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Disability Housing: What's happening? What's challenging? What's needed?

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Abstract

For adults with intellectual or developmental disabilities, a suitable home is sometimes almost impossible to come by. Hundreds of thousands of adults with disabilities across the U.S. sit on housing “wait lists” for home and community-based services. Even if they’re ready to make the move out of their parents’ home into community or independent living, the housing options and funding supports often don’t exist.

Growing populations, decreased funding, and a diversity of strategies is a challenge for federal and state policy leaders as well as for on-the-ground service providers. Research on what makes a “quality” housing option is often conflicted. Best practices in housing design and service delivery have not been sufficiently explored, defined, or shared.

This paper explores the issues facing individuals, families, providers, and policy leaders across the country. Individuals with disabilities and advocates have been fighting for thoughtful supports, inclusion in communities, and independent living since the 1960s “based on the premise that people with even the most severe disabilities should have the choice of

living in the community.” The challenge isn’t new, but rooted in a history of disability services that has evolved from a focus on Care (a Kennedy-driven era of special services), to Choice (a self-advocated Independent Living shift to emphasize self-determination and respect, to Access (an ADA focus on equal access and opportunity). An ongoing tension between Care, Choice, and Access remains today.

Case studies profile four providers with differing approaches to housing and service delivery, and how they face common challenges in staffing, meeting regulatory requirement, and serving a population with diverse needs. Providers and regulators constantly work to find the right balance between integration and independence, risk and autonomy.

This paper concludes with recommendations for organizations and policymakers in order to support the best possible housing choices for the millions of Americans with disabilities, where solutions and services represent a thoughtful balance between Care, Choice, and Access, and should avoid “one-size fits-all” design.

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Introduction

When you stop and think about it, our homes, including the people who share them with us, defines a lot about our lives. A home is the physical space where we greet each day. The people we share it with are fixtures in and influences on our lives. It's where we welcome guests, cozy up when we're sick, and retreat at the end of a long week.

But for many adults with intellectual or developmental disabilities, a suitable home is hard – sometimes almost impossible – to come by. Hundreds of thousands of adults with disabilities across the U.S. sit on housing “wait lists” for home and community-based services.¹ Even if they're ready to make the move out of their parents' home into community or independent living, the housing options and funding supports often don't exist. Some don't even receive the adequate services they need within their family home. As their needs change due to age and circumstance, some wait on corresponding changes to their services or type of residence.

For someone with a disability, the 22nd birthday is often bittersweet. While education of individuals with disabilities is guaranteed through mandates like the Individuals with Disabilities Education Act, support and services, including housing, are not guaranteed in adulthood. Once individuals with disabilities turn 21, they exit the public education system and enter the challenging and underfunded world of adult services. The support they receive depends on funds available, their determined level of need, and the programs and services in their region. Even families who start planning for this transition long before the 21st year find themselves without placement options on that bittersweet birthday.

I've met parent after parent struggling with this issue of housing and transition to adulthood. Parents of a preschooler with Down syndrome is already planning and determining how much money they should (and can) save to fund transition. Parents of a teenager with autism who think their son might be able to live independently with some supports are trying to figure out what kind of housing will be right for him and whether it exists near their hometown. A single mother tries to wrap her head around the complexities of adult services and housing, knowing she does not have the resources to fund her child's needs. An aging parent of an older adult with multiple disabilities still has his child living at home; they have been on a “wait list” for services and housing for over fifteen years. All these parents, like hundreds of thousands across the country, ask the same worrisome question: *Where will my child live and who will support them after I die?*

Increased funding is an important but only partial solution. Beyond the political challenges of securing increased funding, funding increases are constantly playing catch up with increasing numbers of people with disabilities needing support. In 2014 my home state of Connecticut, parents, advocacy organizations, and the disability caucus fought hard for \$4 million for the Department of Developmental Services (DDS) to support housing. Although an important step, that \$4 million placed only 100 people off the wait list of almost 4,000 at the time.² Funding alone won't likely fix the problem.

As the population of individuals with disabilities has grown and institutions for them have closed, advocates have responded by rallying parent support and launching new organizations; they have experimented with new policies, operational structures, and funding sources (especially from the private sector). Strategies

¹ The Arc. 'The Arc, Medicaid Issues.' N.p. 2015. Web. 15 July 2015.

² Connecticut Senate Democrats. 'Press Release From Senator Beth Bye.' N.p. 2015. Web. 18 June 2015.

for housing people with disabilities have diversified to respond to diverse needs.

Growing populations, decreased funding, and a diversity of strategies is a challenge for federal and state policy leaders as well as for on-the-ground service providers. Research on what makes a “quality” housing option is often conflicted. Strict regulations are clear about what is *not allowed* but fall short in defining what is *encouraged*. Best practices and key challenges in housing design and service delivery have not been sufficiently explored, defined, or shared. We generally understand what we want to remove and avoid in disability housing and services, but we lack a consensus about what we want to add or create.

With support from the Joint Center for Housing Studies at Harvard University and the Center for Public Leadership at the Harvard Kennedy School, this paper explores some of the issues facing individuals, families, providers, and policy leaders across the country. Using case studies of four very different housing providers, this paper explores current structures and offerings for housing for people with disabilities, what challenges create the biggest barriers for individuals and providers, and how policymakers can support the best possible housing choices for the millions of Americans with disabilities.

This paper focuses intentionally on the broader picture of disability housing, and aims to:

- Explore best practices and key challenges across different disability housing service providers and models.
- Outline universal policy challenges and areas where policy can better support best practices in disability housing.
- Provide a usable white-paper for those developing new housing for people with

disabilities, as well as for policymakers, agency directors, and service providers, on what we *should* be doing, as well as what we *shouldn't*.

- Identify areas where future research and assessment are needed.

Individuals with disabilities and their advocates have been fighting for thoughtful supports, inclusion in communities, and independent living since the 1960s "based on the premise that people with even the most severe disabilities should have the choice of living in the community."³ The challenge isn't new, but the regulatory approach and structural solutions will need to be.

Terminology: “Persons with Disabilities”

In this paper, the term “persons with disabilities” refers to people with intellectual or developmental disabilities or with autism. The term may refer to and include people with intellectual or developmental disabilities or autism who *also* have mental illness, physical disabilities, vision or hearing impairments, or medical needs. However, the reader should be aware that in this paper “persons with disabilities” *does not* refer to individuals who have *only* mental illness, physical disabilities, vision or hearing impairments, or medical needs.

Acronyms are defined when they first occur and also listed in detail in **Appendix A**

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³ UC Berkeley. 'The Disability Rights And Independent Living Movement - University Of California, Berkeley.' N.p. 2015. Web. 9 May 2015.

What's Happening

Policy Approaches

Many disability advocacy organizations attribute the start of a proactive national disability policy to John F. Kennedy's presidency and his family's continued focus on issues relating to disability because of their sister Rosemary. Even before Kennedy entered the White House, the family had launched the Joseph P. Kennedy Foundation aiming to "seek the prevention of intellectual disabilities by identifying its causes, and to improve the means by which society deals with citizens who have intellectual disabilities."⁴

Kennedy's time in office brought about the founding of the President's Panel on Mental Retardation, numerous public and congressional statements about the importance of supporting and caring for those with disabilities (particularly children), more scientific research into prevention and services, and the start of a national movement away from institutions for people with disabilities and towards "community-centered agencies."⁵ This process of deinstitutionalization continues today. In many ways, the Kennedy administration laid the foundation for subsequent legislation and court decisions (outlined in the following section).

Of course, disability policy has not always been driven by the White House. With more and more individuals with disabilities living independently outside of institutions, a movement of self-advocacy began to take hold in the mid-1960s. People with disabilities pushed for more peer-determined and self-determined decision-making

in policy design and service delivery.⁶ The Independent Living (IL) movement⁷ gave rise to Centers for Independent Living (CILs) across the US, beginning with the first one in Berkeley, CA in 1972 and totaling 403 today.⁸ At its core, the Independent Living movement aims to empower persons with disabilities to make their own decisions about housing and other matters, as opposed to having such decisions made *for* them. Independent Living leaders were key advocates in the disability legislation of the late 1960s and have continued to play a key role ever since. Self-advocates (people with disabilities) serve as key leaders in policymaking and service delivery for people with disabilities today.

One victory for self-advocates, the Kennedy family (particularly the late Senator Ted Kennedy), and disability service providers was the passage of the Americans with Disabilities Act (ADA) in 1990. ADA is considered by many as "one of America's most comprehensive pieces of civil rights legislation that prohibits discrimination and guarantees that people with disabilities have the same opportunities as everyone else to participate in the mainstream of American life."⁹ The ADA includes five titles: Title I focuses on employment issues; Title II is directed at public provision of services at the state and local level; Title III ensures "public accommodations" and addresses many of the physical accessibility barriers generally associated with disabilities; Title IV ensures telecommunications accommodations for those with visual and hearing impairment, a challenge that grows with the introduction of new technology; Title V includes miscellaneous provisions. At its core, ADA is about ensuring

⁴ The John F. Kennedy Presidential Library & Museum. 'JFK And People With Intellectual Disabilities.' N.p. 2015. Web. 3 Aug. 2015.

⁵ The John F. Kennedy Presidential Library & Museum. 'JFK And People With Intellectual Disabilities.' N.p. 2015. Web. 3 Aug. 2015.

⁶ National Council on Independent Living. 'About Independent Living.' N.p. 2015. Web. 28 July 2015.

⁷ National Council on Independent Living. 'About Independent Living.' N.p. 2015. Web. 28 July 2015.

⁸ UC Berkeley. 'The Disability Rights And Independent Living Movement - University Of California, Berkeley.' N.p. 10'5. Web. 9 May 2015.

⁹ ADA.gov. 'Introduction To The ADA.' N.p. 2015. Web. 4 Aug. 2015.

equal access to every facet of life – employment, public services, technology, spaces, and beyond – for people with disabilities.

ADA is just one of many federal laws impacting people with disabilities and their housing and adult services in the United States. **Appendix B** lists major laws impacting individuals with disabilities and their housing and services.

The attitudes to, approaches to, and acknowledged best practices in disability policy have changed over time. In many ways, the early Kennedy service-based approach, the philosophy of the Independent Living movement, and the goals expressed in ADA each define a specific attitude and approach to disability policy and service delivery. Each reflects the period it developed in, but each also still plays a role in how we think about disability policy today, including in the housing space.

I would summarize the underlying principles of these three evolving approaches to disability policy as, respectively, Care, Choice, and Access. Today we may find policies and programs that emphasize one over another: a care approach over a choice approach, an access approach over a care approach, and so on.

- **CARE: A Kennedy-driven era of special services.** Ground-breaking at the time and enabling the approaches to follow, the Kennedy-era approach centered around the idea that people with disabilities deserved special treatment, services, and care. Views on care have evolved since that time to reject the institutional delivery of care. However, there is still an emphasis on placements and services designed to meet the special needs of people with disabilities and emphasizing their care and protection.

- **CHOICE: A self-advocated Independent Living shift to emphasize self-determination and respect.** This period is characterized by “the idea that people with disabilities are the best experts on their own needs” and “do not see themselves as problems to be solved.”¹⁰ Still active today, Independent Living encourages self-advocacy by and choice for people with disabilities.
- **ACCESS: An ADA focus on equal access and opportunity.** The Americans with Disabilities Act is considered the most important legislation for people with disabilities. The ADA's legacy is vast, but perhaps most notable for mandating access for and banning discrimination against people with disabilities in services, physical spaces, and employment.

Understanding these varying approaches is helpful when we consider ongoing challenges for disability housing design, structure, and effectiveness.

Legislation and Litigation

Legislation and changing attitudes towards disability have both led to and been shaped by federal (and sometimes state) lawsuits and rulings. While legislation has sometimes felt slow or overly broad and unclear to public advocates, court rulings have often been more specific, fast-acting, and definitive. The “judiciary has served as an active catalyst, prodding governors, cabinets officials, and lawmakers to live up to their legal and moral obligations to children and adults with disabilities.”¹¹ This section discusses two of the most impactful court decisions affecting persons with disabilities.

Wyatt v. Stickney (1971) originated with the state mental health commissioner in Alabama's fear that planned layoffs at a state institution, Bryce State Mental Hospital, would “leave Bryce so

¹⁰ National Council on Independent Living. 'About Independent Living.' N.p. 2015. Web. 28 July 2015.

