DEINSTITUTIONALIZATION OR TRANSINSTITUTIONALIZATION? BARRIERS TO INDEPENDENT LIVING FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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INTRODUCTION

The state of housing in the United States is in an especially difficult period. Contrary to popular belief, the shortage of affordable, accessible housing is not just in urban centers such as New York and San Francisco; housing shortages affect urban, suburban, and rural communities across the country. In addition to the difficulty of locating affordable housing to rent or own, most housing is not accessible to individuals with disabilities and the elderly.

Consider two scenarios of individuals with disabilities who face similar challenges in acquiring housing with various levels of success. First, Jordan is a man who uses a wheelchair. He receives $794 per month from Supplemental Security Income ("SSI"). In Chicago, the average rent for a one-bedroom apartment is around $1,500. Though he could not afford an apartment based solely on his SSI, together with his wife's income, they can rent. However, the apartment they find is not accessible for Jordan's wheelchair: there are no grab bars in the bathroom and the front door is not wide enough for his chair to pass the threshold. Based on the Americans with Disabilities Act ("ADA"),[1] Fair Housing Act ("FHA"),[2] and Section 504 of the Rehabilitation Act of 1973,[3] Jordan has a right to request reasonable modifications to the unit to make it accessible to him at his own expense. After paying for the necessary adjustments, Jordan and his wife move into the unit.

Now consider another individual with a disability, Alana. Alana is on the autism spectrum and is considered to have an intellectual and developmental disability ("IDD"). She is independent but would need some supports to live fully on her own in the community, such as a few hours per week of a direct

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1. Americans with Disabilities Act, 42 U.S.C. § 12101.

2. Fair Housing Act, 42 U.S.C. § 3601.

3. Rehabilitation Act of 1973, 29 U.S.C. § 794.

support professional ("DSP") to assist with independent living tasks and transportation to and from her job. Based on her SSI income alone, she cannot afford a studio apartment. She is on the waiting list for a Medicaid Home and Community-Based Services ("HCBS") waiver that would allow her to receive funding for a DSP in her apartment and for personal transportation expenses. There are 18,000 individuals on that waitlist in Illinois.[4] Alana has been on the waitlist since she was first legally allowed at the age of eighteen; she is now twenty-two and is estimated to get off the waitlist in three years. Facing a lack of options, Alana will continue to stay at her parents' home if able or could be placed into a State-Operated Developmental Center (a remnant of state-run institutions) or an Intermediate Care Facility ("ICF/DD") in Illinois. Alana's IDD, the incredibly long wait for services through Medicaid, and a lack of system-wide acknowledgement that "accessibility" in housing goes beyond physical structures are inhibiting her dreams of independent living.

This Note will focus on the history of systemic structures and bias that prevent those with intellectual and developmental disabilities from independent living. Specifically, this Note will focus on how the deinstitutionalization movement has coincided with cuts to services, which create barriers for "person-centered" housing. Individuals with intellectual and developmental disabilities face increased barriers to integrated living as compared to other groups even within the disability community. In the landmark decision *Olmstead v. L.C.*, the Supreme Court interpreted the Americans with Disabilities Act, 42 U.S.C. § 12101 *et seq.*, to enforce an integration mandate.[5] However, twenty years later, external barriers persist that prevent individuals with disabilities from moving out of their families' homes, segregated homes, or assisted living homes and into the community. Further, the COVID-19 fatality rate among people with IDD is worse than *any other* minority in the country,[6] which should create closer scrutiny to the types of settings that individuals with IDD currently reside. There are far more individuals with IDD currently living in group or segregated settings than acknowledged in the post-deinstitutionalization era. The disproportionate effect that COVID-19 has had on group living provides an opportunity for the current sentiment against congregate living facilities to be used as momentum for an increase in quality person-centered living and care arrangements.

This Note serves as an overview of the current status of housing and medical services for individuals with IDD. Part I will look at the history of institutionalization of those with intellectual and developmental disabilities, and the subsequent movement away from institutions to other forms of congregate housing settings. Part II gives an overview of the relevant civil rights laws, cases, and federal policies in place that both assist and limit individuals with IDD from gaining person-centered housing. Lastly, Part III examines the broken aspects of the housing and services model for individuals with IDD and

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[4] Maxwell, *infra* note 139.

[5] Olmstead v. L.C., 527 U.S. 581 (1999).

[6] Stevens & Landes, *infra* note 167.

provides the suggestions of increasing wages for direct support professionals and personal care workers, increasing flexible Medicaid waiver programs for individuals with IDD by looking at the case study of the Money Follows the Person program, and targeting enforcement activities before individuals are adults without options. Planning for housing and service needs of individuals with IDD is paramount: it is estimated that between 700,000 to 1,000,000 children with autism will transition to the adult state-by-state funding system over the next decade.[7]

PART I

Individuals with disabilities have extremely varied and unique needs. The Centers for Disease Control and Prevention ("CDC") estimate that 26% of adults in the United States have some disability.[8] Within this diverse population, there is no standard way to divide disabilities into clean categories. The CDC uses a "functional" approach, differentiating between hearing, vision, cognition, mobility, self-care, and independent living disabilities.[9] The federal definition of disability under the Americans with Disabilities Act defines disability as "(A) a physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment."[10] Some examples of "major life activities" include "walking," "working," "thinking," and, notably for independent living, "caring for oneself."[11]

These definitions of disability can be both over- and under-inclusive. State and federal entities struggle to provide nuanced medical and housing services for individuals with varied disabilities. Though strides have been made in advancing independent living and deemphasizing the institutionalization of individuals with disabilities, those with intellectual and developmental disabilities have complex needs and disproportionately struggle to attain their right to personalized, autonomous, community living. And, when it comes to

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[7] Shattuck, *infra* note 21.

[8] *Disability Impacts All of Us*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html#text-version (last visited Sept. 16, 2020).

[9] *Prevalence of Disability and Disability Types by Urban-Rural County Classifications – United States, 2016,* CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/ncbddd/disabilityandhealth/features/disability-prevalence-rural-urban.html (last visited Sept. 16, 2020). The Department of Housing and Urban Development ("HUD") has distinguished between functional limitations (visual, hearing, cognitive, ambulatory) and disabilities that affect daily living (self-care, independent living). NICOLE ELSASSER WATSON ET AL., U.S. DEP'T HOUS. & URB. DEV. OFF. POL'Y DEV. & RSCH., WORST CASE HOUSING NEEDS: 2017 REPORT TO CONGRESS 7 (2017).

[10] Americans with Disabilities Act, 42 U.S.C. § 12102(1).

[11] *Id.* at § 12102(2); *see* 28 C.F.R. § 35 (1991).

housing and disability advocacy, advancing technical standards for ambulatory or mobility disabilities is often the focus.[12]

Moving specifically to intellectual and developmental disabilities, they are characterized by "significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills" diagnosed before the age of twenty-two.[13] A variety of specific types of developmental disabilities are under the IDD umbrella—including Autism Spectrum Disorder, cerebral palsy, Attention-Deficit/Hyperactivity Disorder ("ADHD"), fetal alcohol spectrum disorders, and other learning, language, speech, hearing, and cognitive disabilities.[14] There is a "lack of ongoing nationally representative data collection" regarding adults with IDD, which "severely limit[s] public health surveillance monitoring."[15] However, even though national data collection is weak, an estimated 4.6 to 7.7 million Americans live with IDD.[16]

Further, the prevalence of children diagnosed with IDD is trending upward[17] and is mainly attributable to the rise of Autism Spectrum Disorder in the last twenty years.[18] One in fifty-four children born in 2008 were diagnosed with autism, compared to 1 in 150 in 1992.[19] The population of individuals with IDD is growing, and will continue to do so as life expectancy has risen into the seventies.[20] It is estimated that between 707,000 and 1,116,000 children with

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[12] *See* Purvi Sevak, *Financial Security and Housing for Adults with Disabilities*, *in* DEVELOPING AFFORDABLE AND ACCESSIBLE COMMUNITY-BASED HOUSING FOR VULNERABLE ADULTS: PROCEEDINGS OF A WORKSHOP 17, 18 (2017).

[13] *Definition of Intellectual Disability*, AM. ASS'N ON INTELL. & DEVELOPMENTAL DISABILITIES, https://www.aaidd.org/intellectual-disability/definition (last visited Mar. 22, 2021).

