. The following guidance documents have never been released for public comment and are putting existing and future settings desired by individuals with IDD at risk:

- i) Settings that tend to isolate

Guidance entitled, *GUIDANCE ON SETTINGS THAT HAVE THE EFFECT OF ISOLATING INDIVIDUALS RECEIVING HCBS FROM THE BROADER COMMUNITY*⁶³, provides that if a state government or CMS determines a setting to be “isolating”, the setting will be considered to have institutional characteristics and individuals with IDD will not be able to use their HCBS waiver in that setting. **Specific**

⁶¹ There are also additional enumerated requirements for settings that are provider controlled. Ibid.

⁶² Guidance, [medicaid.Gov](https://www.medicaid.gov). “Settings Requiring Compliance Toolkit (2014); <https://www.medicaid.gov/medicaid/hcbs/guidance/index.html>

⁶³ Guidance, [medicaid.Gov](https://www.medicaid.gov). “Settings Requiring Compliance Toolkit at “Settings that Isolate” (2014); <https://www.medicaid.gov/medicaid/hcbs/downloads/settings-that-isolate.pdf>

examples of settings CMS cited as isolating include: farmsteads, gated/secured “communities” for people with disabilities, residential schools, and multiple use campuses. In September 2016, at the National HCBS Conference, ‘intentional communities’ were added to the list of settings “isolating individuals.”⁶⁴ This guidance expressly contradicts the intent of the Final Rule which states characteristics of HCBS must be based on outcomes and the experiences of those who live and work in a particular setting.

Following this federal guidance, the state has the authority to withhold waiver funding from an individual with IDD if the state, not the individual with IDD, deems their home to be isolating. This guidance not only lays the foundation for discrimination against persons with IDD, but strips them of dignity and equal citizenship as neurotypical government employees have ultimate authority over their home choices.

ii) CMS Guidance on planned construction of home settings

With the growing emergence of local housing solutions being developed to meet the demand, CMS offered additional guidance on planned construction of housing settings. The document states, **“It was CMS’s expectation that after the publication of the final regulation, stakeholders would not invest in the construction of settings presumed to have institutional qualities.”**⁶⁵ **This reveals a government bias and over-reach into the**

⁶⁴ HCBS Conference, Receiving Final Approval and Heightened Scrutiny, August 2016; Slide 59, https://www.eiseverywhere.com/file_uploads/4ce7cec7c72e5947627df9d02ae604e7_HCBSRegSlides.pdf

⁶⁵ <https://www.medicaid.gov/medicaid/hcbs/downloads/fa-q-planned-construction.pdf>

private sector of housing development. As previous CMS guidance described specific settings ‘that isolate’ and thus have institutional qualities, this guidance is explicitly targeting the government's disapproval of such settings despite demand from individuals with IDD.

Additionally, the guidance stated CMS will not give pre-approval to emerging housing development intended to meet the needs of waiver recipients unless they are fully operational. This undeniably limits the market response and restricts the development of housing options to wealthy families who can afford to private pay for property development and support services until granted CMS approval. **This CMS guidance also halts the development of emerging housing options that rely on financing as lenders will not risk lending money to housing development where the potential residents they aim to serve would be restricted for lack of access to their HCBS waiver.**

As millions of adults with IDD are consigned to live in their family home with another million living with caregivers over the age of 60, any government guidance that thwarts innovation of supportive housing options is fiscally irresponsible and intentionally putting more individuals with IDD at risk of institutionalization, homelessness or worse. This is stifling innovative public private partnerships, as proposed by HFL, to create an affordable housing solution. HFL was so concerned about these developments that a letter was sent to then Vice President Biden that included 35 co-signers outlining these matters.⁶⁶

⁶⁶ Letter from to HFL and others to Vice President Joseph R. Biden, dated July 3, 2016 (included in Appendix).

iii) Validity of CMS regulations and guidance

There has been substantial outcry regarding the CMS regulations and their legitimacy has been questioned.⁶⁷ One very significant point is that the CMS regulations and guidance appear to violate the ADA and the Fair Housing Act insofar as they expressly prohibit the provision of Medicaid services to people who live in disability specific communities.⁶⁸ Whether the regulations are eventually overturned or rescinded, however, at present they constitute a barrier to the construction of an intentional community.

CMS guidance is based on the ableist⁶⁹ assumption that individuals with IDD should prefer integrated, in other words, neurotypical-centric settings and relationships.⁷⁰ As absurd as it may sound, CMS guidance also applies to privately-owned or leased, consumer-controlled housing. In one's family home or a private residence, where an individual chooses to live, pays rent to a landlord unaffiliated with a service provider, and can direct their supports and services, according to CMS guidance the state or federal government has the authority to restrict access to one's HCBS waiver and force the individual with IDD to find another home. If public assistance was threatened to be withheld from other minority communities for preferring to live in proximity, LGBTQ couples, African Americans, and Jewish citizens would rise up and protest with their allies. Unfortunately, most individuals with IDD are

⁶⁷ See Legal Opinion of Covington & Burling ("Legal Opinion") (1/17/2017, attached).

⁶⁸ See Legal Opinion at 9 and cases cited therein.

⁶⁹ "discrimination or prejudice against individuals with disabilities;" Merriam-Webster. Merriam-Webster, n.d. Web. 29 Jan. 2017.

⁷⁰ http://coalitionforcommunitychoice.org/wp-content/uploads/2015/12/CMS-SOTA-Call-Slides-HCBSExcludedSettingsHeightenedScrutiny_F.pdf

not aware that their home or workplaces may be at risk.

iv) State Transition Plans (STP)

After the release of the Final Rule, every state was mandated to draft an STP describing to CMS how they would make changes needed to meet the new standard of the federal CMS Final Regulations. The first draft of STPs were due March 2015 after a period of public comment.

As states released their STPs for public comment, some states ignored the intent of the Final Rule and reverted back to using physical characteristics as parameters for determining what is 'home and community'. Examples include a restriction on farmsteads in Ohio, a 25% density limit of HCBS recipients in multi-family residences in New Jersey, and a 5-person limit in MA housing. In these states, there was an outcry from advocates and many revised their STP to preserve the outcome-oriented intent of the federal regulations. As STPs require CMS approval, CMS guidance has and will continue to have a significant impact on how states will interpret and implement the HCBS Final Rule.

Significantly, each state has responded in different ways. Ohio, for example, pushed back against the "no farmstead" edict by letter dated January 16, 2015 signed by former U.S House Speaker John Boehner, Senator Rob Portman, and thirteen additional U.S. Congressmen.⁷¹

In summary, the CMS HCBS Final Rule was developed after many years of public comment and focuses on "outcome-oriented" criteria and individuals rights to accessing a home and community of their choice further protected by their person-centered plan.

⁷¹ Letter from Speaker John Boehner *et al* to DHSS Secretary Sylvia Burwell, dated January 26, 2015 (see Appendix)

Unlike the final rule, **CMS guidance has not undergone any form of public review**; and is nevertheless now influencing state Medicaid authorities in implementation of the HCBS Final Rule.

b) Shared Living: A New Term for Adult Foster Care for Cost Savings

Written and distributed by the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the Shared Living Guide of 2011 describes a model to support individuals with IDD in the community called Shared Living. The introduction of the report states that Shared Living “... has at its foundation the concept we know as **foster care** – an idea about caring for children that was imported to the colonies from England. But shared living is more than foster care because it also has, as its primary intention, the building of lifelong relationships – based on the foundation of person-centered thinking and self-determination.”⁷²

The Shared Living Guide’s emphasis on increasing supports growing from personal relationships is an important positive change to the service delivery models, yet the following concerns emerge:

- The Shared Living Guide lacks discussion on the shift of systemic standards and accountability to warrant the blending of the terms ‘Adult Foster Care’ and ‘Shared Living’.
- The non-hierarchical expectations of shared living as described in the guide cannot be achieved in an inherently unequal power relationship of a Host Family Home/Adult Foster Care setting.
- Incentives are being used to encourage this cost-saving model.

The Guide suggests Shared Living is not “traditional foster care,” but fails to meaningfully explain how the terms are different in practice.

For example, if individuals with IDD live in a home where the homeowner or family is compensated \$1,500-\$5,000 a month and can ask the individuals with IDD to leave at any time, this relationship is inherently imbalanced. Person-centered planning and self-advocacy skills cannot guarantee that an individual with IDD will be able to live in their home for as long as he/she would like.