¹¹ Gettings, Robert M. *Forging A Federal-State Partnership*. Washington, DC: American Association on Intellectual and Developmental Disabilities, 2011. Print, 35.

short staffed that even the most minimal treatment services would have to be terminated” and patients would be left with poor quality of care bordering on neglect.¹² Ricky Wyatt, a patient at Bryce, brought the lawsuit. While the case was directed originally at institutions in the state of Alabama, it was almost immediately transferred to the federal court “to include all state-run mental health and mental retardation facilities.”¹³

The court ruled in favor of Wyatt, with Judge Frank Johnson stating that patients in mental health facilities “unquestionably have a constitutional right to receive such individual treatment as will give each of them a realistic opportunity to be cured or to improve his or her mental condition.”¹⁴ The case was followed by an issuance of an implementation order, in which the court outlined “minimum standards for adequate habitation of the mentally retarded,”¹⁵ now known as the “Wyatt Standards.” The Wyatt Standards helped to improve the care of individuals with disabilities living in institutions, but also set the stage for deinstitutionalization in the United States.

Wyatt v. Stickney wasn't the only case to address the poor quality of care for individuals living in institutions. In many of these lawsuits, including *Wyatt*, the United States Department of Justice (USDOJ) and the Federal Bureau of Investigation (FBI) played a supporting and investigative role.¹⁶ With the 1980 passage of the Civil Rights of Institutionalized Persons Act (CRIPA), the USDOJ was granted the right, after giving notice and an opportunity to correct rights violations, to “file lawsuits in a federal court to affirm the rights of persons residing in publicly operated residential

facilities.”¹⁷ The USDOJ continues to play a key role in investigations and lawsuits about the treatment and housing of persons with disabilities today.

Surely, the most prominent lawsuit in the disability services sphere is the 1999 Supreme Court ruling in *Olmstead v. L.C.* The plaintiffs in *Olmstead*, two women who had been involuntarily committed to a Georgia mental hospital, argued that rights guaranteed them under Title II of the Americans with Disabilities Act were being violated.¹⁸ Title II secures the right of persons with disabilities to receive public services without “discrimination,” whether or not those services receive federal funds; the law thus applies to all state and local service providers.¹⁹ Furthermore, Title II mandates that “a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”²⁰ On these grounds, the court ruled in favor of the two women and their desire to live independently. The *Olmstead* ruling disallowed inappropriate segregation of individuals with disabilities, requiring that services for individuals be delivered in community-based settings when:

*(1) such services are appropriate; (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.*²¹

Olmstead has played a significant role in the national move towards deinstitutionalization.

¹² Gettings, 36.

¹³ Gettings, 36.

¹⁴ Treatment Advocacy Center. 'Wyatt V. Stickney.' N.p. 2015. Web. 21 July 2015.

¹⁵ Gettings, 37.

¹⁶ Gettings, 46.

¹⁷ Gettings, 47.

¹⁸ Gettings, 51.

¹⁹ ADA.gov. 'Title II Highlights.' N.p. 2015. Web. 25 July 2015.

²⁰ *Olmstead v. L.C.* Supreme Court. 22 June 1999. Print.

²¹ ADA.gov. 'Olmstead: Community Integration For Everyone.' N.p. 2015. Web. 1 Aug. 2015.

Olmstead guidelines are applied to Medicaid Home and Community Based Setting waivers and other service delivery. The guidelines are used to encourage Medicaid funding be applied outside of institutional settings, with the ultimate goal that eventually no institutional settings will continue to operate. But, differing interpretations of what constitutes “appropriate” services or when such services can be “reasonably” accommodated still lead to disagreements about *Olmstead* guidelines used in Medicaid and beyond.

Funding Sources

Housing for people with disabilities generally requires funding to cover four areas: housing development, housing operations, support services, and medical services. Housing development includes both the funding required to develop affordable housing units or general residential development (including single-family and multifamily homes and, most recently, farm or campus-like developments). Housing operations include the costs to operate a home, including rent, utilities, and maintenance. Support services include general living supports such as food needs, transportation needs, home care, activities, hygiene supports, medication reminders or administration, and general ‘check-in’ needs. Medical services (not necessarily required by all individuals with disabilities) include more complex medical care at the level of skilled nursing needed by those with more significant disabilities or with additional needs brought on by aging or illness.

It’s helpful to understand these four funding areas – development, housing operations, support services, and medical services – as relatively distinct because the funds, departments, or programs that support them generally distinct as well. Service providers are often also required to account separately for these funding areas; some

states ban the same organization or agency managing the physical property as is delivering services. Additionally, as innovative new housing solutions are launched, those leading them must realize that developing a physical space is only the first of the many expenditures required to support the housing and service needs of adults with disabilities. The four areas outlined above are funded through a combination of federal programs, state developmental or special service budgets, public and private grants, and, more infrequently, individual funds or public-private partnerships.

Medicaid: Beyond covering medical costs for persons with disabilities (like prescription drugs and needs for those with medical issues), Medicaid is a major source of funding for services for individuals with disabilities. Medicaid currently funds assistance for 8 million non-elderly people with disabilities.²² Medicaid is funded through a combination of federal and state funds, with the exact balance varying by state. According to The Arc, “the federal government pays an average of 57 percent of total Medicaid costs, with contributions ranging from 50 to 76 percent.”²³

Medicaid offers both *mandatory* and *optional* services. While necessary and specific medical care (hospital, physician and nursing home services) is guaranteed and mandatory for individuals with disabilities, general support services (like home supports, personal assistance, day services, and beyond) are not automatically guaranteed.²⁴ Each state defines its own eligibility requirements for support services. Services are allocated based on determined level of need, funds available, individual state policies, and the “critical” or “emergency” nature of the needs or situation of the individual.

In the last twenty years, many of the federal requirements for Medicaid funding have pushed

²² The Arc. 'Public Policy And Legal Advocacy: Medicaid Issues.' N.p. 2015. Web. 15 July 2015.

²³ Ibid.

²⁴ Ibid.

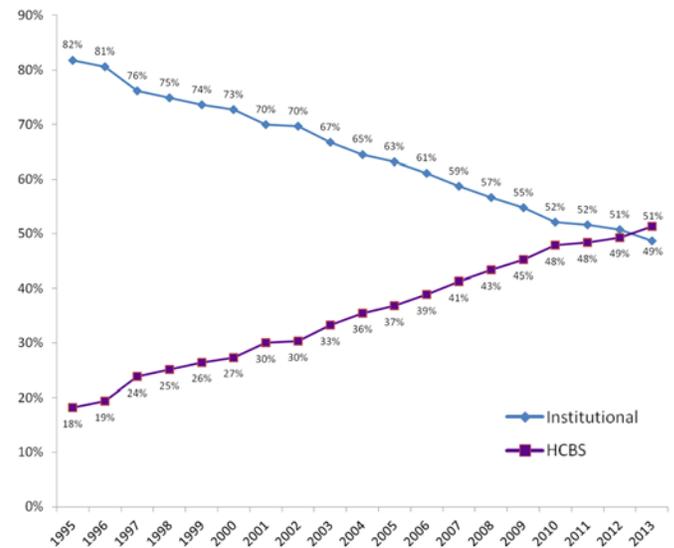
states and providers away from institutional and nursing care and towards more community based care. Medicaid funding for long-term services and supports (LTSS) can be divided into two buckets 1) Home and community-based services (HCBS) and 2) Institutional services, including “nursing homes, intermediate care facilities for individuals with intellectual disabilities (ICF/ID) and mental health facilities.”²⁵ Influenced by the *Olmstead* ruling and the Americans With Disabilities Act, HCBS Medicaid waivers were introduced in 1995 to allow Medicaid reimbursement for services to individuals living outside of institutional settings. The intention of HCBS waivers is to provide individuals with disabilities (and the elderly) “full access to benefits of community living and the opportunity to receive services in the most integrated setting appropriate.”²⁶ To be eligible for funding from the Centers for Medicare & Medicaid Services (CMS), a HCBS the setting must:

1. *Be integrated in and support full access to the greater community.*
2. *Be selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting.*
3. *Ensure an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.*
4. *Optimize, but does not regiment, individual initiative, autonomy, and independence in making life choices.*
5. *Facilitate individual choice regarding services and supports, and who provides them.*²⁷

With the introduction of the HCBS waivers and increasing pressure on states to close public and

private institutional settings, we’re experiencing a national shift in how Medicaid funds are allocated to support LTSS. In FY 2013, HCBS expenditures exceeded half of total Medicaid LTSS Expenditures for the first time since their introduction in 1995.

FIGURE 1: MEDICAID HCBS EXPENDITURES AS A % OF TOTAL MEDICAID LTSS EXPENDITURES (1995-2013)²⁸



Social Security: Many individuals with disabilities are eligible for Supplemental Security Income (SSI). SSI is targeted at individuals with little or no income, generally people with disabilities who are unable to work. SSI provides “cash to meet basic needs for food, clothing, and shelter.”²⁹ Individuals with disabilities generally use SSI to fund housing operations (rent, utilities, personal costs, etc.) and not support or medical services: SSI provides too little to cover any significant portion of service costs. Conversely, Medicaid funds, which do cover some service

²⁵ Eiken, Steve, et al. *Medicaid Expenditures For Long-Term Services And Supports (LTSS) In FY 2013*. Truven Health Analytics, 2015. Print.

²⁶ Department of Health and Human Services. *Final Rule, Medicaid HCBS*. Center for Medicaid and CHIP Services, 2014. Print.

²⁷ This list is abbreviated from Department of Health and Human Services Centers for Medicare & Medicaid Services 42 CFR Part 441 Medicaid Program; Community First Choice Option; Final Rule.

²⁸ Eiken et al.

²⁹ Social Security Administration Website. 'Supplemental Security Income.' N.p. 2015. Web. 10 July 2015.

costs, cannot be used to pay for housing operations or other non-service related costs.

However, most acknowledge that for individuals with disabilities, SSI comes nowhere close to covering the cost of basic needs, or even housing needs alone. According to a 2014 report by the Technical Assistance collaborative, "the average annual income of a single individual receiving SSI payments was \$8,995 — equal to only 20.1% of the national median income for a one-person household and about 23% below the 2014 federal poverty level."³⁰ If someone with a disability desired to live on his own in a one-bedroom apartment, he would face an average national rent of \$780, which is 104 percent of the national average monthly income of a person living on SSI.³¹ Essentially, it's impossible for a person with disabilities to cover the cost of her housing, or other basic needs, on SSI income alone.

HUD Development Funds: Through the Section 811 Supportive Housing for Persons with Disabilities program, HUD provides funding to develop and subsidize rental housing with available supportive services for very low- and extremely low-income adults with disabilities. It was modified by the Frank Melville Supportive Housing Investment Act in 1992 to integrate Section 811 housing into larger affordable housing developments.³²

Individual Contribution: Some individuals with disabilities pay for all or part of their housing. However, given the current climate of underemployment and poverty for individuals with disabilities and the high cost of services, it is usually not possible for them self-fund their housing, service, and personal needs. 2014 report by the United States Senate Committee on Health,

Education, Labor, and Pensions highlighted the daunting economic challenges faced by individuals with disabilities. The committee found that over 28 percent of adults with a disability live in poverty (a higher rate than for *any* other demographic category, including African-Americans and Hispanics); less than 30 percent of working-age Americans with disabilities participate in the workforce; and households with a member with a disability earn 38.4 percent less than households without.³³

Until these economic challenges are overcome, we cannot expect meaningful individual contributions towards housing and service needs. Policies aimed at increasing the employment rate and earnings of people with disabilities could help them cover more of their own housing costs, reducing the need for support through public funds.

Parent and Family Contributions: While many individuals with disabilities are individually low-income, not all families of people with disabilities are. There are many parents, siblings, and extended family members who actively save for and fund the housing and service needs for loved ones with disabilities. More and more parents are "opting out" of publicly funded and operated services, choosing instead to fund their own children. I met one parent who said he and his financial planner had determined he needed to save \$3M to cover his daughter's long-term housing and services.

Many families create "Special Needs Trusts" for their children with disabilities. The trust is carefully created in the name (and control) of someone other than the person with a disability so as to not impact eligibility for federal programs

³⁰ Cooper, Emily, et al. *Priced Out In 2014: The Housing Crisis For People With Disabilities*. Technical Assistance Collaborative, Inc., 2015. Print, 3.

³¹ Ibid.

³² U.S. Department of Housing and Urban Development. 'Multifamily Housing HUD Program Description.' N.p. 2015. Web. 1 Aug. 2015.

³³ United States Senate: Committee on Health, Education, Labor, and Pensions. *Fulfilling The Promise: Overcoming Persistent Barriers To Economic Self-Sufficiency For People With Disabilities*. 2014. Print, 8.

and services. The 2014 ABLE Act has now made it easier for parents to save, tax-free, to fund the long-term needs of their child with disabilities in a structure similar to a college-savings account. The ABLE Act also ensures that funds saved will not significantly impact service eligibility, so we may see parent contributions and savings play an even more active role in adult services in the future.