[14] *See Child Development Specific Conditions*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/ncbddd/childdevelopment/conditions.html (last visited Feb. 22, 2021).

[15] Lynda L. Anderson et al., *A Systematic Review of U.S. Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000*, 57 INTELL. & DEVELOPMENTAL DISABILITIES 421, 421 (2019).

[16] Jonathan G. Lerner & Daniel Pollack, *Where Have All the Developmental Centers Gone? The Federal Push for Community-Based Services for People with Intellectual and Developmental Disabilities*, 43 CAP. U.L. REV. 751, 752 (2015).

[17] *See* BENJAMIN ZABLOTSKY ET AL., ESTIMATED PREVALENCE OF CHILDREN WITH DIAGNOSED DEVELOPMENTAL DISABILITIES IN THE UNITED STATES, 2014–2016, No. 291 NCHS DATA BRIEF 2, CTRS. FOR DISEASE CONTROL & PREVENTION (Nov. 2017), https://www.cdc.gov/nchs/data/databriefs/db291.pdf (finding that from 2014 to 2016 the prevalence of children aged 3–17 with an IDD increased from 5.76% to 6.99%).

[18] *See* CTRS. FOR DISEASE CONTROL & PREVENTION NAT'L CTR. ON BIRTH DEFECTS & DEVELOPMENTAL DISABILITIES, 2016 AUTISM AND DEVELOPMENTAL DISABILITIES MONITORING (ADDM) NETWORK SURVEILLANCE SUPPLEMENTAL SLIDES, slide 17 (Mar. 26, 2020).

[19] *Data & Statistics on Autism Spectrum Disorder*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/ncbddd/autism/data.html (last visited Sept. 25, 2020).

[20] *See* CTRS. FOR MEDICARE & MEDICAID SERVS., LONG-TERM SERVICES AND SUPPORTS REBALANCING TOOLKIT 10 (Nov. 2020), https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-toolkit.pdf.

autism will transition to the adult state-by-state funding system over the next decade.[21] Though there is a focus on the increasing entry of Baby Boomers into the Medicare and Social Security systems, those same individuals will be sharing resources with the growing number of adults with IDD using the same supports.[22] With the demographics moving toward more adults with IDD, planning for a future of independent, integrated living and adequate services has become a primary concern for individuals, families, and policymakers.

A. History of Institutionalization for Individuals with Intellectual and Developmental Disabilities

The history of institutionalization, detention, and segregation of individuals with disabilities is painful to discuss. It is difficult to comprehend this population's level of disenfranchisement that has existed in the United States since the 1650s. This section does not attempt to cover all the injustices and phases of the history of institutionalization but hopes to provide a broad contextual overview of the progression of the independent living movement for individuals with IDD.

1. Segregated Settings

"Segregation and detention have always served to control those on the margins."[23] The nineteenth century brought a call for better services for individuals with disabilities from the poorhouses and almshouses that prevailed in the United States. Trends that began as a positive change for individuals with disabilities unfortunately set the stage for the housing segregation and institutionalization that continued into the 20th century. For example, due to dismal conditions inside the city poorhouses, advocates such as Dorothea Dix fought for setting aside countryside to build residences to accommodate individuals with disabilities outside of the grim and dirty urban conditions.[24] Other advocates, such as Hervey B. Wilbur, established boarding schools for children with IDD.[25] Ironically from a modern perspective, in the 19th century

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[21] Paul Shattuck, *Growing Numbers of Young Adults on the Autism Spectrum*, LIFE COURSE OUTCOMES BLOG (June 27, 2019), https://drexel.edu/autismoutcomes/blog/overview/2019/June/Growing-numbers-of-young-adults-on-the-autism-spectrum/.

[22] *See, e.g.*, Amy S.F. Lutz, *Who Decides Where Autistic Adults Live?*, THE ATLANTIC (May 26, 2018).

[23] Laura I. Appleman, *Deviancy, Dependency, and Disability: The Forgotten History of Eugenics and Mass Incarceration*, 68 DUKE L.J. 417, 419 (2018). *See also id.* at 430–32 (arguing that asylums served as carceral settings).

[24] *See Parallels in Time: A History of Developmental Disabilities, Make the Deviant Undeviant*, MINN. GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES, https://mn.gov/mnddc/parallels/four/4b/1.html (last visited Oct. 16, 2021).

[25] *See Parallels in Time: A History of Developmental Disabilities*, *Hervey B. Wilbur*, MINN. GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES, https://mn.gov/mnddc/parallels/four/4b/6.html (last visited Oct. 16, 2021).

the public and legislatures opposed the growth of educational residential settings not due to their segregated nature, but rather the perception that "not much, if anything, could be done to benefit the feebleminded."[26] Without a commitment of support from the government, schools, and employment opportunities, these schools transitioned over time into essentially asylums; states simultaneously began to build and fund custodial institutions to house individuals with disabilities. By the early 1900s, the use of asylums as "'total institution[s]'" became a "'first resort'" for individuals with IDD.[27] Based on the purported benefits of the countryside, these institutions were "rural" and kept individuals "away from . . . view."[28]

The pattern of re-confining and re-segregating individuals with disabilities in various settings apart from their communities remained the prevailing practice until it peaked in the late 1960s.[29] Thereafter began a shift in mindset surrounding institutions and integration. As a 1970 preface to a book on the state of residential facilities for individuals with disabilities noted, "the most fundamental manifestation of the emerging view is the belief that [an individual with disabilities] is a genuine member of our society with a valid and equal claim to all its privileges, resources, and . . . adversities."[30] In 1961, President John F. Kennedy, whose sister Rosemary had an IDD, established the President's Panel on Mental Retardation, which pushed the passage of the Community Mental Health Act in 1963.[31] The Panel viewed IDD as a "'health and human development problem, one that could be tackled scientifically.'"[32] President Kennedy's sister Eunice Kennedy Shriver led the charge and succeeded in publicizing compelling reports revealing the inhumane conditions inside asylums and state institutions around the country.[33] However, the work of Eunice and others mostly instigated the "improve[ment]" of existing

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[26] ALFRED A. BAUMEISTER & EARL BUTTERFIELD, RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED 8 (1970). By 1890, about twenty residential schools had been established in fifteen states. *Id.* at 16. By the institution's peak in 1968, there were 167 public facilities for individuals with IDD. *Id.* at 20.

[27] Appleman, *supra* note 23, at 427–28.

[28] *Parallels in Time: A History of Developmental Disabilities, From Training School to Asylum*, MINN. GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES, https://mn.gov/mnddc/parallels/four/4c/2.html (last visited Oct. 16, 2021).

[29] *See* Lerner & Pollack, *supra* note 16, at 753 (the number of people in state-run institutions with IDD peaked in 1967 at 194,650).

[30] BAUMEISTER & BUTTERFIELD, *supra* note 26, at v.

[31] *See* Appleman, *supra* note 23, at 453; *The National Association of State Directors of Developmental Disabilities Services: Our Story*, NAT'L ASS'N OF STATE DIRS. OF DEVELOPMENTAL DISABILITIES SRVS., https://nasddds.org/history (last visited Dec. 28, 2021).

[32] Carli Friedman, *The Influence of Residence Type on Personal Outcomes*, 57 INTELL. & DEVELOPMENTAL DISABILITIES 112, 113 (2019) (emphasis omitted).

[33] *See, e.g.*, EILEEN MCNAMARA, EUNICE: THE KENNEDY WHO CHANGED THE WORLD (2018).

institutions[34] and increased access to public education and employment opportunities, instead of creating independent, integrated living for individuals with IDD.

Further, government policies throughout the 1960s and 1970s created incentives that sped up deinstitutionalization. Medicaid coverage and Supplement Security Income ("SSI") went into effect in 1965 and 1972, respectively, but were explicitly unavailable to individuals in institutions.[35] This policy created incentives for states to move long-term residents of institutions into nursing homes to regain funding; in fact, the population in institutions dropped by 13.3% in the first year after SSI went into effect.[36] Therefore, even though advocacy by the IDD community and families themselves resulted in objectively fewer institutionalized individuals, states moved those individuals to other types of congregate settings.[37] Today, a disproportionate number of the IDD population remain in congregate settings,[38] segregated from the community.

i. The Debate Over Types of Congregate Settings

After deinstitutionalization, individuals with IDD entered a wide variety of housing settings. In the last fifty years there has been an acknowledgement

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[34] *Parallels in Time: A History of Developmental Disabilities, Improve the Institutions*, MINN. GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES, https://mn.gov/mnddc/parallels/five/5a/11.html (last visited Oct. 16, 2021).