In terms of systemic concerns, the Guide describes to state developmental disability agencies that “*shared living must also provide reasonable financial resources to assure stability*” followed by an example of a state promoting financial incentives to make this service delivery model more appealing to providers than other choices an individual with IDD may prefer. The guide states “**the cost is half of that of a group home placement.**”

Indeed, it has been made clear by Nancy Thaler, the former Director of the National association of State Directors of Developmental Disabilities Service (NASDDDS), that shared living /foster care or support in the family home are the two least costly support alternatives. Such analysis, however, takes no consideration of the actual needs of any given individual, the nature and extent of their disability, and assumes that all conditions can be adequately addressed in home care.

⁷² Cooper, Robin, Kara LeBeau, and Nancy Thaler. Shared Living Guide. Alexandria: National Association of State Directors of Developmental Disabilities Services , 2011. Print.

Type of Service	Cost per Person	20 yrs. Cost
ICF/MR Institution	\$128,275	\$2,565,600
HCBS 24hrs. staffed Residential	\$70,133	\$1,402,660
Shared Living (Adult Foster Care)	\$44,122	\$882,440
Supports in Own or Family Home	\$25,072	\$502,440

NASDDDS Cost Comparison Chart⁷³

Changing the terminology from Adult Foster Care (AFC) to Shared Living is a semantic attempt to encourage individuals, families, and service providers to choose a residential model that certainly saves the state money. Some individuals with IDD may thrive in an Adult Foster Care placement, but creating financial incentives that can shift the market in such a way that it limits other possibilities in the future may have **harmful long term consequences**.

For those who choose it, the option can be made viable. The problem is when it is forced upon people in emergency placements, and people with IDD may not have a meaningful voice or choice regarding their new home. Many individuals, especially those who are nonverbal or lack capacity, may not be able to report abuse or neglect. Additionally, the reliance on adult foster care is not a sustainable housing solution. Host homes may soon need to make space for their own aging family members to move in, leaving the adult

⁷³ Thaler, Nancy . Presentation before the President’s Committee for People with Intellectual Disabilities (PCPID). Washington, D.C., 26 Sept. 2011.

with IDD in a housing climate that is nearly impossible to secure.

c) Post Olmstead: A World Where Choice Is an Illusion and The Government “Knows Best”

Despite the express language in Olmstead to preserve person-centered options, policymakers have seized upon the decision to launch a movement of policy changes and enforcement efforts called the “integration mandate.” Most recently in October of 2016, the U.S. Department of Justice (DOJ) released guidance titled ‘*Statement of the Department of Justice on Application of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. to State and Local Governments’ Employment Service Systems for Individuals with Disabilities*’.⁷⁴ This guidance describes the emergence of more integrated options, but disregards an individual’s choice to be supported in a so-called “segregated” option like a sheltered workshop or facility-based day program:

This interpretation by the DOJ assumes that all citizens with IDD who gather together are being “segregated” by government edict or by deprivation of choice. This further assumes that such persons would not prefer or want to live, work or spend time in settings primarily with or alongside other individuals with IDD.

There is no research or data to HFL’s knowledge that demonstrates all individuals with IDD prefer to live, spend time and work alongside neurotypicals over others with IDD. Rather, individual choice is paramount subject to the parameters of Olmstead.

⁷⁴ U.S. Department of Justice. Civil Rights Division. *Statement of the Department of Justice on Application of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. to State and Local Governments’ Employment Service Systems for Individuals with Disabilities*. ADA.gov, 31 Oct. 2016. Web. 28 Jan. 2017. <https://www.ada.gov/olmstead/olmstead_guidance_employment.htm>.

Judy Endow, an autistic advocate, describes how inclusion is promoted through the perspective of neurotypicals: "Inclusion looks the way inclusion works for the NT [neurotypical] majority." She recognizes the value of inclusion but maintains that space with other autistics is "where I find the depth of inclusion my heart and soul searched for my whole life."⁷⁵ Endow then describes that it is her access to both "neurotypical inclusion" and "autistic inclusion" that offers the best outcomes: "As autistics, we also need to be empowered to choose how this mix best works for us in our given autistic bodies. My needs wax and wane over time, but it remains constant that to love and to be loved I need access to both inclusive environments and to be able to choose the mix that serves me best. This allows me to belong and to participate fully in the human race."⁷⁶

The 2011 *Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.* reveals in fact an underlying bias that implies that the neurotypical norm is superior to the neurodiverse norm. Olmstead is being turned on its head if it is used to justify denial of supports to people with IDD in settings that individuals, not the government, have chosen.

The push for full inclusion and the integration mandate must be informed by an individualized assessment of physical and

⁷⁵ P.L. No. 111-256, S. 2781, 111th Cong. (2009-10); <https://www.congress.gov/bill/111th-congress/senate-bill/2781/text> ("Rosa's Law) Identity-first language is used within the community of individuals on the autism spectrum, similar to the Deaf community. Person-first language is used throughout this report as it is in government documentation since the passage of Rosa's Law in 2010.

⁷⁶ Endow, Judy. "Advocacy inclusion how it works best for this autistic." Web blog post. N.p., n.d. Web; <http://www.judyendow.com/advocacy/inclusion-how-it-works-best-for-this-autistic/>

intellectual abilities to meaningfully participate as well as one's personal preference of spaces and duration of integration. Instead of removing options, Olmstead enforcement should be focused on identifying barriers to desired community integration and ensuring systemic barriers do not hinder access to the variety of opportunities for citizens with IDD.

Any enforcement of Olmstead that ignores the systemic inequities and lack of growth of HCBS waivers to access an adequate array of meaningful choices is ignoring the intent of the ADA.

5. How Are Others Addressing the Problem? --The Development of Intentional Communities

Outside of the beltway, people in the trenches across the country have been desperately working to help their family members and friends live more meaningful lives.

The CoHousing movement⁷⁷, Fellowship for Intentional Communities⁷⁸, Agrihoods⁷⁹, age-restricted 50+ housing, and other "Live-Work-Play"⁸⁰ planned housing communities are increasing in demand for neurotypicals as a result of a desire to invest in housing that prizes community relationships.

⁷⁷ "The Cohousing Association." Welcome! | The Cohousing Association. N.p., n.d. Web. 29 Jan. 2017; <http://www.cohousing.org/>

⁷⁸ *Fellowship for Intentional Community-About FIC*, N.p., n.d. Web. 29 Jan. 2017; <http://www.ic.org/the-fellowship-for-intentional-community/>

⁷⁹ Murphy, Kate, "Farm to Table Living Takes Root." *New York Times*, 11 Mar. 2014. Web; <http://www.nytimes.com/2014/03/12/dining/farm-to-table-living-takes-root.html>

⁸⁰ Stephen Mutty, "The Live-Work-Play Paradigm is Incomplete." *Colliers International*, 8 May 2015 Web; <http://knowledge-leader.colliers.com/stephen-mutty/the-live-work-play-paradigm-is-incomplete/>

Not only can planned communities be cost effective, they can incorporate strategies to allow individuals with limited access to HCBS waiver funding the opportunity to live in a setting other than their family home. For those who can access an HCBS waiver or private pay for support, it is a community within a community where friendships are readily accessible and natural supports can flourish.

The movement from fierce independence towards more intentional interdependence with neighbors reflects a basic human need for interaction, and thus cannot be presumed only appropriate as a neurotypical phenomenon or preference. Faced with the possibility of forced institutionalization or placement in “the next empty bed”, exploring what models currently exist, many families and local communities across the country see intentional communities for those who choose to be a part thereof as a viable model. In fact, they may be especially well suited for people with IDD who have less social capital than the neurotypical population.

As described in the previous section, those with IDD lack employment options, transportation, and opportunities to develop meaningful friendships with their neighbors. Combined with an extremely low fixed-income, families and local communities are catalyzing conversations and creating affordable, sustainable housing models that meet the physical, financial and emotional needs of citizens with IDD.⁸¹ The State of Delaware has chosen to interpret the CMS guidelines to prevent the development of any intentional community for those with IDD. A number of states, however, have not read the regulations as restrictively.

In California, a number of communities are either fully operational or in development. Sweetwater Spectrum in Sonoma, CA has been operational for several years. Rident Park, also in Sonoma, and Villa de Vida, in Pasadena, have been approved.