Private Foundations: Increasingly, private foundations are engaging in disability housing and adult services. Private foundations have played a role in innovating new housing solutions (ones that were ineligible for public funding), conducting research on the quality and effectiveness of different models and approaches, and directly supporting families who find themselves in crisis without services or supports. Many of these foundations were started by families of people with disabilities who struggled to address the housing and service needs of loved ones. These foundations include the Ruderman Family Foundation, the Doug Flutie, Jr. Foundation for Autism, and the Weinberg Foundation, among others.

Housing and Support Service Types

When people think of housing for adults with disabilities, they often have a specific structure or model in mind. Depending on age, people usually think of something similar to an institution (a large public facility where many people with disabilities live together) or a group home (a typical home in a neighborhood where two or more people with disabilities live and receive supports). However, current housing structures and residence types for people with disabilities varies greatly.

Generally, the first four housing and services operating models outlined below are eligible for

HCBS waivers. Each of these first four settings are considered community-based. Almost all of the current research “establishes clearly and consistently that individuals with Intellectual and Developmental Disabilities (IDD) experience greater personal freedom, more participation in social activities, more frequent associations with family and friends when living in the community rather than institutional settings.”³⁴

Parent/Relative's Home: Some adults with disabilities choose or are required to live at home with their family (parents, siblings, relatives, etc.). Individuals, as eligible, receive home-based services and supports within the physical space of their family home. They usually attend day or employment programs outside of their home on weekdays.

Community-Based Apartments: Some adults with disabilities rent their own apartments. Apartments rented by individuals with disabilities include both market-rate and subsidized units. Many individuals with disabilities qualify for Section 8 vouchers based on income, and some successfully obtain and use those vouchers. Within an apartment setting, people with disabilities may receive varying levels of support, ranging from a few hours a week to 24-hour services.

Community-Based Group Home: While there is no strict legal definition of “group home,” it is usually understood to be a home where two or more unrelated individuals live together and receive services and supports. Group homes can take on different forms and structures and may be operated publicly, or privately by a for-profit or non-profit organization or by the individuals themselves. Group homes that receive federal or state funding must meet certain requirements, including size limitations and building code regulations; they must adhere to certain

³⁴ Lankin, K. Charlie, and Roger J. Stancliffe. 'Residential Supports For Persons With Intellectual And Developmental Disabilities.' *Mental Retardation and*

Developmental Disabilities Research Reviews 13.2 (2007): 152. Print.

operational structures and track and report on service delivery.

Shared Living Arrangements: Often referred to as “adult foster care” or “paid roommates”, Shared Living Arrangements (SLA) occur when “an individual, a couple or a family in the community and a person with a disability choose to live together and share life’s experiences.”³⁵ The person without a disability serves as a general caregiver and is provided a stipend for doing so. States are encouraging more and more SLAs because the costs are lower than other housing offerings. Some also believe that SLAs provide more integration into the community for people with disabilities. In general, SLAs are most effective when the person with a disability needs some supports (more than would allow them to live independently) but does not need services at the level of a group home setting.³⁶ The ideal SLA candidate is thought of as someone who needs some daily supports and values the in-home companionship but does not need help with every daily function and does not have significant medical or behavioral needs.

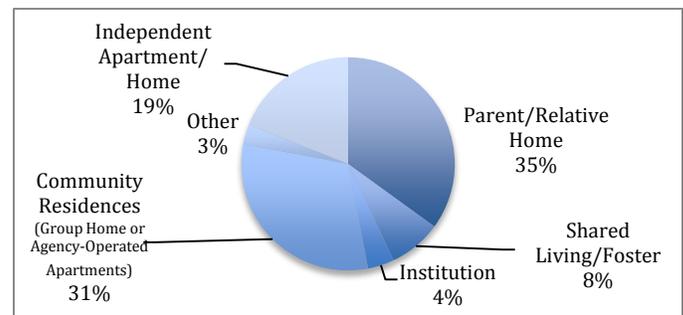
However, many families and service providers question the value and effectiveness of an SLA. Some parents feel that opting for an SLA for their child is “abandoning” their child to live with another family. Other people worry that individuals will choose to participate in an SLA only for the cash stipend and will not provide the best supports to the individuals who live with them. The newest of the housing models, SLAs are being defined, understood, and utilized more and more across the country.

Institutions: Despite national calls for deinstitutionalization dating back to the 1960s,

many individuals with disabilities still live in sate-run institutions or other institutional settings. Medicaid defines institutional settings as “facility-based” where “care is provided in and structured around institutions such as skilled nursing facilities (nursing homes) and, to a lesser extent, assisted living residences and adult family homes.”³⁷ In general, a residence is considered an institution (as opposed to a group home) according to its size, the level of medical care provided, and the amount of control a resident has over daily schedule and choices.

In 2013-2014, a national survey of 15,525 individuals across 30 states, conducted by the National Association of State Directors of Developmental Disabilities Services, showed the breakdown of residence-types in Figure 2.³⁸

FIGURE 2: RESIDENCE TYPES IN 2013-2014



The majority of those reporting their residence type live with a parent or relative, further research would be required to understand whether that was the dominant housing type by choice or whether it was a result of other options being unavailable or unaffordable.

The diversity of residence types reported by people with disabilities is encouraging; setting type is not a simple one size fits all solution. Just as every individual with a disability is different, so

³⁵ Arizona Developmental Disabilities Planning Council. *Shared Living: A New Take On An Old Idea*. National Association of State Directors of Developmental Disabilities Services, 2013. Print.

³⁶ Independence Association. 'Shared Living.' N.p. 2015. Web. 3 Aug. 2015.

³⁷ Centers for Medicare & Medicaid Services. 'Facility-Based Care.' N.p. 2015. Web. 3 Aug. 2015.

³⁸ *National Core Indicators At-A-Glance (2013-2014)*. National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI), 2014. Print.

too should be the housing options provided to the population. Despite their shared label, each person “with a disability” is different. (It’s often said that “if you know one person with a disability, you know *one* person with a disability”). It’s impossible to classify all people with disabilities as needing the same services and support. Even individuals who have the same diagnosis (Down syndrome, autism, intellectual disabilities) vary greatly in their characteristics and needs. Thus, perhaps with the exception of institutional settings, we should encourage a diversity of housing options and support choices wherever possible.

collaboratively by federal agencies, legislators, state directors, service providers, and individuals.

Thinking Forward

2015 marks twenty-five years since the passage of the Americans with Disabilities Act (ADA). In July 1990, President George H. W. Bush, surrounded by leading advocates for the rights of people with disabilities, signed the landmark legislation, proudly calling for the “shameful wall of exclusion [to] finally come tumbling down.” In many ways that wall has come down. The civil rights of people with disabilities are much more protected, and valued, than they were twenty-five years ago. All of us – both with and without disabilities – have benefited from the inclusion and universal design that the ADA and subsequent legislation have brought about. But rights, supports, and services for people with disabilities are far from fully secure. Inclusion has not been fully realized, services are still underfunded, regulation still causes difficulties even as it affords protections, and challenges remain. Housing adults with disabilities is one of those challenges.

We’ve invested a lot of time and funding supporting children with disabilities as they prepare to live independent and integrated adult lives, but those opportunities are often unrealized in adulthood. Twenty-five years after ADA, it’s time to fully realize them. Providing adult services and housing for individuals with disabilities is a challenge that must be addressed

Case Studies

In order to understand the challenges and successes in adult housing and services for people with disabilities, I spent time with four different providers. Each of these providers, profiled in case studies here, represents one of four different “models” in housing and services. Each of the four is quite different in the populations it serves and in its model of housing and service delivery. While these case studies profile only these four organizations, each represents a larger “set” of housing providers similar to it. By studying four different models representative of the disability housing and service space at large, I was able to identify challenges, best practices, and key themes that applied across multiple models as well as specific ones that apply only to single organizations.³⁹

Case Study: Southbury Training School

About Southbury Training School

You can't live in Connecticut and work on anything related to disability services and not know about Southbury Training School (STS). While addressing concerns about a lack of affordable and adequate housing for people with disabilities across the state, Southbury has been the topic of numerous discussions (and much disagreement). Yet, I was struck by how few policymakers, advocates, parents, and individuals had actually visited the grounds.

Southbury is located in western Connecticut on 14,500 acres across the towns of Roxbury and Southbury. When fully operational, Southbury had 69 buildings and 13 structures. Built in the 1930s, the site is protected by The National

³⁹ Note that financial data, as referenced in the case studies, was not fully available or shared for all organization. A detailed financial comparison of the case studies could be conducted but was not done as part of this research. All financial information is shared where available.



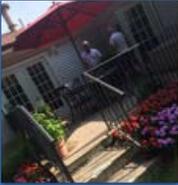
Southbury Training School
Southbury, CT
one of the remaining institutions for people with disabilities still operating in the United States



Sweetwater Spectrum
Sonoma, CA
a parent-founded home for sixteen individuals with autism, support services are provided by regional agencies



L'Arche
International
a global federation across thirty-five countries utilizing an integrated model where direct-service staff also reside in the homes



Looking Upwards
Middletown, RI
a state-wide agency that operates various housing types and adult service programs for people with a range of disabilities

Register of Historic Places.⁴⁰ According to Southbury's Director, Eugene Harvey, who has worked at Southbury for over 30 years, when fully operational the campus had 60 “cottages” housing people with disabilities; today there are fewer than 20. Southbury has been on track to close for over twenty years, so some buildings have been emptied and closed. While closure is planned, Southbury is still very much operational. They employ over 1,200 full-time and part-time staff and provide supports including “medical, vocational, residential, and therapeutic and facility support services”⁴¹ to over 300 residents.

For the most part, institutions are referred to as things of the past – places where people used to live and where bad things happened. We hear leaders and housing directors speaking of efforts

⁴⁰ National Register of Historical Places. 'Connecticut Litchfield County.' N.p. 2015. Web. 4 Aug. 2015.

⁴¹ The State of Connecticut Department of Developmental Services. 'About The Southbury Training School,' N.p. 2015. Web. 4 Aug. 2015.

to "not feel institutional" or "not be institutional" in their provision of supports and services. When you meet older individuals who work in disability services, they often refer to a period of deinstitutionalization. But few acknowledge that we are still in the thick of this period. Institutions are not a failure of the past: they're a reality of the present.

A sitting room in one of the cottages at Southbury contains a mural painted by a doctor who works on site. Careful attention has been paid to the décor at Southbury in an effort to create a welcoming and comfortable atmosphere.



Southbury has many unexpected elements. I was surprised to encounter a music class, a dental clinic, and an accessible fitness facility; staff who had been there for thirty years and who could recall journeying with residents (or "clients") through all the phases of their lives, from moving in, to sharing grief in the loss of loved ones, to the challenges of aging; rolling hills, and a remarkable indoor mural painted by a doctor who works in the facility during his free time; photos on the walls and paintings done by residents lining the corridors. For the most part, Southbury is a place where residents, many of whom have lived there since childhood, seem happy. Guardians are satisfied with the services delivered. Martha Dwyer, sister and guardian of a Southbury resident and head of the STS Home & School Association, says she "believes STS provides superb care to my brother in as integrated a community as is possible for him and that everything he needs is available to him."

The average age of a Southbury resident is 66, and increasing needs with aging are a major challenge. According to a 2015 report released by the State of Connecticut, Southbury serves residents with complex and profound needs:

three-quarters have severe or profound intellectual disabilities; one-quarter cannot walk; 43 percent also have a psychiatric illness; 36 percent have seizures; 16 percent will ingest inedible objects if they are not carefully watched; and 13 percent require a feed-tube at all times.⁴²

These needs are what the state says drive higher costs at Southbury and what guardians say require their loved ones to remain in a place with the supports and level of care that Southbury offers. During my visit, I noticed a range of needs and abilities among Southbury residents. Having admitted no new residents since the 1980s, Southbury had an older population than the other places I visited. One cottage I visited was home to people with significant medical needs and limited ability to leave their homes. Another had individuals who were fully mobile, conversational, and able to be engaged in the community beyond Southbury's campus.

One of the most striking things about Southbury was the physical space. Funded by the STS Home and School association, Southbury has clearly made redesigning spaces to make them more home-like and appealing a priority. But even in its beautiful rooms, Southbury still had elements that did not suggest the same level of self-determination or respect as in other sites I visited. While their Director, Eugene Harvey, spoke lovingly to residents, I noticed the general trend was for staff members to speak *about* clients rather than *to* or *with* them. It was the only provider I visited where I wasn't introduced directly to each client I encountered (something that happened with every single resident during

⁴² 'State: Overtime And Support Costs At Southbury Are Justified.' *The Hartford Courant*. 13 April 2015.

my other site visits). It was the only provider where staff discussed clients and their needs in the presence of those clients but without engaging them in the discussion. When we visited their state-of-the-art medical clinic, a care provider spent several minutes describing a breathing therapy program while a client received the therapy, without directly addressing the client or asking them if they were comfortable with my observation.