[35] Appleman, *supra* note 23, at 454–56. Medicaid is funded jointly by the Federal Government and the states. States have their own plans where they establish Medicaid provider rates within federal requirements, and the Federal Government pays states for a specified percentage through Federal Medical Assistance Percentage (FMAP). *See Federal Medical Assistance Percentages or Federal Financial Participation in State Assistance Expenditures (FMAP)*, U.S. DEP'T OF HEALTH & HUMAN SERVS., ASSISTANT SEC'Y FOR PLAN. & EVALUATION (Jan. 13, 2016), https://aspe.hhs.gov/federal-medical-assistance-percentages-or-federal-financial-participation-state-assistance-expenditures. Many people who are eligible for SSI also are eligible for Social Security benefits. In most states, SSI recipients are also eligible for Medicaid, food assistance, or supplemental payments. To qualify, you must be disabled, blind, or at least 65 years old with "limited" income. *Understanding Supplemental Security Income (SSI) Overview – 2021 Edition*, SOC. SEC. ADMIN., https://www.ssa.gov/ssi/text-over-ussi.htm#:~:text=SSI%20is%20financed%20by%20general,not%20fund%20the%20SSI%20program.&text=SSI%20benefits%20are%20paid%20on%20the%20first%20of%20the%20month (last visited Dec. 28, 2021).

[36] Appleman, *supra* note 23, at 454–56.

[37] *See* Abbie J. Thurmes, Note, *How Minnesota's Reliance on Private Group Homes Impacts the Rights of Individuals with Disabilities*, 38 MITCHELL HAMLINE L.J. PUB. POL'Y & PRAC. 1 (2017); *see also* Appleman, *supra* note 23 (noting that the process of deinstitutionalization has coincided with the rise of the carceral state, meaning many of those deinstitutionalized individuals ended up incarcerated). This phenomenon of moving individuals with IDD to other congregate settings is called "transinstitutionalization." Friedman, *supra* note 32, at 120.

[38] *See* Scott D. Landes et al., *COVID-19 Outcomes Among People with Intellectual and Developmental Disability in California: The Importance of Type of Residence and Skilled Nursing Care Needs*, 14 DISABILITY & HEALTH J. 2 (2021).

that "simply living inside a home located in a community setting is not being a member of the community."[39] Home ownership and housing access is associated with broader citizenship rights in society. This includes having "freedom, authority, and support to exercise control" over one's living situation and daily routines.[40] In fact, disabled individuals' "inability to gain access to housing which meets their particular needs reinforces their partial citizenship."[41] Therefore, there is an active, ongoing discussion over the best form of housing and which housing types are so "congregate" as to still resemble the institutions the individuals left in the first place.

The Joint Position Statement of the American Association on Intellectual and Developmental Disabilities and The ARC states that, "like all Americans, [those with IDD] have a right to live in their own homes, in the community."[42] Defining community is important for determining maximally inclusive housing settings for individuals with IDD. However, there is debate about the vision of "community" that should be the goal. For example, in social science research examining group homes for individuals with mental illness, the authors define community primarily as the "larger social context surrounding the homes into which participants moved."[43] Secondarily, community includes the "ability . . . to become active agents in shaping their futures rather than passive recipients of changes designed by others."[44] Thus, community can be seen as a social process and is necessarily tied to the ability to create and choose social ties, not a precise physical location.[45]

The desire for community with meaningful social ties has led some to argue that congregate settings actually provide more "community" for individuals with IDD who otherwise would be isolated in their own apartments or institutions. For example, some parent-advocates noted that in contrast to the institutions of the past, current congregate settings can be seen as an "intentional community," where there is more opportunity for socialization and interaction than the isolation of living alone in one's own apartment in the community.[46] Congregate living settings, such as intentional communities, should not be grouped in with "institutions" according to those advocates. This argument also arguably has the backing in that, notably, "[n]either the ADA nor *Olmstead* define institution."[47] In fact, the Supreme Court in *Olmstead* said that there is no "federal requirement that community-based treatment be imposed on

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[39] Thurmes, *supra* note 37, at 8.

[40] *Joint Position Statement of AAIDD and The Arc*, AM. ASS'N ON INTELL. & DEVELOPMENTAL DISABILITIES, https://www.aaidd.org/news-policy/policy/position-statements/housing (last visited Jan. 18, 2021).

[41] ROB IMRIE, ACCESSIBLE HOUSING: QUALITY, DISABILITY AND DESIGN 1 (2006).

[42] *Joint Position Statement*, *supra* note 40.

[43] RUSSELL K. SCHUTT, HOMELESSNESS, HOUSING, AND MENTAL ILLNESS 5 (2011).

[44] *Id.*

[45] *See id.* at 29–30.

[46] *See* Lutz, *supra* note 22.

[47] Thurmes, *supra* note 37, at 5.

patients who do not desire [such treatment]."[48] So should those families be given autonomy to choose segregated settings?

In contrast, studies have shown the benefits of the "community" definition above arise from the "meaningfulness of their interaction" with peers chosen for oneself, "not simply time spent together" to reduce feelings of loneliness.[49] Further, some advocates note that as institutions get larger, the potential for abuse and neglect increase.[50] This concern is not unwarranted: almost 70% of female adults with autism have been abused in their lifetimes.[51] This argument has force in the COVID-19 pandemic. The anonymity and lack of person-centered aspects of larger institutions resulted in those institutionalized individuals having a higher mortality rate from COVID-19.[52] The prevention of abuse can arguably be better ensured when individuals have "the opportunity to participate in the greater community and have relationships with people who can notice."[53] Finally, many individuals with IDD who move into congregate settings—such as group or nursing homes—do so to gain stable housing,[54] or due to a lack of options. This begs the question of whether a choice between homelessness or stable housing was in fact an autonomous choice for "community."

The importance of person-centered housing implicates more than just freedom of choice as a human right. Housing is a social determinant of health, which includes "conditions, factors, and environments that impact people's health and quality of life."[55] Housing affects health outcomes: the increases in quality of life post-transition to home and community-based care are thoroughly documented.[56] For example, a study of emergency room visits found that people with IDD "who chose where and with whom to live" saw a 74% decrease

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[48] Olmstead v. L.C., 527 U.S. 581, 602 (1999).

[49] SCHUTT, *supra* note 43, at 92–93.

[50] *See* Lutz, *supra* note 22.

[51] *Id.*; *see also* Robert Chapman, *We Need to Talk About the Domestic Abuse of Autistic Adults*, MEDIUM (July 27, 2017), https://medium.com/the-establishment/we-need-to-talk-about-the-domestic-abuse-of-autistic-adults-5df294504a13.

[52] *See, e.g.*, Justin Wm. Moyer, *St. Elizabeths' Delayed Response to Coronavirus Contributed to 18 Deaths, Report Says*, WASH. POST (Mar. 1, 2021), https://www.washingtonpost.com/local/st-elizabeths-covid-deaths/2021/03/01/b10d9230-7a99-11eb-b0fc-83144c02d676_story.html.

[53] Lutz, *supra* note 22; *see also* Chapman, *supra* note 51.

[54] SCHUTT, *supra* note 43, at 42. When homes were not "intentional" they would lack the "'voluntary, value-based' nature" of communities. *Id.* This would make developing "supportive social ties" in the larger community through work and other routines even more difficult. *Id.*

[55] CARLI FRIEDMAN, COUNCIL ON QUALITY & LEADERSHIP, CHOOSING HOME: THE IMPACT OF CHOOSING WHERE TO LIVE ON PEOPLE WITH INTELLECTUAL AND DEVELOPMENT DISABILITIES' EMERGENCY DEPARTMENT UTILIZATION 3 (2021), https://www.c-q-l.org/wp-content/uploads/2021/06/CQL-2021-Friedman-Choosing-home-impact-ER-visits-IDD.pdf.

[56] *See, e.g.*, ERIC D. HARGAN, REPORT TO THE PRESIDENT AND CONGRESS: THE MONEY FOLLOWS THE PERSON REBALANCING DEMONSTRATION 23–24 (June 2017), https://www.medicaid.gov/sites/default/files/2019-12/mfp-rtc.pdf.

in emergency room visits.[57] So person-centered housing improves health outcomes, quality of life, and reduces system-wide medical costs.