⁸¹ For a more detailed discussion of emerging trends in the housing movement, see Appendix - **National Report “Cohousing Options.”**

Soon after my 60th birthday, I became more sensitive to the truth of my mortality. The question my father asked me days before he died kept echoing in my head: "What will happen to Aaron when you're gone?"

My son Aaron is 23, nonverbal and autistic. When I am gone, he will need a home, a constant stream of supports, and a community that cares about him and for him.

"Home and community" are hot topics in autism today, as federal policy threatens to sharply restrict congregate options where adults like my son can live and receive services. But for Aaron and those with severe disabilities, "community" is a many-layered thing. Living in a solitary apartment with a caregiver, is not community.

The first layer is personal space. For Aaron it starts with private spaces. He has claimed two rooms in our house, his bedroom and a room we call the library. His bedroom is the place he retreats to when he senses the onset of a seizure. It's there where he cuddles under a blanket with his iPad or a book and where he finds a quiet place. The library is a small room lined by bookshelves. Aaron has a mysterious connection with books, one that only he understands.

The next layer is the micro-community of family, friends and helpers that share Aaron's life. During dinner parties Aaron circles the table several times, observing the guests as they reach for another bowl of rice. He smiles and sometimes claps. While Aaron loves his quiet spaces he also thrives around company and likes a social whirl. He is part of a larger world with the nourishment of social interaction, where he is accepted and can be himself. This layer of community is crucial: studies show that social and emotional support is a significant predictor of better cognitive function and a protector of functional decline as one ages.

The third layer of community is the macro-community of the world outside; parks, businesses, shopping centers, and the Y. I have always cherished engagement with community. I loved my apartment in San Francisco on Russian Hill with many attractions. It was a convenient distance to work, the health food store was visible from my studio window and the smells of my favorite restaurants on North Beach was ever present. It was also a place where my friends, local and foreign, were eager to visit.

When I met Larry Grotte, the father of a son with special needs, he asked me the "after you're gone" question. Peter, Larry's son, is non-verbal with a long list of disabilities. In the process of discussing a solution to our mutual quandary Larry and I began to design Rident Park, a home for our sons, where they would live and enjoy the warmth of all layers of community after we are no longer on this earth.

While planning Rident Park we intentionally take the multi-layered approach: private spaces in homes, opportunities for social engagement with friends, a safe environment and access to the riches of the local community. Intentionality of design and operation is imperative.

For adults like our sons, there is no one simple answer or approach. We must build communities that are structured to provide care, love, support, and healthy alternatives. All adults with disabilities deserve to live in community through their lifespan.

-Irma Velasquez - Mother, Artist, Writer, Life Coach, Rident Park, Sonoma California

6. One State's Solution – Florida

With over 70,000 Florida citizens with IDD living with a caregiver over the age of 60, the state of Florida has been particularly progressive in the development of housing to meet the needs of their citizens with IDD. Knowing that one may soon lose their primary caregiver and home, individuals with IDD and their families are highly motivated to develop more options beyond what was currently available. In a state where age 55+ communities are a robust and viable model to meet the needs of the retirement community of Florida, the urge to develop communities specifically designed to meet the physical, social, and support needs of citizens with IDD has also grown in popularity.

The housing guide provided by the Florida Developmental Disabilities Council provides that intentional communities that are designed to meet the needs of people with IDD may be a good option for those who “wish or need to live outside of their families’ home” and desire settings that adequately provide for “safety, social connections, full belonging in the community, affordability, ability to move about their neighborhood freely, and lifelong sustainability.”⁸²

At the urging of a number of very determined advocates, a percentage of Low Income Housing Tax Credits (LIHTC) were secured for the development of housing for persons with IDD.⁸³

⁸² Housing in Florida, A Resource Guide for Individuals with Developmental Disabilities, Florida Developmental Disabilities Council, Inc. (2013).

<<http://www.fddc.org/sites/default/files/file/Housing%20Guide.pdf>>

⁸³“The affordable housing tax credit program is governed by the U.S. Department of Treasury, under provisions of the Tax Reform Act of 1986 and the Internal Revenue Code. Every state is allocated funds based on population and is operated by a state entity such as The Florida Housing Finance Corporation (FHFC). “Madison House Autism Foundation, *“Florida: Paving the Way in Innovative Housing,*

The Arc Jacksonville Village and Noah's Landing were the first two planned communities to be awarded. These planned communities were awarded a total of over \$20 million in LIHTC funding. Together these communities provide 254 units of affordable, accessible housing. Each of these projects cost approximately \$18 million. This LIHTC set aside not only stimulates new construction of homes designed with individuals who have IDD in mind, but is considerably more economically efficient. Most individuals with IDD rely on SSI and SSDI for their income. Using Housing Choice vouchers, the government subsidy for an individual with IDD who relies on SSI to access housing could conservatively be approximately \$610 a month.⁸⁴ Over the course of 40 years using a Housing Choice voucher, it will cost nearly \$300,000 to provide affordable, accessible housing for an individual with IDD.⁸⁵ **The same person who chooses to live in one of the LIHTC funded planned communities would save the government nearly \$200,000 over the course of 40 years in affordable, accessible housing costs.**⁸⁶

<<http://www.madisonhouseautism.org/florida-paving-the-way-in-innovative-housing/>>

⁸⁴ Individuals with IDD who have a Housing Choice voucher need only to pay 30% of their total income with the subsidy covering 70% of the total rent. According to the Out of Reach Report from the National Low Income Housing Coalition, rent for a 1-bedroom apartment in Florida averages \$830 a month. An individual who gets the maximum reimbursement of \$733 a month in SSI would need to pay \$220 in rent. Therefore, the monthly government subsidy in Florida would be approximately \$610 a month, \$7,320 annually, and at least \$292,800 for 40 years of subsidies not including inflation or fluctuating housing costs.

⁸⁵ \$24 million to build 254 calculates to approximately \$94,488 per unit. This unit cost divided by 40 years would reflect \$196.85 in monthly costs, in comparison to the \$610 monthly subsidy for a Housing Choice Voucher.

⁸⁶ Delaware State Housing Authority partnered with the Department of Health and Social Services and the Department of Children, Youth and Families to create SRAP (State Rental Assistance Program). SRAP is a nationally lauded model designed to help individuals and families transition from

Omario was a proud graduate of a post-secondary program developed by The Arc of Jacksonville called the On-Campus Transition (OCT) program. OCT students become immersed in all aspects of college life by auditing University of North Florida courses, joining campus organizations and clubs, and joining in recreational/leisure activities that are available to all UNF students. OCT students follow a unique and customized plan for achievement, rather than a structured curriculum.

Omario reached his employment and independent living goals by moving into his very own apartment with drop-in supports. Although living independently was an important goal, Omario felt compelled to apply to move into The Arc Jacksonville Village, a planned community of triplexes that would provide residents the choice of 1 or 2 bedroom units.

After he moved in, he realized the best part about living at The Arc Jacksonville Village was that there was always something to do or friends he could visit. He was no longer stuck at home on a Friday night for lack of proper planning or money, but instead could choose to go to a Jacksonville Jaguars game with others who lived in the Village, hang out in the community center for a night of gaming, or walk down to his boyfriend's house to make pizza and watch a movie. He was no longer bored. Connecting with friends was just easier and he knew his neighbors were there if he ever needed a helping hand.

Noah's Landing began as a small intentional community of 3 homes. In response to a constant stream of inquiries, an interest survey was developed⁸⁷ to understand what would be desired if a larger planned community would be developed. The survey has garnered over 650 responses. Of the responses, 88 individuals with IDD have completed this survey, 36% of whom have lived independently in the past. The top four priorities as ranked by self-advocate survey participants are as follows:

1. Personal Safety (98%)
2. Transportation (90%)
3. Recreation & Social Activities (92%)
4. Daytime Activities (88%)

Other intentional communities in Florida are being developed without the LIHTC funding. Loveland Village in Venice, FL has 97

institutions and homelessness to stable housing by providing a housing choice voucher for a defined period of time.

⁸⁷ Online interest survey. 2014. Raw data. Noah's Ark Florida, Lakeland.

apartment units as well as a community center.

Promise in Brevard is under construction and is located in W. Melbourne, Florida, with space for 127 residents. This site will include housing for neurotypical family members as well.

Florida is already seeing success stories in their intentional communities. Despite these successes, however, only a very small fraction of the IDD population has been served.