These behaviors towards clients set a definite tone in Southbury that was different than in the other providers I visited. At Southbury, people with disabilities were often spoken about and treated more as clients or patients than residents or people. While design upgrades and restructuring are relatively expensive, adjustments to the staff's manner of engaging clients can be achieved with minimal cost.

Key Themes From Southbury:

Difference Between Deinstitutionalization and Community Creation. Before visiting Southbury, I understood "institutional" care entirely in negative terms: being "institutional," I thought, was what providers ought to *avoid*. Being institutional meant hospital design and fluorescent lighting, abuse and neglect; it meant padded walls, locked doors, shock therapy, and forced time sensory rooms. Our policy-making, legislation, and litigation in the disability services space have reflected this understanding negative understanding of institutional care: they have focused on regulating what providers and support staff *can't* do and *must avoid*. They have focused, in short, on *deinstitutionalization*.

Southbury seems to have achieved much of the "de" in deinstitutionalization. It wasn't all that different from other group homes or residences for people with disabilities I've visited. Yes, some things about Southbury didn't feel right to me, but

it also didn't have the features that I knew to be wrong. The reality is, *avoiding* being institutional isn't enough. Defining rules about what people *can't* do isn't enough. *Limiting* the size, activities, or structures of a home isn't enough. Stripping away "institutional-ities" does not a meaningful home make.

Perhaps where we're missing the boat is that we've spent so much time preoccupied with deinstitutionalization that we've failed to focus (or even hone in) on what it means to create life-giving communities – on what we can add to the life of someone with a disability to make it a happy one.

Heidi Grant wrote a piece for *Harvard Business Review* on "Nine Things Successful People Do Differently."⁴³ Number nine? "Focus on what you will do, not what you won't do." Grant says, "research on thought suppression (e.g., 'Don't think about white bears!') has shown that trying to avoid a thought makes it even more active in your mind." So, successful people focus on what they need to do right in their jobs, relationships, and even diets, rather than on what they should remove or avoid. The same could hold true for our



While residents are supported to design their rooms with paint color options, artwork, and furniture selection, Southbury still has "institutional" elements that include shared rooms and hospital-style beds and floor plans.

approach to the issue of disability housing and

⁴³ 'Nine Things Successful People Do Differently.' *Harvard Business Review*. N.p. 2011. Web. 20 July 2015.

our long, continuing, incomplete journey to create supportive communities for people of all abilities.

In the realm of housing for people with disabilities, we know what we *don't* want to do. But, do we know what we *do* want to do? We understand the process of deinstitutionalization fairly well. Now we need to figure out the nuances of true community creation.

Defining Perceptions of Single Incidents. STS has both strong proponents of its operation and strong advocates for its closure. I noticed that both those who advocated for Southbury's closure and those who desired services to continue often justified their opinion through specific incidents or anecdotes. Examples of these include:

- A *Hartford Courant* article reported on "a DSW supervisor [who] earned \$186,170 last year, including \$114,338 in overtime," and concluded that Southbury's operational costs are too high as a result of salaries and overtime billing.
- The sister and guardian of a Southbury resident explained that her brother's former roommate, who had needs similar to her brother's, moved out into the community and choked to death. Based on this incident, she believes that the community outside Southbury isn't ready to support people with her brother's level of needs.
- Another Connecticut housing provider explains that many of the individuals he serves speak to how much better their current home is compared to Southbury, implying that everyone at Southbury can be equally or better served by outside providers.
- A director at Southbury tells a story about a lifelong resident who sees Southbury as "home" and doesn't want to leave, implying that residents of Southbury won't find suitable homes outside that community.

Are costs at Southbury driven in large part by high salaries, state-worker benefits, and overtime wage? In part, yes. Do community providers need more support and training to serve people with profound needs in integrated settings? Likely. Do anecdotes about the satisfaction of particular residents help us understand the needs of a larger population? Maybe. But these anecdotes and single incidents cannot be the basis of our public policy approach to disability services.

The Scarcity Mindset. The debate around Southbury is also indicative of a large public policy challenge rooted in a concept of scarcity – in the idea that one person's or population's gain is another's loss. Leaders in public policy, service delivery, and advocacy need to do everything they can to combat this "us versus them" approach. In some ways Connecticut, as explained by one Southbury guardian, is "forcing parents who are on the waiting list for services to fight with parents who have them in STS for the limited funds that are available to them."

This scarcity mindset exists both within the disability community and outside it. There have been other concerns and disagreements about people with disabilities displacing low-income populations without disabilities in public housing. Conversely, others argue that low-income populations are receiving subsidies or housing placements that should be targeted at people with disabilities. Scarcity is a real thing. Resources are actually limited. But perhaps a more effective approach than "us versus them" figuring out how services can be designed to serve a wider range of needs and populations at once. It's possible that combining services across different "groups" could actually provide cost-savings. In Connecticut, perhaps the most effective solution is to somehow use Southbury to build a new community that would serve people on the wait list. The dominant voices and discussions right now do not seem to be enabling that kind of collective problem-solving.

Case Study: Sweetwater Spectrum

About Sweetwater

In the next ten years, 500,000 individuals with autism will turn 21 and need housing supports not currently offered in the system. There is a growing trend of families of children with disabilities, autism in particular, attempting to build their own housing placements to serve their children. Sweetwater Spectrum is one such development.

When I went to visit Sweetwater Spectrum in Sonoma, California – having read about their work in the *New York Times* and *Fast Company* – I thought it was going to be a community defined by design, architecture, and innovation. But the Sweetwater story wasn't really about those things. At its core, Sweetwater is a community defined by choice.

In 2006, parents set out on a mission: create a community where their children with autism could live a "life with purpose." Their idea grew to a 2.8 acre, \$9.2 million residential development located a ten-minute walk from Sonoma's town center. The community opened in 2013 with residences for sixteen individuals with autism, currently men and women in their twenties and thirties. The real estate is impressive, and the design challenges any preconceived notion of what specialized housing looks like. Instead of the usual barcaloungers, one finds an eclectic mix of resident-picked furniture and white-washed design with soothing landscaping, an in-ground pool, and sleek interiors.

Yet Sweetwater's executive director, Deirdre Sheerin, doesn't believe the physical space necessarily defines the community she has led since its opening. "I don't think you need to have \$9 million dollars in real estate to do the Sweetwater model. The real estate is fabulous, but I really think it's about the culture of community and collaboration that is the crux of the model and what really contributes to life with purpose."

"Live with purpose" is written above the windows in the community room, penned throughout scrapbooks visitors can browse, and printed on every publication. At Sweetwater, it seems, purpose has a lot to do with independence, freedom, and choice. Longtime resident Andrew, who starts college classes this summer at nearby Santa Rosa Junior College, likes his "sense of independence" at Sweetwater. Yet no two residents are alike: some want independence and others need 24-hour support. Andrew says life at Sweetwater "can be adjusted to the needs of various residents."

I was almost embarrassed as soon as the question "what's a typical day for a Sweetwater resident?"



Andrew provides a tour of Sweetwater and the house he shares there with three other individuals with autism. He explains that life at Sweetwater "can be adjusted to the needs of various residents."

left my mouth. Is there a "typical day" common across residents of other residential complexes? Nope. There is no defined day at Sweetwater, either. Their "resident-centered" model gives residents control. The community generally empties between 9am and 2pm while residents go to jobs, school, vocational training, community outings, errands, and volunteer activities. When they return, they can spend time in the pool, work on the farm, join community art activities, or relax inside their homes. Gwen, a resident who let me tag along with her around Sweetwater, said she likes that she can "be in charge of [her]] own schedule."

Residents also choose housemates. When there is an opening for a room in one of the four four-bedroom houses, Sheerin does initial screening of resident applications and then passes them over

to the current housemates. Residents have the option to invite applicants to join their community. As in any home, there are conflicts and challenges. There are some housemates who are fast friends and spend lots of time together, while others share space but live more individually. Sheerin reminds me that Sweetwater is really "people living with people." While all residents have autism, at the core it is simply a community of people.

Choice at Sweetwater doesn't apply only to schedules. One of the most interesting elements of their structure is that residents, along with their families, can choose support service providers independent of Sweetwater. Sweetwater is itself a landlord (a caring and attentive one). For daily and overnight support, residents choose from regional providers. Right now, residents are supported by three different providers: Lifehouse Agency, Bayberry, Inc., and On My Own.

Thoughtful collaboration and communication with these providers is a key element of Sweetwater's effectiveness. Suzanne Phillips serves as Sweetwater's Enrichment Coordinator – part cruise director, part resident advisor. She collaborates with support staff on resident events and community engagement. At Sweetwater there is an intentional difference between "caring for a resident versus supporting a resident," Phillips says. She and Sheerin cheer on support staff, reminding them that each staff member is "more than a care provider, but a guide that makes a real difference in the long-term life of the resident." And it's not just talk: they also support the support staff through incentives (including massage sessions!), longevity grants to long-term staff, training, and education specific to adults with autism.

I can imagine that some choices built into the Sweetwater model might be at best daunting and at worst terrifying to providers and service administrators. The idea of three different service providers under one roof could seem like a recipe for chaos. It might be scary to think about

residents simultaneously taking a swim, cooking dinner, and working on an on-site farm. It may be frustrating not to have a set schedule that administrators can easily track and manage. Letting residents choose their own roommates could be challenging.

But we have to put the risks, fears, challenges, and uncertainty aside in favor of choice. Choice is closely aligned with respect, dignity, happiness, and independence – things each of us seek daily. And, at Sweetwater Spectrum, choice creates "life with purpose."

Key Themes From Sweetwater

Separating Housing from Services. The idea of delivering support services separately from physical housing isn't new: many adults with disabilities receive services in apartments or family homes. However, separating physical (rental) housing from services within a larger intentional community that serves people with disabilities is relatively unique. Studies show that ability to choose your provider has a direct link to quality of care and satisfaction with services. Sweetwater provides that choice and allows individuals to change service providers or day programs with virtually zero interruption in their home life.

Sweetwater residents work together during a weekly Farm Night. Throughout the week, residents can choose to work in the farm, collect fresh eggs to cook with, or sell produce in their community farm stand.



The separation of housing from services within a single setting also allows each organization (Sweetwater vs. the support service agencies) to capitalize on their comparative strengths. While

mutually reinforcing each other, each organization has its own focus. Sweetwater is able to focus specifically on home life, physical design, and the creation of a residential community. Support providers and their staff can focus on direct support, vocational opportunities, skill development, and community integration.

Parents and Families Can Pay. Services and physical spaces like those at Sweetwater don't come cheaply. But Sweetwater stands as living proof that parents can and will pay for the housing and services they think are best for their children. Sweetwater is a high-cost residence and, of course, not all parents can afford it. Not all housing offerings can or should require the high cost of Sweetwater; it is not scalable. But the reality is that some parents can and will pay. Although disabilities are a significant financial burden for many families, there are also those families for whom finances pose no challenge whatsoever. The ability to save tax-free for children with disabilities ensured by the recent passage of the ABLE Act will allow even more parents to save for and contribute financially to their child's services. Yet "even with all the money in the world," one parent of a Sweetwater resident explains, "I can't buy the kind of housing we want for our child." There are parents ready to be buyers in the provision of intentional and supportive housing for their children with disabilities, but there are few providers or developers creating it.

Choosing Your Ideal Community. After spending the day with a resident at Sweetwater, Gwen, I asked her if she liked living with other people with autism, and specifically how she'd feel about living with someone without disabilities (like me). I tried not to be offended when Gwen said no: although she sometimes wished there was "less of a spectrum," she liked living with people who have autism, and would be "kind of nervous" to live with people who don't. Some people may see her attitude as conditioned or question whether she wants to live with people with autism because it's the only setting she's

experienced. But, her preferences were very clear and we should respect people with disabilities decision-making and desires. Many people without disabilities choose to live with people who are like them – in race, age, gender, or interest. People with disabilities should be afforded that same choice.

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 deinstitutionalization 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.