Since the deinstitutionalization process began in the 1960s, a variety of living settings arose. Their characteristics are overlapping and sometimes difficult to differentiate. For purposes of this Note, these are the current types of relevant housing settings that are still congregate and segregated for individuals with IDD:

State-run institutions. Since Medicaid began in 1965, it required state Medicaid programs to "provide medically necessary nursing facility care," but left funding for home and community-based services optional by the state.[58] This policy has been called Medicaid's "institutional bias."[59] The population of residents with IDD in institutions peaked in 1967 at 194,650, and has declined to 29,809 by 2011.[60] Even though Medicaid has given states increasing flexibility in how to allocate their funding,[61] state-run institutions still operate in thirty-seven states.[62] Further, historically what has been deemed deinstitutionalization from state-run institutions, in reality, can be characterized as *transinstitutionalization*: being transitioned from one congregate institutional setting to another, such as to an intermediate care facility, nursing home, or group home.[63]

Group Homes. Roughly 681,000 individuals with IDD live in congregate settings such as group homes or state institutions.[64] Group homes have been used by many states as an alternative to institutional living,[65] and some view them as "mini-institutions."[66] This term covers congregate residential structures

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[57] FRIEDMAN, *supra* note 55, at 12.

[58] CTRS. FOR MEDICARE & MEDICAID SRVS., REQUEST FOR INFORMATION: RECOMMENDED MEASURE SET FOR MEDICAID-FUNDED HOME AND COMMUNITY-BASED SERVICES 2 (Sept. 2020).

[59] Friedman, *supra* note 32, at 122.

[60] Lerner & Pollack, *supra* note 16, at 753.

[61] The increase of waiver programs, such as Home and Community-Based Services Waivers (HCBS), "allow states to design innovative programs to serve the long-term needs . . . and to avoid the institutionalization of those persons." Sahar Takshi, Note, *Home Sweet Home: The Problem with Cost-Neutrality for Older Americans Seeking Home- and Community-Based Services*, 5 ADMIN. L. REV. ACCORD 25, 31 (2019).

[62] Katelyn Li, *A Crisis in the Making: Disability Housing Policy and COVID-19*, HARV. POL. REV. (Oct. 11, 2020), https://harvardpolitics.com/congregate-care-covid/. Thirteen states plus Washington, D.C. stopped funding for state-run institutions altogether. The states with the most people living in state-run institutions include Texas (3,541), Illinois (1,724), New Jersey (1,701), and North Carolina (1,194). AMIE LULINSKI & EMILY S. TANIS, COLEMAN INST. FOR COGNITIVE DISABILITIES, USE OF STATE INSTITUTIONS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN THE UNITED STATES (2018).

[63] *See* Friedman, *supra* note 32, at 120.

[64] Li, *supra* note 62.

[65] *See, e.g.*, Thurmes, *supra* note 37.

[66] Appleman, *supra* note 23, at 459.

that are "occupied, but not rented" by individuals with disabilities.[67] They may be managed or owned by either a non-profit or for-profit entity that is usually licensed by the state.[68] Though size and characteristics vary, an estimated 90% of group homes serving those with IDD had six or fewer occupants.[69] While not considered institutions, states can categorize group homes as institutional settings through adjusting their capacity definitions. For example, the National Council on Disability defines "institution" as "a facility of four or more people who did not choose to live together."[70]

Assisted Living Facilities and Intermediate Care Facilities. Intermediate Care Facilities for Individuals with Developmental Disabilities ("ICF/DD") are an optional Medicaid benefit that can be offered as an alternative to HCBS waivers for those who need "comprehensive and individualized health care."[71] They are residential programs that can be run by either private or state operators. ICF/DDs are attractive to states, as they are funded by Medicaid and, unlike HCBS waivers, their access and funding is not restricted by cost-neutrality requirements. Thus, in many cases, ICF services "may be more immediately available than other long-term care options."[72] Federal regulations characterize smaller ICF/DDs with populations of six to sixteen as institutions.[73] However, 19% of individuals with IDD are in nursing facilities or ICF/DDs with more than sixteen residents.[74] This, again, raises the issue of whether deinstitutionalization to ICF/DDs is really just transinstitutionalization in disguise. Lastly, it should be noted that studies have found a lack of significant differences in quality of life of individuals with IDD who were transinstitutionalized, or transferred from a privately-operated congregate setting to a group home or ICF.[75] This could imply that these ICF/DDS have similar impacts on individuals as the institutions of the past.

Supportive Housing. Here, an individual receives health and social services at their own home.[76] Individuals with IDD are offered the flexibility of housing choice matched with their level of required personal and medical

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[67] Daniel R. Mandelker, *Housing Quotas for People with Disabilities: Legislating Exclusion*, 43 URB. LAW. 915, 917 (2011).

[68] *Id.*

[69] *Id.* at 918.

[70] *Institutions: Definitions, Populations, and Trends*, NAT'L COUNCIL ON DISABILITY, https://ncd.gov/publications/2012/Sept192012/Institutions (last visited Mar. 10, 2021). As an example of state-specific variances, see IND. CODE ANN. § 31-27-5-3, where Indiana allows up to 10 individuals per group home.

[71] *Intermediate Care Facilities for Individuals with Intellectual Disability*, CTR. FOR MEDICAID & CHIP SERVS., https://www.medicaid.gov/medicaid/long-term-services-supports/institutional-long-term-care/intermediate-care-facilities-individuals-intellectual-disability/index.html (last visited Mar. 10, 2021).

[72] *Id.*

[73] NAT'L COUNCIL ON DISABILITY, *supra* note 70.

[74] *Id.*

[75] *See* Friedman, *supra* note 32, at 120.

[76] *See* Mandelker, *supra* note 67, at 919–21.

care services. Rather than defining supportive housing, it may be easier to define what it is not: nursing facilities, institutions, ICFs, and hospitals.[77] A "true supportive housing model" is "concerned with individual dignity, personal choice, and autonomy."[78] This flexible approach can be achieved through waiver programs, where individuals receive a certain amount of money to spend on housing and services as they choose. Therefore, it consists of a combination of services that is tied to an individual and based in an individual residence. Though the individual could choose a congregate setting such as a group home, the key difference is the individual has the services and autonomy to *choose* that setting.

Lastly, an estimated 77% of individuals with IDD who receive long-term care support live in non-congregate settings, such as in their own home or one of a family member.[79] This situation places a high burden on families of individuals with IDDs to provide personal and medical care.[80]

B. The Independent Living Movement and Brewing Crisis

There is no one-size-fits-all approach for individuals with IDD and independent living. Acknowledging that reality is paramount to breaking the stalemate of the broken system. We are now in the independent living, "person-centered," phase of deinstitutionalization. This person-centered approach looks at the person's needs and desires first, then builds in supports to meet that individual's needs. Instead of fitting people into programs, supports are developed around the individual wherever he or she may live or work.[81] In practice, states struggle to piece together the supports from Medicaid, Social Security, and local affordable housing to adequately transition and support large numbers of individuals with IDD. Though the increased deinstitutionalization of those with disabilities was heralded as a great advancement in the disability rights movement, the lack of supply of affordable housing and adequate social services created a "perfect storm."[82] There are three overlapping issues to the

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[77] Desiree Kameka, MADISON HOUSE AUTISM FOUNDATION, *CMS Final Rule Implementation & State Transition Plans* (2016), Slide 11, https://www.autismhousingnetwork.org/wp-content/uploads/2016/09/ACCSES-Conference_2016.pdf.

[78] Henry Korman, *Clash of the Integrationists: The Mismatch of Civil Rights Imperatives in Supportive Housing for People with Disabilities*, 26 ST. LOUIS U. PUB. L. REV. 3, 7 (2007); *see also* Glenna Riley, Note, *The Pursuit of Integrated Living: The Fair Housing Act as a Sword for Mentally Disabled Adults Residing in Group Homes*, 45 COLUM. J.L. & SOC. PROBS. 177, 184 (2012).

[79] Landes et al., *supra* note 38.

[80] *See infra* Part III.B.

[81] *Parallels in Time: A History of Developmental Disabilities, Home Ownership*, MINN. GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES, https://mn.gov/mnddc/parallels/six/6d1/3.html (last visited Oct. 16, 2021).

[82] SCHUTT, *supra* note 43, at 51 (when the ratio of deinstitutionalization rises along with a reduction in the supply of affordable housing). The "perfect storm" in federal policy consists of cuts

current affordable housing and long-term services crisis in the IDD community: (1) discrimination; (2) an affordable, accessible, integrated housing shortage; and (3) a mismatch between services and available funding for independent living.