III. Challenges in Delaware: A Broken Mirror of The Nation

Delaware, like most states, is in the throes of an affordable housing crisis. The faces of the homeless haunt our cities and towns; shelters are routinely full; couch surfing, that is, bunking down with a friend or relative until your welcome has expired, is now a housing reality for many, even those who have full-time jobs. Rental housing is at the highest demand since the 1960s while credit and mortgage underwriting guidelines have

tightened so that homeownership is less attainable for low and moderate income households. Waiting lists for housing choice vouchers (formerly known as Section 8) and subsidized housing units are very long, exacerbating the problem of households and individuals paying more than they can afford for shelter, leading to housing instability and the possibility of homelessness. Delaware Housing Coalition's annual report *Who Can Afford to Live in Delaware?*⁸⁸ documented a **deficit of 16,820 housing units** for very low income individuals across the state in 2016. Diane Yentel, President and CEO of the National Low Income Housing Coalition, said upon release of the *Out of Reach 2016* data:

"The Out of Reach data reflect a grim reality across the nation. There is no place in the United States where a minimum wage worker can afford a two-bedroom apartment. We as a nation must respond by investing in affordable housing for the lowest income households in America."⁸⁹

However, what kind of housing options that might mean and how public funds should be spent to increase options is the cause of divergent opinions and voices. As the demand for rental housing has increased, so have the costs. A minimum wage earner in Delaware will need to work **105 hours per week – or hold down 2.6 full time jobs** - to rent a two bedroom apartment at Fair Market Rent (FMR).⁹⁰

Delaware is the **12th most costly rental market** in the U.S. with a housing wage of

\$21.70⁹¹ (the amount that must be earned per hour to rent at FMR), but a minimum wage of \$8.25. Therefore, if a housing choice voucher (formerly known as Section 8) or subsidized unit is unavailable, many are forced to spend more than 50% (or more than 100% if they survive on Social Security payments) of their household income on housing and skimp on other necessities - such as nutrition and healthcare – or to live in units that are inadequate or dangerous. And in fact, Delaware's waiting lists for vouchers are either closed or encompass several thousand persons.

In Delaware, there are only 32 affordable and available units for every 100 ELI renter households.⁹² And there are worries that the new federal administration will continue to cut entitlement programs and will not invest the desperately needed funds in more housing choice vouchers and subsidized units. Low income and vulnerable populations may face even greater housing risks in the coming years.

In 2010, the Delaware Housing Coalition, in partnership with Delaware State Housing Authority and the Housing Sub-Committee of the Governor's Task Force on Community Based Alternatives for People with Disabilities, began the process of developing a report on the housing needs of people with disabilities. The needs of many with disabilities reflected the same struggles as those of low and very low income populations: affordability; availability; choice; location; and access to services, employment, transportation and other factors essential to an integrated life in a healthy and vibrant community. The finished 2012 report, *Community and Choice: Housing Needs for People with Disabilities in Delaware*, states:

⁸⁸ Delaware Housing Coalition. *Who Can Afford To Live In Delaware?* Rep. N.p.: n.p., 2016. Print at 1; housingforall.org/wp-content/uploads/2016/06/WhoCanAfford2016.pdf ("Who Can Afford Delaware")

⁸⁹ *Out of Reach 2016: No Refuge for Low Income Renters*. National Low Income Housing Coalition, 2016. Web. 24 Jan. 2017. <<http://nlihc.org/oor/delaware>>.

⁹⁰ *Who Can Afford Delaware* at 4.

⁹¹ *Ibid*.

⁹² *Ibid* at 1.

“Among the estimated 108,500 people with disabilities in the State of Delaware, **incomes are typically lower than among those without disabilities, with a higher overall percentage in poverty or at risk of falling into poverty, and a much higher need for housing assistance.** The **need for accessible, affordable housing is a major barrier to people with disabilities living in the community,** and housing needs severely limit the options of people with disabilities choosing to live in the **least restrictive setting of their choice.** Independence, choice, and integration are critical and still overlooked issues which must be factored into the consideration of housing needs for people with disabilities.”⁹³

Recommendations from the report included the following:

Better raw data is needed about disability housing needs (populations, immediate needs, long-term projections). This includes updating and revisiting primary data available in Delaware (providers, state and local agencies) and reviewing national data sources.

Secondly, income poverty and disability interact in ways that mutually reinforce one another. So, a more careful analysis is required of the relationship between income poverty, disability, and specific housing needs.

There is a spectrum of disability housing needs, each of which requires different solutions and resources. People with disabilities are over-represented among the homeless, living involuntarily in shelters and institutions instead of a home of their own.

⁹³ Delaware Housing Commission, Housing Sub-Committee for the Governor’s Commission on Community Based Alternatives for People with Disabilities, and the State Council for Persons with Disabilities. Community and Choice: Housing Needs for People with Disabilities in Delaware. Rep. April 2012: n.p., n.d. Print; <http://housingforall.org/wp-content/uploads/2015/10/2012-03-29-Executive-Summary-Full.pdf>

The need for rental housing is aggravated by the need for higher rental subsidies, absence of support services, and lack of accessibility. Similarly, the needs of owner-occupants span a range of their own, from the need for retrofits to remain in the home or financial help to offset housing cost burdens, on the one hand, to homebuyer financial preparation, asset building, universal design in general housing construction, and special lending products, on the other.

The answers are neither simple nor cheap. The inadequacy, or actual absence of housing for the up to 8,300 Delaware households who face homelessness each year, leads to expensive and unwanted outcomes in our society. Therefore, more investment is needed in housing choice vouchers, affordable rental housing, permanent supportive housing for special populations and the chronically homeless.

1. The Housing Needs of Delaware’s IDD Population

It is notoriously difficult to find accurate numbers for those in Delaware with IDD, because as previously reported, they may not be “disabled enough” to qualify for state services or live with family who undertake all of their care without applying for outside help. Currently, only 8% of Delaware citizens with IDD live in a supervised setting outside of their family home.⁹⁴ The SOS report provides that:

- 27 individuals live in nursing facilities
- 61 live in State Institutions
- 69 in an ICF
- 18 in supported living
- 961 in group home or adult foster care
- 10,993 live in the home of a family caregiver⁹⁵

⁹⁴ SOS Report, Delaware Data.

⁹⁵ Ibid.

This may be a distressing situation for all parties as the adult children yearn for their own home, aging adults no longer have the energy or resources to care for their loved ones, and there is the constant nagging fear that if something happens and they can no longer care for their adult child, there is no plan in place for where they might go or with whom they might live. Those who are not eligible for the HCBS waiver face the following harsh economic realities:

On average, a person with a disability receiving SSI would have to pay **107%** of their monthly income to rent an efficiency unit and **126%** of their monthly income for a one-bedroom unit.⁹⁶ Simply put, this is not economically feasible.

Delaware's HCBS waivers include the Delaware Renewal for the Division of Development Disabilities Services (DDDS) and Pathways to Employment. Delaware is one of the top ten states for Medicaid spending for persons with IDD; according to the *State of the State* report, it is the most expensive HCBS waiver per participant state.⁹⁷ **Remarkably, however, 93% of the people in Delaware cannot access a waiver.**⁹⁸

If Delaware's waiver program is not financially successful, is it at least successful in community integration? Data indicate it is not. Although the HCBS waiver is designed to encourage community integration and more independent living, the National Core Indicator Project reports that among those currently receiving waiver benefits:

- 40% feel lonely

⁹⁶ *Out of Reach 2016: No Refuge for Low Income Renters*. National Low Income Housing Coalition, 2016. Web. 24 Jan. 2017. <<http://nlihc.org/oor/delaware>>.

⁹⁷ SOS Report, Delaware Data.

⁹⁸ *Ibid*; 954 people have access to a waiver. Total population is 14,558. Expressed as a percentage, then, 6.6% have access to a waiver, and over 93% do not.

- 15% are afraid at work or in their day program / activities
- 16% are afraid at home
- 43% have never talked to neighbors
- 48% who attend a day program or activity and want to do something else
- 45% of those who have a job in the community would like to work somewhere else⁹⁹

It is DDDS's policy to not maintain an official "waiting list" but as reported anecdotally and by the Families Speaking Up survey, it is known that hundreds, perhaps, thousands, are waiting for housing and LTSS. The crisis age is 21 when young people with IDD graduate from the school system and must then apply for Medicaid eligibility. At an age when their neurotypical peers are building their own independent lives, they are faced with the reality of many more years in the family home, whether they want to live there or not.