Case Study: L'Arche International

About L'Arche

In 1964, a man named Jean Vanier invited two men with disabilities to leave the institutions they lived in at the time and instead to "share life" with him in Trosly-Breuil, a village an hour outside Paris. Vanier, a Catholic theologian, was inspired by faith to start this first "community," which has had spiritual roots since its founding and which is still run on those principles today. L'Arche is French for "The Ark," referring to Noah's Ark. Celebrating over 50 years of service in 2014, L'Arche now consists of a federation of 147 communities in 35 countries. Each community still adheres to the mission by which the three original L'Arche community members defined themselves in France:

We are people, with and without developmental disabilities, sharing life in communities belonging to an International Federation. Mutual relationships and trust in God are at the heart of our journey together. We celebrate the unique value of

*every person and recognize our need of one another.*⁴⁴

L'Arche first came to the United States in 1972 as a community in Erie, Pennsylvania.⁴⁵ Today, there are eighteen L'Arche communities in the United States (Iowa, Virginia, Illinois, Pennsylvania, Ohio, Florida, Kansas, Alabama, Massachusetts, Washington, Oregon, New York, California, Washington, D.C., Georgia, and Missouri). Each community operates as a separate 501c3, with its own Board of Directors, funding, and leadership team. In 1997 L'Arche USA was established to support L'Arche communities across the country, including the eighteen established and the seven currently emerging communities. L'Arche USA also operates as its own independent 501c3 with a Board of Directors and staff of eleven (eight full- and three part-time).

I spent time in two United States L'Arche communities: L'Arche Boston North (formerly L'Arche Irenicon) and L'Arche Greater Washington, D.C. (GWDC). L'Arche Boston North is based in Haverhill, Massachusetts, thirty miles outside Boston. Founded in 1983, the community consists of three homes and one apartment building. The L'Arche Boston North community includes fifteen individuals with disabilities and approximately eighteen without. L'Arche GWDC also opened in 1983 and includes two homes in a neighborhood in Arlington, Virginia and two homes in Adams Morgan in Washington, D.C. The GWDC community includes eighteen individuals with disabilities and twenty-five without. In addition to visiting those communities, I conducted interviews with international L'Arche leaders in Europe and Canada.

Structurally, a L'Arche home is similar to a group home for adults with disabilities. Yet it differs in that individuals without disabilities – at least one, but sometimes equal in number to residents *with*



Eileen in her bedroom at one of the L'Arche Greater Washington DC houses in the Adams Morgan neighborhood. She's well known for her tours of the large townhouse. Eileen also works in the L'Arche offices a short walk from her home.

disabilities – also live in the homes. Financially, L'Arche also operates similarly to a group home, receiving funding through Medicaid and government disability services contracts, individual donations, grants, and individual contributions, as well as earned income through rentals.

According to their most recent IRA annual filings, L'Arche Boston North operated with \$1.3 million in annual expenses (2014) and L'Arche GWDC with \$2.5 million (2013). L'Arche Boston North serves fifteen core members with disabilities for approximately \$79,000 per person in direct costs. L'Arche GWDC serves their sixteen core members for approximately \$128,000 per person. These differences in costs are likely due to differing costs of living in the two cities, varying operational structures, and varying personnel structures and costs (the cost of living is probably the most impactful difference). Comparing ten different L'Arche USA communities for whom annual filing data was available, the average direct per-person cost was \$72,000, with a low of \$36,000 (Wavecrest in Orange, CA) and a high of \$128,000 (GWDC).

In 2014 Boston North had total annual revenues of \$1.4 million, with 91 percent from government grants and program and service revenue and 9 percent from private contributions. GWDC had

⁴⁴ L'Arche USA. 'Identity And Mission, L'Arche USA.' N.p. 2015. Web. 2 Aug. 2015.

⁴⁵ L'Arche USA. 'History Of L'Arche USA.' N.p. 2015. Web. 2 Aug. 2015.

revenues of \$2.7 million in 2013, with 84 percent from government grants and program and service revenue and 16 percent from private contributions. Both L'Arche communities raise funds through rental income, paid by assistants who choose to live in the community (ensuring that live-in and live-out assistants are compensated at the same rate).

Each independent L'Arche community – including Boston North and GWDC – belongs to the international L'Arche Federation. Membership comes with dues and certain requirements, but also provides access to training, best-practice support, brand use, and international gatherings to share and network with communities from across the globe. The international parent organization is “careful to ensure the values of the Federation are lived in harmony with local cultures, traditions and socioeconomic contexts, avoiding imposing a ‘one-size-fits-all’ outlook on widely varying cultural environments.” For an international federation of almost 150 communities on six continents, a key question is what requirements and ensured values should be standard across all communities and what should vary based on local culture, needs, and policy.



A Core Member and Assistant share dinner at L'Arche Boston North. Shared meals are an important tradition in all L'Arche homes around the world.

One thing common across all L'Arche communities is the intentional and specific language used. People with disabilities who live and are supported in L'Arche communities are called “Core Members.” People without

disabilities who work in L'Arche communities are called “Assistants”; there are both Live-in Assistants and Live-Out Assistants. When Assistants are working in a L'Arche home, they refer to it as “Sharing Time” (rather than as being “on shift,” “on the clock,” etc.). Assistants and Core Members are paired with each other as “Accompaniers”; they directly support each other in all facets of life, personal, spiritual, social, and medical. The support within “Accompaniment” is mutual; A core belief at L'Arche is people with disabilities support people without as much as if not more than the inverse.

These language choices help standardize operations across the L'Arche Federation; a community in which members visit each other and share best practices needs a shared terminology. But the language choices also set a very specific tone for how homes operate and how service is delivered. The term “Core Members” is a reminder that persons with disabilities are generally in the community more permanently, while the Assistants may come and go. The term “Sharing Time” is a reminder that the “work” of L'Arche is less a matter of performing tasks and duties than of supporting individuals, understanding what they need when, and building real relationships.

Vanessa Henry is the Community Coordinator at L'Arche Boston North; before coming to L'Arche, she served as a case manager for people with disabilities in Virginia. Henry says concepts like Sharing Time and other intentional choices about service delivery make L'Arche different from other providers she has encountered. “We’re not just here to take care of basic needs but to feed people’s souls,” Vanessa explained. “We’re gaining something and forming people.”

Shared language at L'Arche isn't just logistical; common language is also used by community members and leadership to define their values and identity. L'Arche International has done an exceptional job of making sure language and values from the international office are translated

to individuals at the local level. At L'Arche GWDC, community members from one of the Arlington homes and visitors from an emerging community in Mexico joined together in an activity to contemplate the what it means to be Members of L'Arche. Their word map included many of the same words used by other leaders and members of L'Arche in publications, reports, and the organization's vision statement, including: solidarity, belonging, relationships, vulnerability, and celebration.

Interestingly, while L'Arche's founding was quite strongly based in Catholicism, the words mapped did not include specific religious references. Still, the spiritual identity of L'Arche was apparent across all of the homes I visited and with all of the community members I interviewed. Each home included a time of prayer after evening meals. During prayer, or in one-on-one discussions, some L'Arche community members referred quite specifically to a Catholic or Christian identity. Others identified more with a general spirituality, humanistic approach, or culture of "mindfulness" and "contemplation." Christian and beyond, the spiritual identity of L'Arche seems to connect community members and provide the foundation for almost all of L'Arche's operational structures and service delivery.

At its core, L'Arche defines itself through relationships – with God, with one's L'Arche community, and with the outside world. Relationships rooted in love and mutual respect at L'Arche are what GWDC Executive Director says help L'Arche achieve its "vision of what it means to be truly human" for community members both with and without disabilities.

Key Themes From L'Arche

Value of Collective Identity. L'Arche defines itself around a shared spiritual or religious identity. While that specific identity is important to L'Arche's mission and operational structure, the more valuable takeaway from L'Arche is that any

intentional shared community identity is valuable in itself. This is particularly the case when creating a community where people with and without disabilities live together. Having an intentional shared identity means that immediately community members have something in common, beyond the idea that "I'm here to support you" or vice versa, that meaningfully unites and connects them. Shared identity provides an additional tool for staff recruitment, development, and retention. And, shared identity is a way for a community designed to meet the needs of people with disabilities to connect to the broader community outside. Shared identities don't need to be religious, as L'Arche's is. They could center around health and wellness, the arts, innovation, and beyond.

Encouraging and Using Integration. What sets L'Arche apart from other group homes or community living for people with disabilities is the fact that individuals without disabilities are there not solely as support staff but as members of the community. This integrated approach means that individuals with disabilities who live in L'Arche have access to more meaningful relationships, community experiences, and perhaps even enhanced quality of service. At L'Arche, integration may also be a tool for cost-savings and revenue generation: L'Arche raises funds from former Assistants and members of the community who donate back to the mission, and from rental revenue from live-in assistants.

Rejecting a Clinical Approach. There are lots of things that happen at L'Arche which look, sound, and feel different than at other disability service providers I've encountered. You hear the word "love" a lot. Physical contact is encouraged: hugs are never in short supply, and you may even find community members and assistants exchanging backrubs and food massages after a long day. Together, Assistants and Core Members take vacation and go out with friends, to family events, and into the community. L'Arche Core Members with disabilities are supported to make choices and take appropriate risks to the fullest extent

possible. L'Arche works hard to bring down the traditional boundaries between direct service professionals and the individuals they support. L'Arche's relationship-driven and self-directed approach directly aligns with the Independent Living Movement's push to reject the idea that "disabilities are impairments to be cured through medical intervention."⁴⁶

Executive director of L'Arche GWDC, John Cook, says that L'Arche's model challenges in the best possible way "what it means to be a professional" in the disability services space. They announce their unique culture and approach up front when recruiting staff and support it through training and coaching. Cook and the L'Arche community recognize that bringing down the commonly accepted professional barriers between staff and those they serve "is not a one size fits all." Not every relationship within L'Arche looks the same, that diversity and humanism is embraced. People will connect differently with different people, relationships will evolve over time, and barriers will shift. The common theme will be that while relationships will form and evolve differently, the L'Arche values of love, mutual support, and community will be held common and permanent.

Case Study: Looking Upwards

About Looking Upwards

It's safe to say Looking Upwards has experienced it all when it comes to modern disability housing and services. Founded in 1978, the organization has seen deinstitutionalization up close and personal as they welcomed individuals previously institutionalized into community-based settings. They operated through the passage of legislation from CRIPA to ADA to ACA. They have served people with diagnoses that didn't exist when the organization was founded.

Today, 37 years after its launch, Looking Upwards is one of the largest disability service providers in the state of Rhode Island.

With an annual budget of \$13 million, Looking Upwards provides services and supports to over seven hundred individuals with disabilities. The agency is a member of the Keystone Group, a group of three disability service provider organizations in the State of Rhode Island, that plays a key advocacy role in state and federal disability regulation and policymaking. Looking Upwards offers services for both children and adults, sometimes following and supporting an individual from diagnosis throughout each phase of his life. Their mission is simply stated as:

*Supporting adults with disabilities and children with diverse needs in living fulfilling lives.*⁴⁷

In adult services, Looking Upwards' supports "include vocational, day enrichment and a variety of residential options."⁴⁸ The *variety* of residential options and the range of needs of the individuals they serve set Looking Upwards apart. Their executive director, Carrie Miranda, who started out as a direct-service professional thirty years ago, says that at Looking Upwards "anybody can walk through the door and we can work really hard to figure it out." They support adults with disabilities that range from intellectual disabilities, cerebral palsy, autism, traumatic brain injury, mental illness, and beyond. They were also the only provider I visited that supported individuals in every single type of HCBS-eligible residential setting (family home, apartments with varying levels of care, group homes, and Shared Living Arrangements). Looking Upwards says they're "limited by what's allowable" and work hard to creatively meet the needs of the widest possible range of individuals.

⁴⁶ National Council on Independent Living. 'About Independent Living.' N.p. 2015. Web. 3 Aug. 2015.

⁴⁷ Looking Upwards. 'Welcome to Looking Upwards.' N.p. 2015. Web. 20 Aug. 2015.

⁴⁸ Looking Upwards. 'About Looking Upwards.' N.p. 2015. Web. 20 Aug. 2015.

According to IRS filings in 2013, Looking Upwards spent \$6.8 million on their adult residential services. With approximately 100 individuals receiving services in that program, their average per-person costs was \$68,000. That cost varies quite significantly based on diverse individual needs and the different housing structures: care for someone living independently with 15 hours of supports per week costs less than for someone with significant medical needs who requires 24-hour support. In a residential group home model, Looking Upwards typically has an annual cost of \$90,000 per person. Looking Upwards owns the homes where they operate group homes; some of these homes were purchased on the market and others were "sold" to Looking Upwards by the state for \$1. Operating costs vary depending on whether the home has a mortgage. Rental payments (which residents usually pay with their SSI) generally cover those home operating expenses. Some homes are able to cover all operating costs with rents, while others are supplemented by other Looking Upwards funding.

I visited two of Looking Upwards' group homes, in Newport and Middletown, RI. Eustis Avenue, in Newport, is a home for four women of varying ages and abilities. William Lane in Middletown is a home for six men with diverse needs, on average more complex than the needs of Eustis residents.