First, individuals with IDD face discrimination in renting and buying homes. For example, in the City of Chicago, complaints from individuals facing discrimination in renting and selling outpace racial housing complaints.[83] Landlords and sellers discriminate against individuals with disabilities based on their perceptions, biases, and unwillingness to make reasonable modifications and accommodations to units as required by federal law.[84] Further, there are over ten million individuals with disabilities in the U.S. who receive Social Security Disability Insurance ("SSDI") or Supplemental Security Income ("SSI").[85] For individuals with IDD who cannot work, or are in and out of employment, SSI is often their exclusive income for decades.[86] People with disabilities receiving SSI on average need to pay 104% of their monthly income to rent a modest one-bedroom apartment.[87] The huge disparity between rents and SSI means that individuals with IDD who do not have family supports are forced to choose between homelessness or an institutional setting. Lastly, there is no federal law preventing landlords from rejecting housing vouchers or social security income.[88] In one study, high-priced cities such as Los Angeles and Fort Worth had vouchers denied by landlords over 75 percent of the time.[89]

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to supportive housing and a shortage of affordable, accessible housing. EMILY COOPER ET AL., PRICED OUT IN 2012: THE HOUSING CRISIS FOR PEOPLE WITH DISABILITIES 1 (May 2013).

[83] Natalie Moore, *Disability, Not Race, Leads Housing Discrimination Complaints in Chicago*, WBEZ CHICAGO (Sept. 6, 2018), https://www.wbez.org/stories/disability-not-race-leads-housing-discrimination-complaints-in-chicago/cfbce40d-bd78-420a-af47-a5e5337cd402.

[84] *See* 42 U.S.C. § 12132.

[85] *Annual Statistical Report on the Social Security Insurance Program, 2016,* SOC. SEC. ADMIN. https://www.ssa.gov/policy/docs/statcomps/di_asr/2016/sect01.pdf (last visited Oct. 16, 2021).

[86] *See* Gina A. Livermore et al., *Supplemental Security Income & Social Security Disability Insurance Beneficiaries with Intellectual Disability*, 77 SOC. SEC. BULL. 17 (2017), https://www.ssa.gov/policy/docs/ssb/v77n1/v77n1p17.html.

[87] COOPER ET AL., *supra* note 82, at i. There are 181 markets and 33 states where average rents exceed 100% of monthly SSI. *Id.*

[88] ALISON BELL ET AL., CTR. ON BUDGET & POL'Y PRIORITIES, PROHIBITING DISCRIMINATION AGAINST RENTERS USING HOUSING VOUCHERS IMPROVES RESULTS 1 (Dec. 20, 2018). Only one in three vouchers is protected by local and state non-discrimination laws. *Id.*

[89] *Id.* at 8. HUD provides a variety of rental assistance programs. One such program is a housing choice voucher program that allows low-income families, the elderly, and the disabled to find suitable housing. The voucher is then paid directly to the landlord by the local public housing agency (PHA). *Housing Choice Vouchers Fact Sheet*, U.S. DEP'T HOUS. & URB. DEV., https://www.hud.gov/program_offices/public_indian_housing/programs/hcv/about/fact_sheet (last visited Nov. 6, 2021).

Second, there is both a lack of accessibility in existing units as well as an affordable housing shortage nationwide.[90] The U.S. has a shortage of more than 7.2 million rental homes for extremely low-income renter households.[91] The shortage of affordable rental housing is a "major barrier" to community integration.[92] Community integration refers to the degree in which people with disabilities have "the opportunity to live, work, and recreate in the same manner as peers without disabilities," and is an important indicator of how successful deinstitutionalization policies have been.[93] In addition to the nationwide shortages of affordable housing, in the disability community specifically there is an even greater absence of suitable housing. In HUD's last study, they reported that only one-third of American housing is modifiable to be made accessible to individuals with moderate mobility challenges, and a mere 1% are currently wheelchair accessible.[94] As noted above, people with disabilities tend to have lower incomes that are often fixed by SSI/SSDI, which cannot cover most rents. Around 10% of individuals in the U.S. have a disability, but 20% of individuals in poverty have a disability, and 40% of homeless individuals have a disability.[95] In fact, over one million extremely low-income, non-elderly households with disabilities pay 50% of their income for housing costs.[96]

Further, there are barriers in construction funding and building of new units. Titles II and III of the ADA mandate physical accessibility requirements in public housing and common use areas in housing developments.[97] However, the new ADA standards only apply to housing built after 1991; in one HUD study, only 40% of the current housing stock was built after 1991 and 0.15% was already accessible.[98] Even though builders themselves are held to the

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[90] Before and during the 2008 housing crisis, "higher housing prices that resulted from supply restrictions reduced the ability of Americans to become homeowners." CLAUDE GRUEN, NEW URBAN DEVELOPMENT: LOOKING BACK TO SEE FORWARD 14 (2010).

[91] NAT'L LOW INCOME HOUS. COAL., THE GAP: A SHORTAGE OF AFFORDABLE HOMES 15 (Mar. 2018).

[92] ANN O'HARA & JIM YATES, TECHNICAL ASSISTANCE COLLABORATIVE, INC., CREATING NEW INTEGRATED PERMANENT SUPPORTIVE HOUSING OPPORTUNITIES FOR ELI HOUSEHOLDS: A VISION FOR THE FUTURE OF THE NATIONAL HOUSING TRUST FUND 1 (Apr. 9, 2015); "The single most important community development issue facing our nation today is the critical and growing shortage of decent and safe rental housing [for] ELI households." *Id.* at 7.

[93] Yin-Ling I. Wong & Victoria Stanhope, *Conceptualizing Community: A Comparison of Neighborhood Characteristics of Supportive Housing for Persons with Psychiatric and Developmental Disabilities*, 68 SOC. SCI. & MED. 1376, 1376 (2009).

[94] LUKE BO'SHER ET AL., U.S. DEP'T HOUS. & URB. DEV., OFF. POL'Y DEV. & RSCH., ACCESSIBILITY OF AMERICA'S HOUSING STOCK: ANALYSIS OF THE 2011 AMERICAN HOUSING SURVEY (AHS) 1 (Mar. 9, 2015).

[95] Sevak, *supra* note 12, at 18 (internal citations omitted).

[96] O'HARA & YATES, *supra* note 92, at 7. Extremely low-income households are those that are between 0% and 30% of the area median income. *Id.*

[97] 28 C.F.R. §§ 35, 36 (2016).

[98] BO'SHER ET AL., *supra* note 94, at 26. 1.1 million families in HUD's voucher program live in units built before 1978. U.S. GOV'T ACCOUNTABILITY OFF., LEAD PAINT IN HOUSING: KEY

ADA's technical standards, there can be bias against such requirements that they are a "cost and an irrelevance."[99] For people with IDD specifically, the technical standards implemented by policymakers "reduce[] disability to a 'type'"—primarily a "wheelchair user[]"—and so in many ways these standards do not view housing quality as a "multidimensional phenomenon" that "facilitate[s] ease of mobility, movement and use" for all individuals.[100] Across the country, there is less supply of affordable housing being built than before,[101] and the construction of a "few thousand units" has not made a "serious dent" in the affordable housing crisis.[102]

Third, the funding for housing, health care, and independent living is not in alignment for those with IDD who seek person-centered living arrangements. In all states, "Medicaid is seen as a significant resource for maintaining or establishing community-based services as an alternative to institutional care."[103] However, states face high Medicaid budget pressures, thus limiting HCBS to cost-control.[104] While Medicaid will pay for the services of supportive housing, the procurement and payment of rent falls on affordable housing programs.[105] In addition, HUD has rental assistance programs that make up 83% of HUD's budget in a given year.[106] As the movement toward deinstitutionalization accelerated, the funding to support housing and supportive in-home services did not keep pace with either the costs of housing or the needs of low-income individuals. Thus, persons who were deinstitutionalized were then linked to the community-based treatment and housing that *was* available—namely ICFs or assisted living facilities.[107] In order for deinstitutionalization to be effective, individuals with IDD need a host of other supports that include "publicly funded

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CONSIDERATIONS FOR ADOPTING STRICTER LEAD EVALUATION METHODS IN HUD'S VOUCHER PROGRAM 13 (May 2021).