Medicaid is already overburdened and the number of housing choice vouchers has stagnated in recent years, mainly due to sequestration, so where will new residential options come from? Additionally, improvements in overall quality of life as well as in healthcare mean that people with IDD are living longer but also most cope with the early onset of certain illnesses such as Alzheimer's. This means that the costs of their care will increase as they age.

⁹⁹ "NCI Charts: The proportion of people who feel lonely." National Core Indicators. N.p.: n.p., n.d. N. pag. NCI Chart Generator. Web. 28 Jan. 2017. <<http://www.nationalcoreindicators.org/charts/?i=107>>.

In sum, the crisis in housing for all low income Delawareans, and in particular those with IDD, is caused in the first instance by a stark lack of units which leads to a lack of choice and reduced quality of life. It is then further exacerbated by a lack for funding for needed supports in the home.

The State has created some noteworthy and innovative programs that have been transformative for the participants: SRAP¹⁰⁰ and the Section 811 program.¹⁰¹ But these options will not bridge the gap. There is not enough housing in Delaware, **particularly housing for people with IDD, that is safe, affordable and accessible.** An intentional community may not be the choice for many, but will provide the perfect home for others. Just as neurotypicals have a range of housing options – renting, buying, living in 55+ communities - **the same range should be offered to the neurodiverse population without the dictates of philosophical and social constraints.** At different points in the lifespan, different housing options are needed; no one size fits all, all the time. More overall investment is needed in affordable, accessible and supportive housing, but uncertainty in federal policy and the looming budget crisis in Delaware does not mean that investment will be made by our governments in the near future.

¹⁰⁰Delaware State Housing Authority partnered with the Department of Health and Social Services and the Department of Children, Youth and Families to create SRAP (State Rental Assistance Program). SRAP is a nationally lauded model designed to help individuals and families transition from institutions and homelessness to stable housing by providing a housing choice voucher for a defined period of time.

¹⁰¹The Section 811 program had a significant impact on group home housing in Delaware and was modified in recent years to subsidize units in designated participating properties for people with disabilities. This too could be expanded to help those with IDD, particularly as it is focused on those who earn less than 30% of AMI and long term supports must be provided by DHSS or one of their providers. The 811 program is project based while SRAP provides a voucher directly to the tenant.

Delaware Math

Does NOT add up...

- **There are approximately 15,000 Delawareans with IDD**
- **Only 8% live in a supervised residential setting**
- **Most Delaware citizens with IDD have SSI or SSDI as their sole source of income**
- **107% is the percentage of the income of a Delawarean living on SSI required for the average efficiency apartment**
- **\$24,250, or below is the poverty level for a family of four: \$11,770 is the amount for an one person household**
- **16,820 deficit of affordable and accessible units for extremely low income households**
- **Growth of residential placement using HCBS waiver funding has averaged 28 additional people per year over the last decade**
- **3,000 Delawareans with IDD live with caregivers over the age of 60**
- **93% of Delawareans with IDD do NOT have access to a waiver**
- **Delaware has the most expensive waiver cost per person**

IV. Feasibility Analysis of an Intentional Community in Delaware

The urgency of public-private partnerships to meet the demand for housing in Delaware cannot be overstated. In the past, HFL has risen to meet this challenge and is willing to do so again. The following questions identify potential barriers and opportunities to be addressed.

1. Is There a Demand for an Intentional Community in Delaware?

As HFL conducted an online housing survey to which 116 people responded; with an overwhelming demand for an intentional community in Delaware.¹⁰² Key insights from the HFL interest survey include:

- 45% responded they would like to move in as soon as the community is available, 43% responded a desired move in date of 2 - 5 years
- 65% said private-pay for additional residential LTSS was a possibility
- Only 6% were employed full-time, 58% were not working in paid employment, and 39% had a part-time job of 20hrs or less
- 78% currently live in their family home, 18% live in a group home, 2 respondents live in their own home in the community independently
- 71% are receiving at least some support from the Delaware DDDS
- 31% cannot be left alone, 18% can be left alone for 1 - 3 hours, 17% 4 - 6 hours, 32% 7 - 12 hours or overnight, only 6% can be left alone for several days

¹⁰² Online interest survey. 2016. Raw data. Homes for Life Foundation, Wilmington. < [http://us5.campaign-archive1.com/?u=156c251f7195312e675afe7c9&id=9870687790&e=\[UNIQID\]>](http://us5.campaign-archive1.com/?u=156c251f7195312e675afe7c9&id=9870687790&e=[UNIQID]>)

The top 5 amenities identified were: 93% planned recreational activities, 82% gym, 77% pool, 73% game room, 67% community cooking classes. Therefore, there is a demand for communal, organized activities with peers.

2. Do Policy or Regulations Restrict Access to Comprehensive LTSS and/or Specific Home Settings?

I. There remains a need for more residential supports and a strategic plan to meet that need

Nearly 11,000 Delaware citizens currently live with a family caregiver.¹⁰³ Approximately 3,000 Delaware citizens with IDD live with a caregiver over the age of 60. As of July 2016, 38 citizens with IDD were in crisis at the “emergency” level of need, and an additional 381 identified as “high risk” crisis.¹⁰⁴ Simply because Delaware chooses not to maintain an official waitlist, does not mean substantial numbers of people are not waiting to receive critical services.

Crisis placements will continue to occur when aging caregivers can no longer support their loved one with IDD. Like most states across the country, Delaware has no apparent plan to meet the need and mitigate forced institutional placements in the future. Adult foster care alone is not the appropriate answer.

II. Upcoming restrictions in the State Transition Plan (STP)

The CMS HCBS Final Rule requires all states to develop a STP which can include more stringent criteria than the federal standard. Having reviewed the Delaware STP which has been initially approved by CMS, there is no

¹⁰³ SOS Report, Delaware Data

¹⁰⁴ DDDS Monthly Census Data, DDDS Services Registry System (July 2016)

additional language or further state-specific restrictions added that would create barriers to the development of a consumer controlled intentional community.

III. Restrictions in current waiver regulations

It is the guidance from the federal government, not the state, that identifies intentional communities as a presumably institutional setting. The state is then responsible for supplying evidence that an intentional community is indeed home and community based, and not institutional in nature.

preliminary review” program to encourage expansion and mitigate risk of HCBS settings planning construction on October 31, 2016.¹⁰⁵

IV. Delaware’s Reliance on Provider Controlled Housing

As a best practice and following federal trends, intentional communities being developed across the country are predominantly consumer-controlled settings. As Delaware has a strong bias towards waiver use in provider-controlled settings, inaccessibility of waiver supports that can be used in a consumer-controlled setting must be

Having a child with an Intellectual Disability is hard. It affects the whole family. Rose, now 24, was three when she was diagnosed with autism.

Educating Rose in the most nurturing environment meant moving two times in six years. Their most recent move was to a special, well-known program, called the Consortium in Delaware where she completed high school with a full diploma at the age of 21.

Although far from their extended family the Campbells found a community that was small and inviting, a community that got to know Rose and her wonderful qualities. In addition, they found a church home, which welcomed Rose on Sundays.

Now Rose is happy to be working at two local restaurants for a total of 11 hours each week. She spends an additional 16 hours in a supported day program through Autism Delaware, where she enjoys volunteering and exploring the local community with her Direct Support Professional. She hopes to work more hours when the employers feel that she is ready.

Rose has been telling her parents for years that she wants her own apartment. Now her younger sister has an apartment at the college she attends. Her parents are 65 and 66 and Rose continually tells them, “I can’t live with you forever”. Her mother, a cancer survivor who lost a sister to cancer a year ago, knows that it is time to make plans that are appropriate for Rose.

An intentional community offering apartments and drop in support, along with recreational opportunities within the larger community would be perfect for Rose. But for now, that option does not exist in Delaware. Until such a community is established the Campbells can only pray that they remain healthy and able to watch over Rose for as long as they are able.

-Cynthia Campbell, Mother, Advocate, Lewes, DE

Additional guidance from CMS has stated that states cannot receive pre-approval for settings until constructed and operational. To address this problem, former Delaware Governor Jack Markell wrote to CMS suggesting a “pilot

¹⁰⁵ Letter from Honorable Jack Markell, Governor, State of Delaware to Mr. Andrew Slavitt, Acting Administrator, Center for Medicare & Medicaid Services, October 31, 2016 (see Appendix)

considered a barrier to access for many Delawareans in the development of a consumer-controlled, intentional community in Delaware. An intentional community can consist of clustered provider-controlled homes, but would not offer residents maximum control of their home or staff. Additionally, clustered, provider-controlled housing may elicit further federal heightened scrutiny in accordance with guidance from CMS on “settings that tend to isolate.”