The newest and youngest resident at Eustis, Kelsey, 28, moved in five years ago. As Kelsey was approaching her 21st birthday, her parents reached out to Looking Upwards to explore what housing options might be available for her. Kelsey, who has multiple disabilities and uses a wheelchair and sign language, was already receiving child services through Looking Upwards. Her parents were interested in creating a new community where individuals with disabilities could live connected to the local university, Salve Regina, and alongside people without disabilities. They struggled to realize this vision. "There was a lack of flexibility from the state," Miranda recalls; "the state was so rigid on

Residents in a Looking Upwards group home help cook breakfast. Looking Upwards offers services within group homes, shared living arrangements, apartments, and at home-supports.



its willingness to provide funding, that every idea that was creative wasn't viable." As they were exploring the development of a new home, a space opened up at the Eustis Looking Upwards home. However, the home wasn't accessible to someone with Kelsey's needs.

At that point – with challenges from the state and a housing possibility they thought could work for Kelsey – her parents shifted their focus. Rather than building a new home, they offered to fund the renovations needed to accommodate Kelsey at Eustis. The renovations were approved (not without challenges) and Kelsey moved in as the newest Eustis resident. This approach serves as an example of how parents, within the context of a larger agency, can play an impactful role in providing housing and services for their children with disabilities.

At both Eustis and William Lane, I met residents who had come to Looking Upwards after leaving a Rhode Island institution, the Ladd School, which closed in 1986. When asked what that experience was like, Larry quickly shook his head and waved his hand as he responded, "no good!" Another resident, Hope, explained all the things she liked about her home at Eustis compared to Ladd: "I have my own house, my own room, my own kitchen, and my own porch." That sense of ownership and self-determination is supported by Looking Upwards, and directly contrasts with the past institutional experiences of many of their residents.

Looking Upwards doesn't only operate group homes but also supports individuals living in their family home or independent apartments. Seven individuals receiving services through Looking Upwards live in an apartment building in downtown Newport. The apartment building, the Paramount, is a Section 8 building with 63 apartments. Four of the Paramount residents receive 24-hour support from Looking Upwards and three receive periodic supports. One unit is home to a husband and wife who have transitioned from periodic supports to 24-hour care while living in the same space. Having multiple units within one building means Looking Upwards directors and staff can check in on residents all together, share supports across the different units, and support community integration across their seven-person community and within the apartment complex.

Key Themes From Looking Upwards

A Range of Needs and A Range of Options. While there is space for specific housing models and supports designed to target specific needs within the disabilities community, Looking Upwards



Mary is supported by Looking Upwards in her independent apartment in Newport, RI. She lives with her husband, who also has disabilities. As their needs grow, Looking Upwards is able to add on services and staff hours without requiring them to move to a new housing setting.

achieves the important goal of meeting diverse needs and supporting choice through the customization of housing and support services. Understanding a range of needs and providing

options also means that Looking Upwards can serve individuals as their circumstances change, providing some consistency in services even as the required services change. For example, there are Looking Upwards clients who first received supports and services as adults living in their family home, then in an independent apartment setting, and then in a group home setting that could meet the increasing complexity of their needs as they aged.

Strategic Parent Engagement. Parents' involvement in services and supports for their adult children with disabilities is both a potential challenge and an undervalued resource. Parents may be able to financially support their adult children and their services. Families can play a meaningful role in the community integration of their children and of people with disabilities who live with them. When agencies like Looking Upwards encourage meaningful parent engagement within their larger agency structure, as they have with Kelsey's family and others, it benefits not only that specific individual but also the larger population served.

When Kelsey's parents paid for a renovation to make Eustis accessible, they also funded a kitchen upgrade, the addition of a backyard deck and an upstairs laundry room, and ramp accessibility that directly benefited the other three women in the home. They hosted a "shower" so that Kelsey's family and friends could purchase gifts for Kelsey's new home and let all four women register for items they wanted for their house. When they come into the home to share a meal with Kelsey on Thursday nights or take her on outings, they also include her roommates. Their presence, both socially and financially, enriches the lives not only of Kelsey but of the three other women she lives with.

Parent engagement requires compromise on both sides. Miranda says Kelsey's parents have had to be "gracious and generous in their compromises." There were times when they wanted to add or do something in Kelsey's home that wasn't possible

due to regulations or funds available, and they had to be open to adjustments. Having parents like Kesley's stop by homes was also something Looking Upwards staff had to get used to, realizing that they weren't coming to "check up" but to support and contribute. Kelsey's dad says they've made a conscious effort to "not get in their [i.e., Looking Upwards'] shorts" when it comes to service delivery, and acknowledges that they "don't have any more rights than other parents" just because they contribute. Yet their ongoing presence in Kesley's home has allowed them to provide (intentionally gentle) feedback to Looking Upwards and their staff on how they may better meet their daughter's needs.

Linking Policymaking and Service Delivery. As one of the three largest providers in a relatively small state, Looking Upwards has made a specific choice to be engaged in policymaking and regulation, both in Rhode Island and at the federal level. They are active members in professional groups and associations and work with lobbyists directly. When a process began a few years ago to select a new director for Rhode Island's Department of Behavioral Healthcare, Developmental Disabilities and Hospitals (BHDDH), Looking Upwards was able to advocate directly for what they hoped to see in the new state director and for the priorities they thought were most pressing. "Being a small state," explains Miranda, "we get to be involved in administration selection and in bringing challenges to the table and promoting solutions," and this involvement gives Looking Upwards a "strong ability to influence" the policies that affect their work.

This influence doesn't mean Looking Upwards controls public policy or sees all the regulations (or removal of regulations) they desire. But, it does mean they can move things in the right direction. They have achieved an effective feedback, communication, and influence loop between those on the ground delivering services and those in state and federal offices creating the policies for those services. That connection

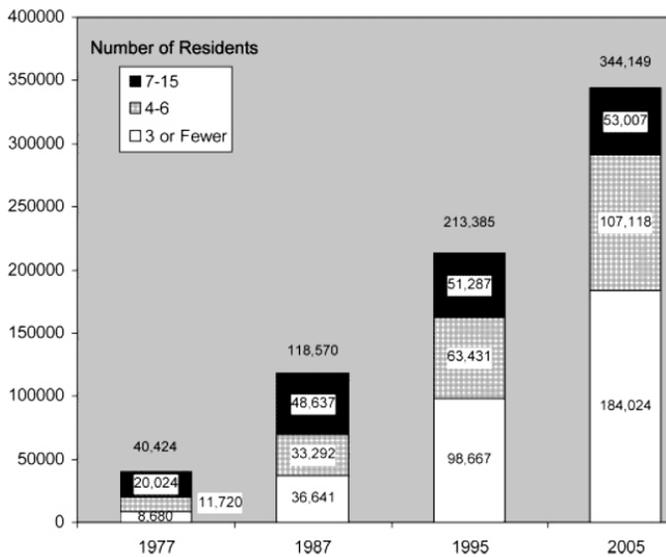
between policymakers and implementers should be encouraged and supported in states big and small.

What's Challenging

Understanding the Impact of Size

There is a growing trend towards serving individuals with disabilities in smaller settings. This shift likely results from a combination of institution closings and increased use of SLAs and independent apartments.

FIGURE 3: CHANGING RESIDENTIAL SIZES⁴⁹



In 2014, the National Council on Disability released a report on the impact of size of settings on outcomes for people with disabilities. The report summarizes research done by institutions and scholars that points to a conclusion “that people with disabilities living in smaller settings are more likely to achieve positive outcomes and to experience an improved personal and support-related quality of life than individuals living in larger settings.”⁵⁰ The report reviewed outcomes that included self-reported loneliness, ability to self-direct, and presence of challenging behaviors as they related to size and generally advocated for settings of four or less (ideally one to three)

residents. Similarly, a 2006 report by Stancliffe et al. “found residents of larger settings, especially >6 residents, more likely to report loneliness and less likely to say they liked where they lived.”⁵¹

Some policymakers, advocates, and organizations link quality of life to size of setting. They believe that, as more people live together, indicators of quality of life decline. In an interview, Dan Berland, of the National Association of State Directors of Developmental Disabilities Services (NASDDDS), echoes these sentiments. “The nature of the problem is affected by congregation. It’s impossible to ignore the economies [the impact of size on outcomes] when it comes to the size of the home.”

This is true: when you start to have more individuals within one home diseconomies of size start to take hold. Once a residence exceeds a certain size, schedules may become more standardized with fewer options for choice. Transportation will likely be more limited, and community integration may become more challenging. Each resident will have a greater number of individuals with whom she must compromise. Carrie Miranda of Looking Upwards acknowledges that in any group residential setting, “you have to create little systems of rules in order for people to function together, live together, and meet requirements.” And it may be the case that those systems become more rigid, leading to less positive outcomes, for residences exceeding a certain size.

But you can’t have a discussion linking quality and size without looking at resident needs, staff-to-client ratios, and setting structure. “So much depends on the people who are providing support and the people who are living in the homes,” says Bethany Keener of L’Arche USA. If you have one support staff per six residents, of course those six

⁴⁹ Lankin and Stancliffe, 153.

⁵⁰ *Home And Community-Based Services: Creating Systems For Success At Home, At Work And In The Community*. National Council on Disability, 2014. Print, 23.

⁵¹ Lankin and Stancliffe, 154.

residents will have less direct support and less choice in their daily activities than in a residence with four staff per six residents. Additionally, size may have different impacts on residents with different abilities. The NCD report noted that “for people with Intellectual and Developmental Disabilities, outcomes achievement was additionally related to the person’s level of disability.”⁵²

While size is an important factor, size may be less important than the quality and number of the staff, the needs of the specific resident, and the structure of service delivery. In housing and services, it is possible for big residences to be good and for small residences to be bad.

Recruiting and Retaining Staff

While the nature of the link between size and quality is somewhat contentious, the importance of staff in the quality of a home and outcomes for residents is universally understood. Support staff for people with disabilities – whether labeled Direct Service Professionals, Personal Care Attendants, or Assistants – may be the single greatest influence on quality of life for the individuals they serve. Deirdre Sheerin of Sweetwater Spectrum talks of “people supporting people,” and Cook of L’Arche speaks to the importance of “life-giving relationships.” At the end of the day, disability services are about the people who provide them and their relationships with individuals with disabilities.

Universally, though, the providers I met with talked about the challenges they face in recruiting and retaining quality staff: low wages, sometimes challenging work, virtually no national training or professional development entities for the field, and a lack of “professional respect” for the business of providing disability services.

Two providers I spoke with, Looking Upwards and Ability Beyond Disability (CT), also spoke about their concerns that raising the minimum wage will impact their staffing challenges. Every provider I interviewed paid above minimum wage, and they see that higher pay as a key to recruitment: getting higher than minimum wage is what initially gets some staff through the door; then, they stay in the long run because they value the work. Providers were careful to explain that working as a direct support professional for people with disabilities is not equivalent to working other near-minimum wage jobs: it takes a special person, with different skills than other minimum wage earners, to be successful in their agencies. To continue recruiting such people in the event of a higher minimum wage, providers would have to increase their wages – an increasingly difficult (if not impossible) feat because of budget cuts and low reimbursement rates for service delivery.

Burdensome Policies and Regulations

Our public policies on disability are based heavily in a cultural desire to care for and protect a vulnerable population, a legacy of the Kennedy-era care-driven approach. An upsetting history of institutional neglect, coupled with well-publicized tragedies, only exacerbates this desire to protect. Driven by federal legislation and state and federal litigation, regulations have been put in place to prevent exposure to predatory or abusive individuals (staff) and to make physical structures safer. Beyond protection, some of these policies help to standardize services. Programs like Medicaid, which serves 8.8 million adults with disabilities, need policies ensuring that services delivered on such a massive scale meet quality standards and desired outcomes.⁵³

Many of these regulations make sense; the providers I met with agreed with many of them.

⁵² *Home And Community-Based Services*, 24.

⁵³ Medicaid.gov. 'Medicaid By Population.' N.p. 2015. Web. 21 Aug. 2015.

But all providers and support staff also noted the “burdensome nature” of policies designed to protect the residents they serve.

Building Requirements: Miranda, at Looking Upwards, noted that building requirements create “burdens on people with disabilities that are greater than for other populations.” These burdens include increased costs (usually without increased funding) and obstacles to design decisions that would make buildings feel more homelike and less institutional. Cook at L’Arche noted similar issues, citing the fire inspector’s ability to require his homes to have features (or remove features) based on an opinion of what is “best” solely because people with disabilities live in the space. For example, there were specific regulations on the placement of electrical outlets, required signage that made the residence feel more institutional, and limits on the design of spaces.