[99] IMRIE, *supra* note 41, at 4.

[100] *Id.* at 25, 43 (noting that disabled individuals' "housing circumstances . . . are characterized by an absence of quality."). Imrie also laments the lack of "any substantial debate" amongst policymakers and academics about the "interrelationships between disability and housing quality" other than to discuss "technical standards" that respond "primarily to the access needs of wheelchair users." *Id.* at 43.

[101] *See* GRUEN, *supra* note 90, at 27–28 (commenting that less companies produce housing today due to the "increased capital and organizational capability required to successfully meet the challenge of obtaining entitlement from the body politic").

[102] *Id.* at 62.

[103] Lerner & Pollack, *supra* note 16, at 759.

[104] *See* Korman, *supra* note 78, at 15–16.

[105] *Id.* at 17.

[106] Erika Poethig, *The Five Dimensions of Housing Policy*, *in* DEVELOPING AFFORDABLE & ACCESSIBLE COMMUNITY-BASED HOUSING FOR VULNERABLE ADULTS: PROCEEDINGS OF A WORKSHOP 10, 11 (2017) (contrary to popular belief, housing affordability "touches suburban, urban, and rural communities").

[107] Olga Golik, *Is Integration for Persons with Disabilities Resulting in Contradictory Barriers to Housing?*, 16 FLA. COASTAL L. REV. 205, 208 (2015).

social programs" that actually allow for "full participation in civil life."[108] Further, there are great disparities between states in their levels of funding and support for supportive housing. This is important, as it is "almost always" necessary to combine state and federal resources to find supportive housing.[109]

These three overlapping concerns point to the failure of a housing and funding scheme that is truly person-centered. In theory, when determining housing services, a system should (1) assess applicant needs, (2) consider the social mix or community integration, and (3) consider the applicant's own choices.[110] The idea of person-centered housing means directing resources to *individuals* instead of to services such as group homes. Giving resources to individuals ensures greater "control and flexibility" in choosing housing and support services based on needs, social mixing, and choice.[111] Again, this compels the acknowledgement that there is no "one-size-fits-all solution to making housing more affordable and accessible."[112] For individuals with IDD to achieve success in independent living, we must match people to services, not disabilities to units, since housing and treatment needs are separate.[113]

PART II

As former Department of Health & Human Services ("HHS") Office of Civil Rights Director Roger Severino noted regarding the rationing of care and de-prioritization of those with disabilities during COVID-19, "civil rights laws are not suspended during an emergency. In fact, that's when we need them the most."[114] There are, thankfully, strong civil rights protections for individuals with disabilities, at least as black letter law. There are also federal policies—such as receiving Home and Community-Based Services ("HCBS") waivers—that become so confusing and complex that arguably neither states nor individuals with IDD can fully take advantage of them to create person-centered living. This Part will first give a brief overview of the relevant federal statutes, important litigation, and Medicaid/Medicare policies affecting individuals with IDD.

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[108] Korman, *supra* note 78, at 12.

[109] *Id.* at 24.

[110] *See* Ilan Wiesel, *Allocating Homes for People with Intellectual Disability: Needs, Mix and Choice*, 45 SOC. POL'Y & ADMIN. 280, 282 (2011).

[111] *Id.* at 288.

[112] Joe Alper et al., *Opening Remarks*, *in* DEVELOPING AFFORDABLE AND ACCESSIBLE COMMUNITY-BASED HOUSING FOR VULNERABLE ADULTS: PROCEEDINGS OF A WORKSHOP 3, 3 (2017).

[113] *See* Korman, *supra* note 78, at 36.

[114] Shira Stein, *Disability Bias Protections Get Final Push from Trump's HHS*, BLOOMBERG LAW (Jan. 15, 2021), https://news.bloomberglaw.com/health-law-and-business/disability-bias-protections-get-final-push-from-trumps-hhs.

A. Civil Rights Protections - Legislative Enactments

A number of civil rights laws overlap to protect individuals with IDD in the housing context. In the 1970s, Congress passed Section 504 of the Rehabilitation Act of 1973 ("Section 504").[115] Section 504 applies to all programs and activities receiving federal financial assistance. It prohibits discrimination on the basis of disability and mandates compliance with accessibility-related requirements in those programs and activities. It also created funding for the establishment of Centers for Independent Living ("CILs"), which provide the four core services of information and referral, independent living skills training, peer counseling, and advocacy. In 1975, Congress passed the Developmental Disabilities Assistance and Bill of Rights Act,[116] which notably created Protection and Advocacy Systems ("P&As") in every state and territory "to protect the legal and human rights of individuals with developmental disabilities."[117] P&As played a key role in the deinstitutionalization process through their advocacy and direct service resources for individuals and families.[118]

Congress failed to include protective provisions for persons with disabilities in the Civil Rights Act of 1968. However, there was an understanding that discrimination against individuals with disabilities in housing was pervasive. Congress ultimately amended the act in 1988 to include such protections.[119] The Fair Housing Act applies to the activities of renting or buying a home, getting a mortgage, seeking housing assistance, or engaging in other housing-related activities.[120] In effect, the Act: (1) prohibits discrimination in the rental or sale of dwellings due to disability, (2) allows tenants with disabilities to request reasonable modifications in order to make the unit accessible, and (3) allows tenants to request accommodations as long as those accommodations don't cause an undue financial or administrative burden.

Finally, in 1990, Congress passed the hallmark protection for individuals with IDD—the Americans with Disabilities Act ("ADA").[121] In 2008, Congress

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[115] 29 U.S.C. § 794.

[116] 42 U.S.C. § 15001.

[117] 42 U.S.C. § 15041.

[118] *History of the DD Act*, ADMIN. FOR CMTY. LIVING (Dec. 1, 2017), https://acl.gov/about-acl/history-dd-act (P&As are "designed to protect and advocate for the rights of people with developmental disabilities and to pursue legal, administrative, and other remedies to accomplish these ends.").

[119] Title VIII of the Civil Rights (Fair Housing) Act of 1968, 42 U.S.C. §§ 3601–19. Notably, Congress did not add disability as a protected class in the FHA until 1988. Fair Housing Amendments Act of 1988, Pub. L. No. 100-430, 102 Stat. 1619 (including "because of a handicap" within the definition of discrimination).

[120] 42 U.S.C. § 3601.

[121] 42 U.S.C. § 12101 *et seq.*, *amended by* ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553. President George H.W. Bush when signing said that the ADA would "bring [America] closer to that day when no Americans will ever again be deprived of their basic

passed the ADA Amendments Act, which broadened and clarified the definition of disability as a "major life activity."[122] Among other widespread protections, the ADA explicitly clarified that states should serve individuals with disabilities "in the most integrated setting appropriate."[123] Further, Title II of the ADA applies to state and local public entities, prohibiting them from discriminating based on disability in all programs, services, and activities, regardless of whether they receive federal financial assistance.[124] While Title II of the ADA doesn't strictly cover residential units, it covers many related activities, such as public housing, zoning regulations, and construction of new homes.[125] Together, these federal anti-discrimination laws should strengthen individuals with IDDs' ability to live independently in person-centered housing arrangements.

B. Medicaid

The most limiting component to the jigsaw puzzle of laws, regulations, and services for individuals with IDD is Medicaid and Medicare. Medicaid is administered by the states and funded jointly by states and the Federal Government.[126] Most Medicaid programs operate as reimbursement-models based upon the level of care required. Individuals with IDD are some of the poorest in the country, with over ten million individuals qualifying for Medicaid based on disability.[127] The Medicaid services available to an individual depend on which state they reside. While every state must provide basic services, such as the "core services" of hospitals, nursing homes, and physician care, the state can also opt to cover a "broader range" of services, such as "'rehabilitative services, personal care services, [and] case-management services.'"[128] Or the state may apply for waivers to receive federal-matching funding for home and community-based services such as health aides, personal care, adult day care, or respite care.[129] One such program is HCBS.[130]

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guarantee of life, liberty, and the pursuit of happiness." George H.W. Bush, U.S. President, Remarks at the Signing of the Americans with Disabilities Act (July 26, 1990).

[122] Congress passed the ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3554, as a response to the Supreme Court's narrowing of the definition of a disability in cases such as *Sutton v. United Air Lines, Inc.*, 527 U.S. 471 (1999).

[123] 28 C.F.R. § 35.130(d) (2016).

[124] *See generally* 42 U.S.C. §§ 12131–12134, and its implementing regulations, 28 C.F.R. § 35.