Delaware has used one HCBS waiver to meet the residential needs of their citizens with IDD. Under the 1915(c) authority, the Delaware Renewal DDDS (0009.R07.00) waiver, commonly called the DDDS HCBS waiver, was first approved in July 1981, was last renewed in July 2014, and will expire June 2019. The waiver provides:

- day habilitation
- prevocational services
- residential habilitation
- supported employment-individual
- supported employment-small group
- clinical consultation-behavioral
- clinical consultation- nursing
- supported living for individuals with autism and IDD from age 12

Delaware has a unique state system of partnership between Division of DDDS and The Arc of Delaware which owns and maintains housing that is leased to a number of provider agencies.¹⁰⁶ The Arc offers comprehensive property management, including a 24-hour maintenance team to provide emergency services as needed to keep these residences safe and comfortable for the residents and attractive to their neighborhoods. Additionally, a monitoring program engages volunteers to visit and evaluate both the

¹⁰⁶ <http://www.thearcodelaware.org/homes/>

interior conditions and curb appeal of all properties on a regular basis.

Individual residents who live in these group homes are served by the same service provider and cannot choose to have a different service provider than their housemates. Provider-controlled Adult Foster Care / Family Host Homes are also utilized in Delaware; however, they are euphemistically described as ‘Shared Living.’¹⁰⁷

Do Delaware citizens Access Long-Term Support Services in Consumer-Controlled settings?

HCBS in consumer-controlled settings is possible through Supported Living Services, but utilization is limited to individuals with IDD who require a maximum of 40-hours per week of in-home supports.

The State of the States (SOS) data reflects that Delaware disproportionately relies on residential rehabilitation in provider-controlled settings at \$96,000 annually per participant. As of 2016 data, only 35 individuals have access to supported living services which allows them to live in a home of their own for nearly half the cost of a provider-controlled setting.¹⁰⁸ It is worth noting that Delaware has the lowest utilization rate of supported living / personal assistance in the entire country.¹⁰⁹ Of course, without knowing the specific needs of the individuals, it is difficult to determine the efficacy of these choices. Functional support needs and level of intellectual disability varies among individuals with I/DD. Many states serve a

¹⁰⁷ "DE Waiver Factsheet." Medicaid.gov. Centers for Medicare & Medicaid Services (CMS), n.d. Web. 31 Jan. 2017. <<https://www.medicare.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/Waiver-Descript-Factsheet/DE-Waiver-Factsheet.html#DE0009>>.

¹⁰⁸ DDDS Monthly Census Data, DDDS Services Registry System (July 2016)

¹⁰⁹ SOS Report, Delaware Data

much higher percentage of citizens with I/DD using a supported living or personal care waiver which offer the supports needed to live in a home of one's own as underscored by the SOS Report,

"Supported living has been the fastest growing residential service option for persons with IDD in the US since 1993...constituting 46% of total out-of-home residential placements."

Delaware may be primarily focused on meeting crisis placements of citizens who have higher support needs than the reimbursement for supported living would allow. At the very least, however, it does suggest a review is in order to determine whether additional waiver recipients would benefit from a supported living option in a consumer-controlled setting.

Furthermore, Delaware does not have an option for citizens with I/DD to self-direct one's services in their own home despite having a streamlined option by CMS for the past decade to incorporate this service delivery model in their existing 1915(c) waiver program. *Delaware citizens with physical disabilities or the aging population can currently self-direct services in their own home, but not citizens with IDD.*¹¹⁰

Are there waiver amendments or expansion planned to meet the need?

Unfortunately, Delaware does not provide transparent information about accessing waiver supports in a variety of settings. When exploring options on the Delaware.gov website under the page entitled, 'Developmental Disabilities Services'¹¹¹,

¹¹⁰ Mann, Cindy. "Approval letter to amend the "Diamond State Health Plan (DSHP)" Medicaid section 1115 demonstration (No. 11-W-00036/4)." Letter to Ms. Rita M. Landgraf. 19 Dec. 2014. N.p.: n.p., n.d. N. pag. Community Living Policy Center. Centers for Medicare & Medicaid Services. Web. 31 Jan. 2017. <<http://clpc.ucsf.edu/sites/clpc.ucsf.edu/files/CMS%20Approval%20DSHP%20DSHP-Plus%202014.pdf>>.

¹¹¹ <http://www.dhss.delaware.gov/dhss/ddds>

individuals with IDD and their families are only given information about accessing family support services. Even when clicking on a photo of an elderly man with the label 'Waiver Services', the subsequent page only describes "Family Support" without any other mention of access to services in one's own home, a group home, or other non-family setting. This lack of information on residential options is alarming.

As promoted on the homepage, a **Lifespan Waiver** will be introduced in July 2017 as an amendment to the current 1915(c) waiver serving citizens with IDD. Important details to note:

- **\$2,700 annual cap** on community living supports
- Individuals who are already receiving day program assistance will be prioritized.
- **Only 60 placements** are available for individuals who require out of home placement due to the lack or incapacity of a caregiver.

a) What Can Delaware Residents with IDD Afford to Pay in Rent?

Rent must be considerably lower than market-rate to be affordable or citizens with IDD will need to have access to a Housing Choice Voucher. An individual with IDD would need to work full-time at \$15.00 per hour – that almost twice the minimum wage--just to afford a studio apartment.¹¹² The National Core Indicator project reports that for 2014-2015, only 17% of citizens with IDD in Delaware even have a paid job in the community, with most earning less than \$600 per month. 28% have a job in facility-based

¹¹² *Out of Reach 2016: No Refuge for Low Income Renters.* National Low Income Housing Coalition, 2016. Web. 24 Jan. 2017. <<http://nlihc.org/or/delaware>>.

setting and make less than \$300 per month.¹¹³ SSI and SSDI are likely the main form of income for most citizens with IDD. If one's only income is \$733 of SSI per month, affordable rent is calculated to be \$220.

b) Analysis Conclusions in Consideration of an Intentional Community

Development of an intentional community as consumer-controlled housing would offer Delaware citizens with IDD an option of the utmost control and stability of their home.

Alternatively, for those who prefer service delivery in a provider-controlled setting, homes within the intentional community could also be leased to service providers. It is highly recommended that the intentional community also include homes for neurotypical residents who can provide a safety net and natural supports for their neighbors with IDD, as well as further integration goals.

As the projected growth of residential LTSS options in Delaware is dismal, HFL should seek a partnership with service provider/s who can create a suite of private-pay services for those who will not be able to access publicly-funded LTSS, but whose family can pay privately for the individualized supports for their loved one with IDD. Additional built-in supports and services, smarthome and assistive technology, and/or amenities that can supplement the lack of funding for comprehensive LTSS in some circumstances.

As the HFL survey indicated, 97% of potential residents either rely on SSI, SSDI, and make less than \$350 a month. Rent must remain at a fraction of the cost of market rate housing and fixed for it to be financially accessible to most Delawareans with IDD. If HFL can raise the money and build the intentional community

debt-free, low rent can be secured and used for operational and maintenance expenses.

The amenity most requested by 93% of survey respondents was creation and coordination of planned activities. Incorporation of a gym, pool, and game-room were also the next three valued amenities. Therefore, when determining built-in supports, funds should be budgeted for a community coordinator who would be responsible for organizing all details of voluntary planned activities for residents. To further goals of integration, use of the gym, pool, and gameroom by individuals or organizations who are willing to provide natural supports to residents or coordinate community activities should be considered.

Determining the size and number of residents per units must be informed by potential residents, but should also include consideration of LTSS arrangements. If access to HCBS in consumer-controlled homes is only limited to persons with low support needs, this will influence the population of a strictly consumer-controlled community to those with low support needs or others who can private pay for residential supports. Therefore, creating space for provider-controlled home's needs to be considered, and discussion with potential providers before home plans are drawn would be valuable.



The Campbell Family

¹¹³ Human Services Research Institute (HSRI), The National Association of State Directors of Developmental Disabilities Services (NASDDDS). National Core Indicators. N.p., n.d. Web. 26 Jan. 2017. <<http://www.nationalcoreindicators.org/charts/>>.

Continued Discussion with DDDS on the Intention and Plans to Develop an Intentional Community.