Tracking Activities: Medicaid funding requires direct-service professionals to report on all activities relating to individuals receiving Medicaid funds, as the vast majority of persons with disabilities do. This requirement was a particular challenge for L’Arche, which intends Assistants and Core Members to share life in an “authentic” way. One Assistant, heading out on vacation with a Core Member, found it strange that she “was going on a trip with [her] friend and needed to keep a running tally of every activity” they did and any potential “incident” that should be noted. It seemed unnatural to her. On the whole, L’Arche addresses this problem by making daily reporting more of a journaling exercise and less of a clinical one (except when certain events require the latter).

Limiting Activities and Exposure to the Community: While there seems to be national agreement that community integration is a goal of disability service providers, some state and federal regulations that require background checks and training don’t help realize that goal. Two staff members at Looking Upwards who had

worked there thirty years ago recalled that staff members used to be able to take residents to family events and parties, to use a friend’s pool, to the beach in the summer, or out to meet their friends. Today, such actions are often not permitted. A L’Arche Assistant noted similarly that when a resident forges a relationship with someone at her church or place of employment, there are sometimes restrictions on how the resident can interact with new acquaintance if that person does not have training or a background check.

In an effort to protect the safety of individuals with disabilities, we may be creating barriers to their authentic integration into their communities and undermining their self-determination. This is particularly the case with “one-size-fits-all” regulations that do not consider individual needs and diverse settings. While all providers and direct-service professionals acknowledge the need for some protections and safety regulations, those regulations should be both absolutely necessary and as unrestrictive as possible.

Linking Housing, Employment, and Transportation

Housing isn’t an isolated issue for people with disabilities; it is closely linked to issues of employment and transportation.

Transportation: Ease of access to the outside community was an important factor for each of the providers I met. Sweetwater’s location was chosen because it was in walking distance to the Sonoma town where residents had access to employment and recreation. L’Arche GWDC had access to public transportation. The Looking Upwards apartment was in downtown Newport close to public transportation and other destinations. At L’Arche and Looking Upwards, homes have their own vans or cars to take into the community, which means that residents, most of whom do not drive, need a staff person to go into the community. Requiring staff transport isn’t

necessarily a burden, particularly for individuals who wouldn't go into the community independently regardless, but can be a barrier for some individuals.

Janice Lehrer-Stein, a member of the National Council on Disability, says this link between housing and transit is one they're looking at in depth, particularly as it applies to suburban and rural populations. As things are now, Leher-Stein explains, "people can make a choice to live in rural areas, but life will be more challenging." The NCD is working on identifying what states can do to mitigate this challenge and is "advocating for inclusive transportation programs." Accessibility and use of ride-sharing services (like Uber and Lyft) were key points of discussion during the NCD's July 2015 quarterly meeting.

Employment: Individuals with disabilities experience lower rates of employment than those without. Lower to begin with, their rate of employment is often the hardest hit in economic downturns. People with disabilities' employment rate dropped more significantly (from 52.2 percent to 41.1 percent) between 1990 and 2010 than the rate for individuals without disabilities (from 84.4 percent to 79.1 percent).⁵⁴ Employment can help people with disabilities not only to improve their quality of life and self-determination, but also to pay for their own housing (rather than relying on public assistance). All providers spoke to the unmet vocational needs of their residents, most of whom are capable of contributing meaningfully to the workforce.

Meeting a Diverse Set of Needs

The needs and abilities of individuals with disabilities are incredibly diverse. How, therefore, can we design housing and supports specifically to meet different levels of needs? The question is twofold: 1) *are certain types of housing right for*

different types of abilities? and 2) *is it effective and possible to mix different needs within the same housing offering?*

One general theme of my interviews with leaders and parents from Southbury Training School was that STS residents had needs so significant that only an institution like STS could meet them. One parent explained various scenarios that demonstrated "the need for larger facilities that can care for the members of the community who are profoundly disabled." When I visited Looking Upwards, though, I saw people with more "profound" needs receiving services both in group home settings and in apartment settings with 24-hour support.

Conversely, it is widely felt that people with fewer needs are best served in independent apartment settings. Yet two different individuals with disabilities who seemed capable of independent living, one at L'Arche and one at Looking Upwards, said their favorite thing about their residence was their roommates. They valued the social opportunities afforded by living with others.

It's important to acknowledge that individuals with similar disabilities will not universally desire the same things. One "type" of individual will not necessarily be best served by one "type" of setting. We need to build and support many different housing types and sizes and give individuals with disabilities choice about what works best for them.

In some states and in some agencies, people are placed in group homes by needs and abilities. Other agencies, like Looking Upwards and L'Arche, who serve a wide range of abilities, do try to mix abilities and design group homes as that serve a more diverse community of people together. Funding, because it is allocated to individuals rather than to homes, complicates this

⁵⁴ Long, Ananya. 'America Still Leaves The Disabled Behind.' *CNNMoney*. N.p. 2015. Web. 26 July 2015.

task considerably. Providers have to puzzle together different individuals and consider their funding levels as they look at a home's total operating income and expenses.

Individuals are allocated different levels of funding to support their needs. A house creates its budget based on the combined needs and funding of the people in it. In a house there could be two people with needs and funding at \$50,000, one person with \$75,000, and another with \$100,000. If that \$100,000 person moves out and the best fit to move into that community is someone with less need and less funding (say \$50,000), the house will now have a \$50,000 loss to make up. A new resident with less need might allow for savings in some areas, but many of the home's costs will be fixed. The loss will be hard to make up.

If we determine that people with different needs can and should live together, which I believe we have, we also need to consider how funding structures and regulations can make this goal achievable.

Realizing Independence Varies

While some individuals with disabilities require 24-hour support and services, many (including individuals receiving services within each of the case study organizations) can live their lives with some independence. An Australian study showed that settings favoring semi-independent living had significantly better results across 22 different outcomes.⁵⁵ With the exception of Southbury, each organization made it a goal to support their residents' independence to the fullest extent possible. That independence will look different for different individuals. For some, it's living completely on their own; for others, it's being able to manage their own transportation to work and recreation; for others, it might mean getting their morning coffee and breakfast on their own.

Regardless of the level, we should continue to support independence where possible.

Supporting the Right to Risk

In 2005, filmmakers invited eight individuals with disabilities, some significant, on a 225-mile rafting trip down the Colorado River. The theme of the film, *Right to Risk*, was that individuals with disabilities should be able to "take responsibility and make choices for themselves."⁵⁶ But risk isn't limited to extreme outdoor adventure. Nowhere is the right to risk more important than in the home and daily life of someone with a disability.

"We understand that our system needs to make sure there's oversight and people aren't being neglected or taken advantage of," explains Bethany Keener of L'Arche, but we also need to see "a variety of options and choices that people can make for themselves." People have a right to risk, and a right to make choices that others may disagree with. L'Arche leader Cook believes that many of our regulations fail the test of the strict scrutiny clause: they are not absolutely necessary based on 'compelling government interest,' and they are not implemented through the 'least restrictive means.'

Over and over, providers and support staff pointed to regulations in personnel policies, building codes, and required service delivery models that limited their ability to provide choice and to support individuals with disabilities in living authentic and integrated lives. "Do they have a right to risk?" Miranda from Looking Upwards answers her own question: "Not according to the regulations."

⁵⁵ *Home And Community-Based Services*, 38.

⁵⁶ Right to Risk. 'Trailer, Right To Risk.' N.p., 2015. Web. 10 July 2015.

What's Needed

Across all case studies, efforts in certain activities, when implemented correctly, succeeded in improving services and ensuring quality. All of these efforts require further exploration and support to be as impactful as possible in adult services and housing for people with disabilities. These four areas are Engaging Parents and Families, Staffing, Supporting Choice, and Making Space for Innovation.

Engaging Parents and Families

Parents and families have always played an important role in advocating for the needs and rights of their family members with disabilities. Their advocacy role continues to be important in legislation (including the recent ABLE Act), program design, organizational leadership, and service delivery. Parents may also provide a valuable source of direct funding for, and community integration within, disability housing and services. Parents' willingness to pay for housing for their child should not be overlooked by for-profit and not-for-profit housing developers. Agencies should continue to find ways to include parent-directed funds and parent-supported activities in their operations, ensuring that their contributions benefit both their individual child and other individuals served within the agency.

Adult disability services, perhaps influenced by the American cultural value of independence, sometimes encourage or cause parents to separate from a children once that child moves into a home or apartment. That separation should not be a paramount goal. Instead, appropriate parent involvement should be encouraged and enabled.

Staffing

Every single provider said the support staff that worked directly with individuals with disabilities was the most important and most challenging

factor in their service delivery. Personnel are also the single largest line item on every single organization's budget. Staffing is the most important factor because, aside from the individuals themselves, staff have the most direct impact on the daily lives of people with disabilities. It is the most challenging factor because wages are generally low, screening and onboarding can be costly and time-consuming, professional development and training aren't available, and the direct service profession isn't generally well respected, making recruitment and retention difficult.

But when staff works, it works. Well-recruited, high quality, trained, and retained staff directly is likely the biggest determinant of the quality of services. Every single organization's leader said their team was their greatest asset. The direct service workforce is full of exceptional service providers. Funding and regulation should work to support those professionals as much as possible.

Supporting Choice

We have often designed social services, particularly services for individuals with disabilities, to standardize, streamline, and achieve scale. In doing so, we can unfortunately undermine the choice and freedom of those we seek to serve. Regulations are designed with standardization in mind. They are intended to fit to every person and every setting type. Yet each provider noted that they were most effective when they were able to provide choice for individuals with disabilities and customize services based on individualized needs. Several staff privately referred to "bending" or "forgetting" regulation in order to provide more choices to the individuals they served. Individuals with disabilities often used words like "freedom," "independence," and "choice" when they described what they liked about their homes. Legislation, regulation, and program design should continue to support choice wherever possible.

Home and Community Based Service (HCBS) waivers are a key factor in continuing to make choices and customization of services possible. Some advocates for achieving community integration and quality services through smaller settings wish to limit HCBS waivers to settings of three or fewer people; such a limitation may limit choice unnecessarily.

Making Space for Innovation

Housing and adult services for people with disabilities present a challenge of massive scale and scope. This challenge is also an opportunity for innovation, creativity, and entrepreneurship.

Looking Upwards is testing ways to expand parent involvement across their adult services. L'Arche is working outside their traditional home model as they experiment with apartment and college campus living. Sweetwater, still a young organization, consistently adjusts their operational structure and service delivery approach. Each of these three organizations was created by an entrepreneurial leader who saw a problem and innovated a solution.

Federal and state policymakers should do as much as they can to encourage innovation in the disability housing and adult service delivery space. Regulations that limit innovation should be carefully scrutinized. Funding should be allocated to innovate new solutions and then measure the quality of different models.

Beyond these four areas, there are additional policy and strategy considerations that may help meet the needs of more adults with disabilities, increase available funding, and improve the quality of services.

Policy and Strategy Considerations

Linking Disability and Other Housing Needs

There is a broad need for subsidized housing among many different populations, including but not limited to individuals with disabilities. Connecticut recently developed an interagency committee on supportive housing of which DDS is now a named and voting member. (The committee includes the Department of Housing, CHFA, DDS, DCF, Veterans Affairs, DMS, Court Services, Corrections, and CFCH). More of these interagency partnerships should be encouraged. "Pulling disability out of just disability focused issues is critical," says Lehrer-Stein of NCD. "Our goal is full inclusion." Thinking about disability in the context of larger non-disability public policy and community development issues provides opportunity for integration as well as potential for cost-savings or new funding sources.

In particular, continuing to think about disability within the larger context of subsidized housing may help to expand financial support for these individuals to live independently. In fact, housing subsidies are already directed to a fair degree to people with disabilities. "Approximately one fifth of families receiving public housing have a family member with a disability living with them" already.⁵⁷ The issues are already linked by population overlap, and could be better linked in program design, funding streams, and support service delivery.

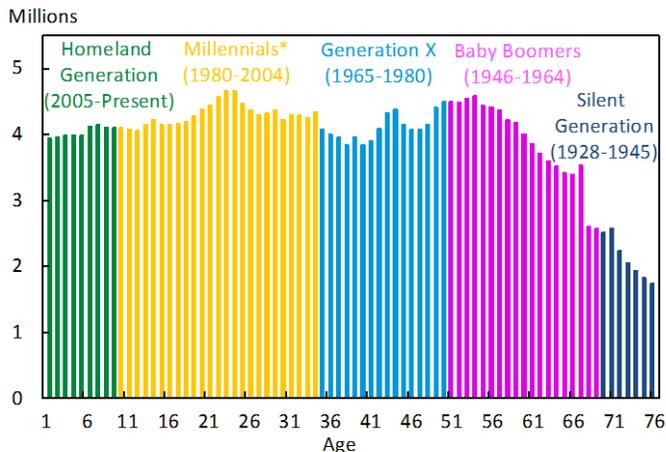
Engaging Millennials

Millennials, born between 1980-2004, are the largest and most diverse generation in the United States. They make up one third of the total population.⁵⁸

⁵⁷ *NCD Progress Report*. 2015. Print, 83

⁵⁸ *15 Economic Facts About Millennials*. The Council of Economic Advisers, Executive Office of the President, October 2014. Print.