[125] *Id.*

[126] Julia G. Gaughan, Comment, *Institutionalization as Discrimination: How Medicaid Waivers, the ADA, and § 1983 Fail*, 56 KAN. L. REV. 405, 408 (2008).

[127] *People with Disabilities: Eligibility*, MEDICAID & CHIP PAYMENT ACCESS COMM'N, https://www.macpac.gov/subtopic/people-with-disabilities (last visited Oct. 16, 2021).

[128] John V. Jacobi, *Federal Power, Segregation, and Mental Disability*, 39 HOUS. L. REV. 1231, 1283–84 (2003).

[129] *Id.* at 1284.

[130] As an example, in Indiana, residents who have a HCBS waiver get assigned an evaluation rating based on their level of care and a corresponding budget from the state. The

Non-institutional assistance and other forms of home and community-based services that did not involve skilled nursing were unavailable until 1981 when Congress amended the Social Security Act to include § 1915(c) waivers for HCBS.[131] Section 1915(c) waivers offer substantially more "flexibility"[132] in housing and service options and provide a "vehicle by which states could seek waivers from federal Medicaid law to establish more limited Medicaid coverage for HCBS."[133] HCBS waivers allow states to "waive" provisions of the Social Security Act to create and expand long-term services and supports ("LTSS") that can be "tailored to populations that would typically require institutional care."[134] They are not tied to age, so elderly as well as non-elderly individuals with disabilities can apply for such waivers.[135] The demand for HCBS spending has increased significantly in the last thirty years: in 1990, HCBS accounted for 4.3% of all Medicaid long-term care expenditures, while it accounted for 45% of such expenditures in 2009.[136]

However, the HCBS waivers are bound to a cost-neutrality requirement, where states cannot spend more on these services than the amount spent on nursing facility care.[137] Since the federal costs of Medicaid in a state waiver program cannot exceed the costs of Medicaid without the program, states apply for the waiver programs to cover a certain amount of individuals and fill those spots as "space (and funding) become[] available."[138] The cost-neutrality requirement is a substantial limit on states and creates waiting lists for HCBS waivers that are years long; over 800,000 individuals in the United States are on such HCBS waiting lists.[139]

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individual can then purchase services with that budget. Telephone Interview with Matt Harrington, President of LOGAN Community Resources, Inc. (Feb. 26, 2021).

[131] Laura D. Hermer, *Rationalizing Home and Community-Based Services Under Medicaid*, 8 ST. LOUIS U. J. HEALTH L. & POL'Y 61, 67 (2014).

[132] *Id.* at 74.

[133] *Id.* at 68.

[134] Friedman, *supra* note 32, at 113.

[135] This is an issue as 10,000 baby boomers are entering Medicare and Social Security every day, draining the "'one big pool of money shared by the aging and the disabled.'" Lutz, *supra* note 22.

[136] Hermer, *supra* note 131, at 68.

[137] Takshi, *supra* note 61. The cost-neutrality formula does not take into account litigation, liability insurance, administrative or non-service costs—all of which would add to institutional settings. *Id.* at 47.

[138] Gaughan, *supra* note 126, at 410.

[139] MaryBeth Musumeci et al., *Key State Policies Choices About Medicaid Home and Community-Based Services*, KAISER FAM. FOUND. (Feb. 2, 2020), https://www.kff.org/medicaid/issue-brief/key-state-policy-choices-about-medicaid-home-and-community-based-services/. In Illinois, the PUNs list has 18,000 children and adults. *See* Mark Maxwell, *Illinois 'Unlawful' Underfunding Leaves Thousands With Developmental Disabilities Waiting in Line for Services*, WCIA.COM, (Mar. 30, 2021) https://www.wcia.com/illinois-capitol-news/illinois-unlawful-underfunding-leaves-thousands-with-developmental-disabilities-waiting-in-line-for-services/.

Lastly, HCBS waivers do not cover institutional settings. The different types of congregate settings discussed in Part I demonstrate that the line between "institutional" and "non-institutional" living is not particularly clear. Medicaid acknowledges the haziness between these settings. It presumes "any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS" to have the same quality as an institution and may need to undergo heightened scrutiny by the state to receive funding.[140] Though Medicaid is not the "sole component" to achieve integration and person-centered living for those with IDD, it can be "an enormously positive force in permitting the unnecessarily institutionalized to rejoin the community."[141]

C. Major Court Cases

Lastly, this section will overview a few major court cases interpreting integration and affecting housing. There is much room for judicial evolution and expansion of the federal anti-discrimination laws such as the ADA and FHA. But, the major increases in person-centered housing and adequate services to match deinstitutionalization has been achieved through appropriate legal enforcement activity in the courts. *Pennhurst State School & Hospital v. Halderman* opened the door for the later landmark *Olmstead v. L.C.* challenge.[142] In *Pennhurst*, a class action lawsuit was filed on behalf of residents at the Pennhurst School and Hospital alleging abusive and inhumane conditions under the Eighth and Fourteenth Amendments.[143] In finding for the residents, the Third Circuit noted, "Pennhurst provides confinement and isolation, the antithesis of habilitation."[144] The deinstitutionalization litigation of the 1970s and 1980s focused on achieving constitutional protections for individuals with disabilities.[145] However, after the ADA passed in 1990, the focus of advocates turned to the new wide-reaching federal law. *Olmstead* is the pivotal case in the IDD movement for person-centered housing.

The Court in *Olmstead* interpreted Title II of the ADA, 42 U.S.C. § 12132 (1990), as explicitly recognizing institutionalization and "segregation" as

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[140] Kameka, *supra* note 77, at Slide 12.

[141] Jacobi, *supra* note 128, at 1285.

[142] Pennhurst State Sch. & Hosp. v. Halderman, 465 U.S. 89 (1984); Olmstead v. L.C., 527 U.S. 581 (1999). An earlier case, *Wyatt v. Stickney*, held that individuals who have intellectual or developmental disabilities have a constitutional right to treatment in the least restrictive setting necessary, but the case was ongoing through multiple consent decrees until 2004. Wyatt v. Stickney, 325 F. Supp. 781 (M.D. Ala. 1971).

[143] *Pennhurst*, 465 U.S. at 92.

[144] Halderman v. Pennhurst State Sch. & Hosp., 612 F.2d 84, 113 (3d Cir. 1979).

[145] *See* David Fergleger, *The Constitutional Right to Community Services*, 26 GA. ST. U. L. REV. 763, 765–66 (2012). For example, the *Pennhurst* Court found residents had three distinct sets of constitutional rights under the Equal Protection and Due Process Clauses of the Fourteenth Amendment, and freedom from physical harm under the Eighth and Fourteenth Amendments.

"forms of discrimination against individuals with disabilities."[146] Further, it found that states must maintain a "comprehensive, effectively working plan for placing qualified persons with . . . disabilities in less restrictive settings, and a waiting list that move[s] at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated."[147] Title II required placement of persons with mental disabilities in community settings when "(1) the state's treatment professionals determine that such a placement is appropriate, (2) the transfer is not opposed by the individual, and (3) the placement can be reasonably accommodated given the resources available to the state and its obligation to provide for the needs of others with mental disabilities."[148] However, as a defense, "the public entity can demonstrate conclusively that making the modifications would fundamentally alter the nature of the service, program, or activity."[149]

Therefore, *Olmstead*'s rationales for finding institutionalization as a form of discrimination were based on the notion that "placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life."[150] Second, "confinement in an institution" deprives the individual of participation in a broad spectrum of important activities.[151] Thus, *Olmstead*'s focus on state resource-allocation decisions attaches a broader integration duty to a state's administration of its "'services, programs, and activities,' which may involve services that are paid for by the state but provided directly by private entities."[152] At the same time, a state's "'fundamental alteration' defense" looks at whether "in the allocation of available resources," "immediate relief for the plaintiffs would be inequitable."[153]

In theory, after *Olmstead* the ADA could be used to enforce access to a state's public and private home and community-based services. However, "it is systemic access—not individual access—which is protected."[154] *Olmstead*'s power is in its enabling of disabled individuals to obtain community services in a state, "precisely because the state's failure to provide such services will predictably lead many individuals to become institutionalized."[155]

In practice, the deinstitutionalization litigation before *Olmstead* was driven by a political alliance between civil libertarian and fiscal conservatives, but fiscal conservatives only shared the goal of shrinking expensive

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[146] *Id.* at 764–65 n.7 (quoting 42 U.S.C. § 12101(a)(2), (5) (2006)).