Delaware's Medicaid authority, Division of Medicaid & Medical Assistance (DMMA) has the power to deny or support access to Delawareans' essential life supports through HCBS waivers. Therefore, it is imperative that DMMA is aware of their constituents' desire for a home in an intentional community.

Areas of advocacy include increasing access to supported living services, lifting funding caps that limit consumers, and expanding the emerging self-directed option in order to increase access to HCBS in consumer-controlled settings. Additionally, advocacy is needed to add flexibility and terminology for individuals to hire a host family or supportive roommate in their own home without having to resort to the traditional adult foster care structure.

V. HOMES FOR LIFE Intentional Community Plan

1. Preliminary Fundraising Plan for Delaware Intentional Community

Homes For Life, founded by Micki and Lanny Edelsohn, is a 501(c)(3) foundation located in Wilmington, Delaware. Their journey into the world of disabilities began in 1972 with the arrival of their second son, Robert. Birth injuries that occurred during a difficult delivery resulted in Robert suffering significant intellectual disabilities. As the extent of these disabilities slowly unfolded, the Edelsohns knew that Robert's challenges would be different from his older brother and yet their goals for him were the same. Robert would get the best education possible to reach his full potential and someday hold a job, live in his own home and enjoy life in his community.

In 1989 they had a small dream; find a way to raise the funds to build a group home where Robert could live with his peers when he completed his schooling. There were a few group homes in Delaware; but their vision of what a group home should look like was a little different! When the first home was completed other families liked what they saw and the State of Delaware asked for more. Homes For Life Foundation was established.

For twenty-five years, determined to break the "NIMBY" barrier, this all-volunteer foundation has raised millions of dollars and designed and custom-built 25 homes and purchased two condominiums in beautiful neighborhoods throughout northern Delaware. These homes provide their one hundred and four residents choice and privacy, camaraderie and support. The HFL residential model has always been one of affordable and accessible housing for those with IDD. A public-private partnership between the foundation and the state of Delaware has been developed whereby HFL raises the initial capital to pay in full for

homes. Making these homes debt free allows for the savings to be passed on to the residents and establishes affordable rent.

The following preliminary fundraising plan is for a proposed Intentional Community (IC) that would initially provide housing for 30 people with IDD in Delaware. To date HFL has 2.5 million dollars but to achieve its goal of making this community debt free, must raise an additional six million dollars. This plan has taken into account the analysis of current barriers and risks reflected in this report. The HFL plan: make rent affordable, which can be paid for with SSI or SSDI. HFL believes that through economy of scale, this community will provide affordable and permanent housing that permits access to the greater community.

If, after the first phase, HFL has met its fundraising goal, the project will proceed.



Edelsohn family at HFL Group Home dedication adjacent to University of Delaware Campus

Market-Rate Housing	Planned/ Intentional Communities
Expensive	Intentionally affordable for extremely limited income
Not accessible and modifications may be limited	Designed for accessibility, incorporates “Smart Home” technology, and prepared for people to age in place
Higher potential for predatory relationships and abuse	Higher accountability through neighbors who know and want to ensure your safety and dignity
Transportation barriers	Transportation within and without the greater community is coordinated by an Administrator.
People feel isolated	Residents never have to be alone because they have access to friends or may join a spontaneous or planned activity
Lack of safety-net of on-site activities	Individualized schedules with varied optional activities for a purposeful, meaningful life

2. Identified Risk Factors

As identified in the previous section of this plan, there are substantial risks to building this community as follows:

1. Funding is necessary to support the daily care of persons living within the community. Such funding must either come from the government, such as an HCBS waiver, or from private sources.
2. At present, it is unclear whether the State of Delaware would preclude funding of support which will vary according to the needs of each resident within the IC. The care costs may have to be borne privately until this discriminatory policy is rescinded.

3. Upon completion of construction and commencement of operations, HFL will face risks from a variety of sources, all of which are manageable with due diligence and knowledgeable guidance as follows:

- Continued resistance of state and federal regulators to see an IC as being an “authentic” community experience.
- Significant economic events such as recessions or severe inflation that impact target markets.
- Unforeseen circumstances that disrupt the limited cash flow of operations during the first few years of operations

3. The Proposed Community

This plan is a preliminary estimate of the projected cost to construct and manage this community. In order to keep the rental of the units affordable for adults with IDD, the IC will use the current HFL model and will be debt free through solicitation by HFL of private donations for 100% of land, construction, pre-

opening costs and a one year operating fund reserve. Furnishings for the housing units will be provided by the residents and/or their families. Individual services to support each resident will be the responsibility of the person with IDD and their family/legal guardian. The building of this community is consistent with the need for more affordable housing for the almost 11,000 adults with IDD in Delaware who currently reside at home with their families.

The IC will be totally inclusive and accessible to the greater community. It will assist each resident to find the supports that they need to live independently and be able to access the community for work and social activities. Community members will each have a person-centered plan for their care and supports. They will have a choice of either a one or two-bedroom unit; all with private baths, and full kitchens. Each community member will furnish their own residence to their style and taste.

This initial plan for the community is small in scale as this a new housing in Delaware.

4. Mission of the IC

The IC intends to provide adults with IDD their community of choice by providing an innovative, affordable, and supportive housing option that encourages independence, respects choice, supports a safe and healthy lifestyle, and promotes taking full advantage of employment, recreational, social, and educational opportunities in the broader community.

5. Products and Services

HFL will focus on obtaining land and raising the needed capital to build a consumer controlled IC that will be the community of choice for persons residing there. Incorporated as a 501(c)(3), the community will be home to 30 persons with IDD in 4 stand- alone cottages and six 2 bedroom apartments. The

community will provide a safe environment for all residents to move freely around the property to visit friends or go for meals. A Community Center will serve as a gathering area for meals, social activities and visits with family and friends. The center will contain a commercial kitchen that could be used to expand a HFL supported bakery, Proof Bakers, that employees individuals will IDD. There will be transportation in and out of the community that is accessible to all residents for work and for social activities. Open recreation areas will be part of the design and the community will support and encourage a lifestyle that takes into account mind, body and spirit including arts, entertainment, recreational and sports activities. Being a consumer controlled, intentional community, it will offer residents greater choice and control of where and how they can access the greater community and who will provide support for their daily living needs.

Land for the development of this community is currently being researched in both the Middletown and Lewes areas of Delaware. Property obtained will be of a size that if the need and opportunity arise, expansion could occur.

6. Site Plan Description

Layout of the IC will be pedestrian-oriented, keeping cars located on the periphery to optimize safety as well as spatially connect residents for neighborly social interactions.

A community center will be developed to bring together residents and their community through:

- Multi-purpose Room (community meetings, entertainment and socials)
- Community Kitchen (parties, potlucks, cooking classes, and possible site for HFL supported Proof Bakers, employing persons with IDD)
- Dining Room

- Activities/Workshop / Art Studio

In addition the IC will have:

- Six 2 bedroom apartments
- Office space
- Two 1 bedroom apartments for neurotypical residents
- 4 cottages at 3500 square foot each containing two 2 bedroom and one 1 bedroom dwelling units.
- 1 house for neurotypical family at 2,400 square feet

7. Individual Support Services & Providers: Publicly and Privately Funded

Residents will be persons with IDD who choose to live in the IC. Residents may need full-time help in daily living activities; some may live more independently with support of their families and friends.

Infrastructure services will include:

- 24 hour a- day electronic video surveillance on the property.
- Health and exercise program.
- Social activities in the community and in the greater community.
- Consideration is being given to the option of offering an evening meal in the community center through a meal plan at an additional cost. Residents will always have the option of cooking in their units.
- Transportation to work and social activities coordinated through Delaware’s public transportation system.

The IC will be inclusive of and accessible to the greater community. Accordingly, it will meet the letter of the current regulations for full community inclusion allowing HCBS waiver

funding to be used for direct supports of the residents.

The IC will not be a service provider. In order to thrive and participate in the community, residents will choose their own service provider. Because the IC will be consumer-controlled, residents will be able to change providers at any time without having to relocate. Cost may initially preclude some people from becoming residents unless HCBS waiver funds are available.



HFL’s intentional community and commercial kitchen will provide a permanent home for Proof Bakers.