FIGURE 4: MILLENNIALS AS A % THE US POPULATION⁵⁹



Most millennials are what I'd call "Inclusion Natives." A diverse population themselves, they have been educated in more inclusive schools than the generations prior to them and have participated at high rates in programs with their peers with disabilities (Unified Theater, Unified Sports, Best Buddies, Friendship Circle, I Am Norm, etc.). They also value connections within and contributions to the community around them. According to a 2014 White House report, "high school seniors today are more likely than previous generations to state that making a contribution to society is very important to them."⁶⁰ And despite being highly educated and engaged in their communities, millennial face a challenging job market. The unemployment rate for young workers ages 18 to 34 was 7.7 percent in the first third of 2015.⁶¹

In relation to disability housing and services, millennials should not be overlooked as potential roommates, neighbors, and direct service professionals. Many of the things millennials seek in their consumption habits – connection to community, a "for good" impact, and a larger social purpose – may all be realized by becoming

neighbors or roommates of people with disabilities. As Shared Living Arrangements are more encouraged by disability service providers and policymakers, millennials may actually serve as perfect caregivers.

Additionally, we face a shortage of direct service professionals. The issue will become even more prevalent as the number of individuals 65 and older (the age of many clients) exceeds the number of women age 24 to 44, who make up the largest proportion of that workforce.⁶² Millennials will be required to fill this gap, and more should be done to encourage and support their entering the field. Policymakers and disability organizations may considering exploring the creation of a corps of millennials to work in direct service supporting people with disabilities within the structure of National Service (like Teach for America or City Year). If young people work in disability service, even for a year or two, they will both help increase the numbers of direct service professionals and develop an increased understanding of disability and inclusion.

Making Direct Service a Professional Career

Whether targeting millennials or the workforce overall, the direct-care field often lacks respect in the general population as not being a professional career path. Part of this perception is due to low wages. But it is also influenced by a lack of growth opportunities within the industry, unclear career pathways, and a scarcity of professional development organizations outside union membership.

Making direct-care more of a professional career may also require us to rethink labor laws. As billing for Medicaid now operates, all direct service staff much be hourly non-exempt staff. Salaried employees who have a leadership

⁵⁹ Ibid.

⁶⁰ Ibid.

⁶¹ Fry, Richard. 'More Millennials Living With Family Despite Improved Job Market.' *Pew Research Center's*

Social & Demographic Trends Project. N.p. 2015. Web. 22 Sept. 2015.

⁶² 'NASDDDS On Direct-Service Workforce.' 2015. Presentation.

position and also perform billable direct-care support are difficult to track and utilize in a manner that aligns with regulation. Labor laws and hourly employee regulations make it challenging for direct service professionals to interact with individuals with disabilities whom they serve in informal settings (like at parties or community events).

Understanding Disability as Individuals Age

The life expectancy for individuals with disabilities has increased significantly over time. In general, the life expectancy for people with intellectual disabilities now aligns with that of the general population. As a result, "the number of adults with I/DD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030."⁶³

Supporting an aging population of individuals with disabilities is a relatively new challenge for providers and policymakers. With age, medical needs often become more challenging and more expensive. As people live longer but new populations turn 21 and need services, the system has more people to serve with limited resources.

But the challenges go beyond medical needs and increased costs. As with the general population, what individuals with disabilities want in housing or how they spend their day might depend on the phase of life they're in. A young adult may prefer a home with several roommates. A woman in her forties might want to live somewhere quieter on her own. An 85-year-old man might require skilled nursing care. We should be prepared to address how needs and desired housing arrangements change over time.

We also need to further consider retirement and end-of-life care, which are increasing realities in the disability housing and service area that we may not be fully prepared to meet. Two providers spoke of resistance by their state agency to letting

their residents retire. One Assistant at L'Arche spoke of a Core Member who is 89 and wants to "retire and stay home to watch Bonanza on TV all day." But Medicaid billing and care standards do not encourage and sometimes do not even allow people to live more homebound or sedentary lives. So that 89-year-old person with a disability still needs to fill his days with part-time work, community engagement, and other activities that don't include only Bonanza on the couch and walking in the neighborhood. The nuances of retirement for people with disabilities need to be further explored.

Additionally, end-of-life care should be treated with the same respect we desire for ourselves or older relatives. One agency shared the story of an older member of their organization passing away in hospice at home after battling cancer. When he passed, the staff said, "the local police sent a homicide detective and medical examiner in an orange vest to investigate." This is an extreme example, but indicative of the lack of understanding around end-of-life care and protocol for people with disabilities. While steps should be taken to mitigate abuse or neglect, we also must be careful not to limit the choice or privacy of individuals with disabilities as they enter the final stages of life.

Further Research Required

There are several areas where data is conflicting or unavailable. The following research areas may be important and productive of insight as disability housing and service providers continue to develop and grow:

- **Comparisons in personnel and per-person costs** to better understand how different housing service models or residence types differ in cost. Measuring the correlation between those costs with quality outcomes would also be beneficial. Personnel and per-

⁶³ Institute on Community Integration, University of Minnesota. 'Impact Newsletter: People With Intellectual

And Developmental Disabilities Growing Old: An Overview.' N.p. 2015. Web. 4 Aug. 2015.

person costs are currently challenging to fully compare or comprehend because of different billing, accounting, and operational structures.

- ***Continuing research on the link between quality of life and size of residential setting*** should be undertaken before any regulatory restrictions are made that limit homes to be a certain size or require more individuals to live in apartment settings. Right now much of the data seem to favor smaller offerings because data on outcomes for large offerings come from institutional settings, which are large organizations with different staff-to-client ratios. We need to control for these variables (being an institution, or staff-to-client-size) before we determine that smaller size is correlated with better outcomes.
- ***Better understanding of the Shared-Living Model*** should be supported for providers, families, and potential care-givers. The SLA model is poorly understood and oversimplified as “adult foster care” or “paid roommates.” If the SLA model is to serve as an effective housing option for people with disabilities, it must be more clearly articulated and understood. Best practices in creating a match and building a successful arrangement should be assessed and disseminated.

caring professionals, and innovative thinking from providers and policymakers. Solutions and services should represent a thoughtful balance between Care, Choice, and Access, and should avoid “one-size fits-all” design wherever possible.

Yet housing and adult services is also an opportunity. It's an opportunity to better integrate our communities. Thinking about these issues helps us rethink what it means to support quality and affordable housing for all populations, not just those with disabilities. It's an opportunity to re-evaluate and innovate around how we create communities, connect with our neighbors, and age within our homes. With the right program design and service delivery, we can start to change the predominant concerns of parents of children with disabilities. No longer will they worry, “Where will my child live after I die?” or “Who will care for my child?” Instead, they can wonder: “Which housing option is right for my child?” And most of all: “What community will be lucky enough to have my child as a member?”

Conclusion

The reality is that people, with or without disabilities, seek generally the same things in their living arrangements. They want to feel safe and supported. They want respectful care that acknowledges their choices as autonomous individuals. They want to live somewhere they can feel relaxed after a long day, proud when they invite in visitors, and content as they fall asleep at night: a place to call home.

But housing and adult services for people with disabilities is a challenge. The needs of the millions of adults with disabilities are vast and various. Meeting those needs requires significant funding, thoughtful policies, experienced and

Appendices

Acronyms

APPENDIX A

Acronym	Name
ADA	The Americans With Disabilities Act
CEC	Council for Exceptional Children
CFC	Community First Choice (option)
DSW	Direct Service Worker / Direct Service Workforce
FFP	Federal Financial Participation
HCBS	State Plan Home and Community-Based Services (HCBS)
ICF/ID (ICF/MR)	Intermediate Care Facilities for Individuals with Intellectual Disability (Intermediate Care Facilities for Individuals with Mental Retardation)
ID	Intellectual Disability
IDD	Intellectual and Developmental Disabilities
MFP	Money Follows the Person
MR	Mental Retardation
NACSMPR	National Association of State Programs for the Mentally Retarded
NARC	National Association for Retarded Children
NASMHPD	National Association of State Mental Health Program Directors
NCD	National Council on Disability
NICHCY	National Dissemination Center for Children with Disabilities
PAS	Self-directed personal assistance services (PAS)
MC	Managed Care

Relevant Legislation

APPENDIX B

The following are key laws that have impacted housing and adult service provision for individuals with disabilities. Legislation focused on education, early intervention, and other areas of disability services not related to disability housing are not included.

YEAR	LEGISLATION	OVERVIEW
1935	The Social Security Act (SSA)	Provided public assistance to people qualified as having a disability.
1968	The Architectural Barriers Act (ABA)	“Requires access to facilities designed, built, altered, or leased with Federal funds.” ⁶⁴
1973	The Rehabilitation Act	“Prohibits discrimination on the basis of disability” in programs funded or managed by the federal government. ⁶⁵
1980	Civil Rights of Institutionalized Persons Act (CRIPA)	Authorizes the U.S. Attorney General to investigate conditions at state and local institutions. ⁶⁶
1991	The Fair Housing Act (FHA)	An amendment that expanded the coverage of the Fair Housing Act (1968) to prohibit discrimination based on disability. ⁶⁷
2000	Developmental Disabilities Assistance & Bill of Rights Act	Provides federal financial assistance to support service delivery to individuals with developmental disabilities, focused on community-based services that promote independence and integration. ⁶⁸
2010	The Affordable Care Act (ACA)	Expanded Medicaid eligibility for people with disabilities and added “Community First Choice” option which allows individuals to receive LTSS in their homes or communities rather than in institutions. ⁶⁹
2014	The Achieving a Better Life Experience Act (ABLE Act)	Encourages and assists individuals to save “private funds for the purpose of supporting individuals with disabilities” and helps ensure that funds can be saved tax-free to “supplement, but not supplant” federal benefits. ⁷⁰

⁶⁴ Access-board.gov. 'Architectural Barriers Act - United States Access Board.' N.p. 2015. Web. 30 Aug. 2015.

⁶⁵ Ada.gov. 'A Guide To Disability Rights Laws.' N.p. 2015. Web. 4 Aug. 2015.

⁶⁶ US Department of Justice (Justice.gov). 'Civil Rights Of Institutionalized Persons.' N.p. 2015. Web. 4 Aug. 2015.

⁶⁷ US Department of Housing and Urban Development (Hud.gov). 'Title VIII: Fair Housing And Equal Opportunity.' N.p. 2015. Web. 4 Aug. 2015.

⁶⁸ The Administration for Community Living (Acl.gov). 'AIDD: The Developmental Disabilities Assistance And Bill Of Rights Act Of 2000.' N.p. 2015. Web. 1 Aug. 2015.

⁶⁹ Department of Health and Human Services. *Report To Congress Community First Choice: Interim Report To Congress As Required By The Patient Protection And Affordable Care Act Of 2010.* 2014. Print.

⁷⁰ Congress.gov. 'H.R.647 - 113Th Congress (2013-2014): ABLE Act Of 2014.' N.p., 2015. Web. 4 Aug. 2015.

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Mostly, with admiration and gratitude to the residents of each of these communities who invited me to visit their homes, peek into their bedrooms, sit at their dining room tables, chat on their couches, and even share a cup of coffee.

Always, for Kelsey.



About the Author

Micaela Connery is an MPP Candidate at Harvard Kennedy School focusing on disability, inclusion, and community development. She is a member of the inaugural class of New World Social Enterprise Fellows at the Center for Public Leadership at Harvard. She will continue with her studies as a Mitchell Scholar next year, pursuing her MBA at the Smurfit School at University College Dublin.

Inspired by her cousin Kelsey, Micaela is the founder of Unified Theater, an organization she launched at age 15 and served as CEO of from 2002-2014, expanding operations across the country. She blogs on issues of disability and inclusion for the Huffington Post. Micaela serves as a Global Shaper for the World Economic Forum and a Coca Cola Scholar. She has spoken at the Annual Meeting of the World Economic Forum in Davos, the Vatican Summit on Social and Economic Exclusion, the National Conference on Inclusion, the National Collegiate Leadership Conference, and Chicago Ideas Week. Her work has been profiled by the TODAY Show, VH1, FastCompany, USA Today, The Hartford Courant, ABC, and CNN.