8. Costs

a) Construction Costs

The total costs to build the HFL Intentional Community are about \$8 million as is detailed in the table below:

Use of Funds	Amounts	Timing
Land Acquisition:	\$1,500,000	End of 2017
Development Costs: Site Paving Construction and Materials Appliances & Fixtures Landscaping and Sidewalks	\$1,250,000	2017 – 2018
House -2,400 square feet Home for family to administrate and maintain community	\$350,000	2017-2018
Multi-Family Building -20,000 square feet Includes 6-2 bedroom apartments and 2- 1 bedroom apartments plus offices, dining, kitchen, gathering and activities rooms	\$2,200,000	2017-2018
Cottages – 4 @ 3,500 square feet Each cottage contains 2-2 bedroom and 1 1-bedroom dwelling units (12 units total)	\$1,120,000	2017-2018
Construction Contingency	\$300,000	2017
Soft Costs: Architectural Fees --\$100,000 Engineering Fees -\$100,000 Legal - \$50,000 Environmental –Phase I - \$10,000 Utility Fees (TAP Fees) Allowance -\$50,000 Township & Fire Marshall/County Review Fees Allowance - \$50,000 Developer/CM Fees - \$500,000 General Conditions for Construction Activities - \$400,000	\$1,260,000	2017
TOTAL	\$8,060,000	

b) Operational Costs

i) Facility

The future site on 5-10 acres of land has not yet been selected for the proposed community. This acreage will allow for expansion that would increase overall efficiency and reduce costs. HFL is currently exploring property in Middletown and Lewes, Delaware in commercialized areas and on public transportation routes. If funding is secured, construction could begin in early 2018. Construction costs are based on estimates from a development and management company that HFL is currently working with.

ii) Management

HFL is working with a developer and management company and the estimate of their costs to run this community is reflected below. Residents will be expected to pay monthly rent which will cover operational costs.

In their projections, the developer has stated that if the IC were to be built at the size outlined in this plan, HFL would have the space and the ability to more than double the number of living spaces for residents without

needing to increase the size of the common areas/facilities they will be managing. This will allow for economy of scale to decrease the monthly unit fee or rent for residents in the community.

iii) Employees

In order to attract experienced, high quality administrative workers for the operation of the facility, the HFL community will have to offer competitive wages. This will be challenging when operating an affordable housing community for residents with IDD. To attract highly qualified staff, HFL will offer rent free housing to the Administrator/Activities Coordinator of the community. A 2,400 square foot house will be built and offered rent free (not to include utilities) to this individual. Two one bedroom apartments located in the community center will be designated rent free (Utilities included) for two support staff for residents in the community. Prorated salaries will be paid to these employees. The cost for these employees will be shared by all residents through a monthly service fee.

Use of Funds	Costs
Maintenance Costs: Utilities and Upkeep Building Insurance Insurance Utilities property taxes	\$288,642
Administrative Costs: .5 FTE Community Coordinator .5FTE Staff .5FTE Staff	\$50,000 \$26,000 \$26,000
Total Non-Development Annual Needs	\$390, 642



VI. CONCLUSION

“The test of our progress is not whether we add more to the abundance of those who have much it is whether we provide enough for those who have little.”

– *Franklin D. Roosevelt*

Thanks to Ford Foundation we are “put[ting] ourselves back in the narrative” and “telling our story.”¹¹⁴

With almost 3,000 citizens of Delaware with IDD who are currently living at home with parents over the age of 60, Homes For Life remains committed to provide them with affordable and accessible housing.

As Winston Churchill said " Never, never, in nothing great or small, large or petty, never give in except to convictions of honour and good sense." It is HFL's intent to ensure that the right of choice for those with IDD be recognized by our governments and that arbitrary restrictions be abolished. Life, liberty and the pursuit of happiness should be available to all.

HFL has illustrated that:

- Despite restrictions imposed by the federal government, some states have shown flexibility in creating a wide array of housing options.
- Support from Delaware's state government is necessary in addressing the over-reach of present CMS regulations and guidance.
- The misinterpretation of Olmstead is detrimental to those with IDD.
- The “one size fits all” approach ignores the diversity of the IDD population.
- Intellectual capacity matters as we strive to protect all those with IDD.
- The reality remains that those with IDD frequently are exposed to physical, sexual, emotional and financial abuse and available housing options should consider these issues.

As a country, we can and must reverse the inequality that has been unjustly imposed on our most vulnerable citizens. We must “never give in.”

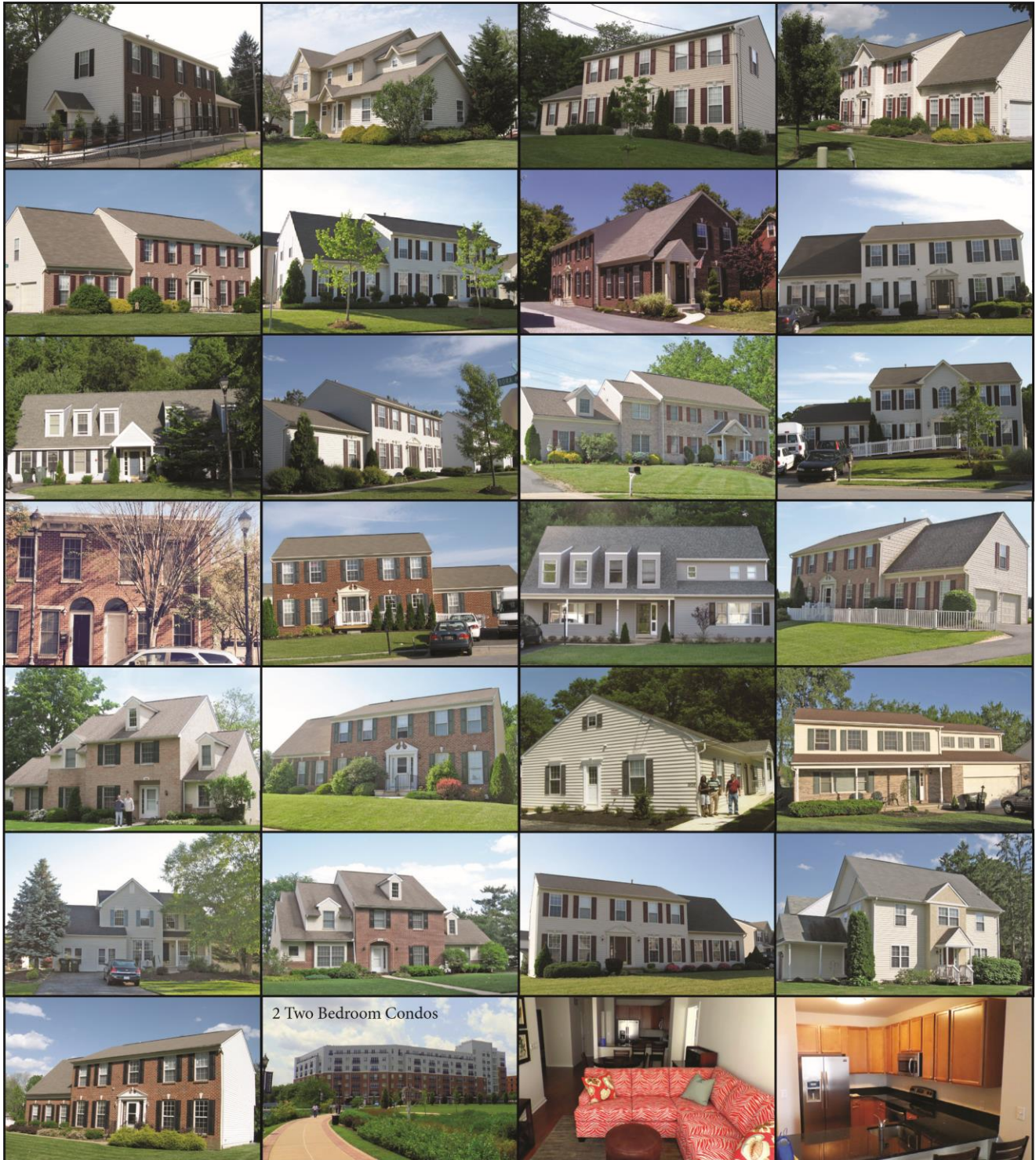
Appendix can be found at:

<http://www.familiesspeakingup.com/wp-content/uploads/2017/02/HFL-Planned-Community-Appendices.pdf>

¹¹⁴ Miranda, Lin-manuel/ Mccarter Jeremy. Hamilton The Revolution. N.p.: Grand Central Pub, 2016. Print.

Homes For Life

F O U N D A T I O N



104 Adults Have A Home For Life!