[147] Riley, *supra* note 78, at 220 n.287.

[148] Fergleger, *supra* note 145, at 767–68.

[149] *Id.* at 769, 773 (quoting 28 C.F.R. § 35.130(b)(7) (2001) (emphasis omitted)).

[150] Olmstead v. L.C., 527 U.S. 581, 583 (1999).

[151] *Id.* at 601.

[152] Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 CARDOZO L. REV. 1, 33 (quoting 28 C.F.R. § 35.130(d) (2001)).

[153] *Id.* (quoting *Olmstead*, 527 U.S. at 604).

[154] Gaughan, *supra* note 126, at 417–18.

[155] Bagenstos, *supra* note 152, at 34.

institutions—not of building out community services.[156] After *Olmstead*, the fiscal politics of ensuring adequate services in the community has shifted to large budget fights, and led advocates and litigation to now center on state services and resource allocation.[157] The budget fights even play out in *Olmstead* enforcement. In 2009, President Obama launched a "Year of Community Living" and directed the Department of Justice to redouble its enforcement of the *Olmstead* decision.[158] According to its website, the Department of Justice has enforced sixteen cases related to institutions for individuals with IDD, mainly through entering into long-term settlement agreements with states such as Rhode Island, Illinois, Arkansas, Georgia, and Nebraska.[159] Due to state budget woes (or their lack of prioritization), settlement agreements and consent decrees are drawn out close to a decade. For example, in Illinois a court monitor found the state out of compliance with a federal consent decree for five years in a row.[160] A state cannot achieve consent decree compliance without political will from the state legislature to increase the HCBS budget. Enforcement without the backing of state legislatures and budgets means that individuals with IDD lose out on the services that would allow them to live independently. Unfortunately, neither the ADA nor *Olmstead* has been able to make the right to access home and community-based services enforceable under Medicaid, the primary funding source.[161] Since systemic, not individual access is protected, without an effective system, individuals inevitably lose out.

PART III

This section will address specific policies and attitudes toward independent housing for individuals with IDD that can be adjusted to achieve greater success. It argues that advocates and policymakers should focus on three hinge points that would greatly increase person-centered housing for individuals with IDD: wages, waivers, and flexibility.

The 103rd Congress stated in the 1994 Amendments to the Developmental Disabilities Assistance and Bill of Rights Act:

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[156] *See id.* at 5, 21.

[157] *See id.* at 6, 42–45.

[158] *Olmstead: Community Integration for Everyone*, U.S. DEP'T OF JUST., ada.gov/olmstead/ (last visited Nov. 16, 2021).

[159] *Id.*; *see, e.g.*, United States v. North Carolina, No. 5:12-cv-557 (E.D.N.C. Sep. 21, 2017) (eight-year settlement agreement with State of North Carolina that the state will provide community-based supported housing to 3,000 individuals who currently reside in, or are at risk of entry into, adult care homes).

[160] Maxwell, *supra* note 139 ("'This Court finds that defendants are not in compliance with the Consent Decree by failing to provide the resources of sufficient quality, scope, and variety based on the ample evidence presented to the Court that individuals protected by the Decree have experienced a reduction of services and have suffered substantially as a result.'" (quoting Ligas et. al v. Eagleson et al., 1:05-cv-04331 (N.D. Il. Mar. 3, 2020))).

[161] *See* Gaughan, *supra* note 126, at 434–35.

> [D]isability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society, and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society.[162]

Still, roughly 681,000 individuals with IDD live in congregate settings such as group homes or state institutions.[163] People with IDD are some of the poorest citizens, and among those receiving exclusively SSI, about 14% have intellectual disabilities.[164] During the COVID-19 pandemic, individuals with IDD in congregate settings were disproportionately impacted, jumpstarting a renewed push by advocates for integrated living settings.

In the face of these daunting numbers, what are the most impactful levers that policymakers and advocates can place their focus? First, increasing the wages for personal care workers and direct support professionals so individuals with IDD who could live independently, but need some supports, are able to find and retain such assistance. Second, funding waiver programs, such as HCBS and Money Follows the Person, to allow states to give the maximum flexibility for person-centered housing decisions. Finally, advocates and policymakers should be open to acknowledging that there is no one-size-fits-all approach to housing for individuals with IDD, who have independent living needs that are often unique in comparison to individuals with mobility, hearing, and vision disabilities.

A. COVID-19 Crisis Revealed the Ongoing Housing Inequities

Though no one is exempt from the unpredictable effects of COVID-19, individuals with underlying conditions are at a higher risk for infection and complications. The COVID-19 fatality rate among people with IDD is worse than *any other* minority in the country.[165] In fact, adults with disabilities "are three times more likely" than other adults to have an underlying medical condition.[166] For example, rates of pneumonia were up to 5.8 times higher in 2017 for those with intellectual disabilities, a known co-morbidity with

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[162] Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1994, 42 U.S.C. § 6000 (1994).

[163] *See* Li, *supra* note 62.

[164] *See* Livermore et al., *supra* note 86.

[165] In one study of New York, the case-fatality rate was 15% among people for IDD, compared to 7.9% for the general population. Notably, CMS did not require reporting of COVID-19 cases for facilities housing IDD individuals. *See* Li, *supra* note 62.

[166] *People with Disabilities*, CTRS. FOR DISEASE CONTROL & PREVENTION, https://www.cdc.gov/ncbddd/humandevelopment/covid-19/people-with-disabilities.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fneed-extra-precautions%2Fpeople-with-disabilities.html (last visited Oct. 16, 2021).

COVID-19.[167] Part of this disparity is due to how individuals with disabilities have historically lacked equitable access to the medical care necessary to manage conditions such as heart disease, diabetes, or cancer.[168] Specifically connected to housing, a study of California residents with IDD found the COVID-19 mortality rates were the highest in the settings with the "largest number of residents."[169] In addition to the co-morbidity risks, a vast proportion of individuals with IDD require in-person care or critical therapeutic support, which increases their contact with others or else results in prolonged interruption of services.[170] In state and federal public health plans, there was "nothing that specifically addresse[d] people that have intellectual developmental disabilities."[171] In light of the disproportionate effect on individuals with IDD, there should be a renewed focus on the difference between deinstitutionalization and transinstitutionalization to other congregate settings, which can face similar problems of neglect and isolation.

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[167] *See* Dalton Stevens & Scott D. Landes, *Potential Impacts of COVID-19 on Individuals with Intellectual and Developmental Disability: A Call for Accurate Cause of Death Reporting*, LERNER CTR. FOR PUB. HEALTH PROMOTION (Apr. 14, 2020), https://lernercenter.syr.edu/wp-content/uploads/2020/04/Stevens_Landes.pdf.

[168] John N. Constantino & Mustafa Sahin, *Letters to the Editor: The Impact of Covid-19 on Individuals with Intellectual and Developmental Disabilitie*s, 1771 AM. J. PSYCHIATRY 1091, 1092 (2020). Further, the Centers for Medicare & Medicaid Services' Office of Minority Health only formally recognized that people with disabilities are at risk for health disparities in 2015. *See* Alixe Bonardi et al., *Enriching Our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities*, ADMIN. ON INTELL. & DEVELOPMENTAL DISABILITY 14 (Sept. 2019), https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/Final_State_Data_Paper_09.25.2019%20word%20master%20508%20compliant.pdf.

[169] Landes et al., *supra* note 38, at 3. Further, in New York, there were an estimated 12,743 nursing home resident deaths, some of which include individuals with disabilities, while the numbers of deaths at group homes and other congregate settings has not been fully released. *See* DISABILITY RTS. N.Y., INVESTIGATORY REPORT: NEW YORK STATE'S RESPONSE TO PROTECT PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN GROUP HOMES DURING THE COVID-19 PANDEMIC (Mar. 5, 2021); Jesse McKinley & Luis Ferré-Sadurní, *N.Y. Severely Undercounted Virus Deaths in Nursing Homes, Report Says*, N.Y. TIMES (Jan. 28, 2021), https://www.nytimes.com/2021/01/28/nyregion/nursing-home-deaths-cuomo.html.

[170] Constantino & Sahin, *supra* note 168, at 1091. COVID-19 mitigation efforts, such as social distancing, have a disproportionate effect on individuals with IDD, who have no backups for prolonged interruptions of service, employment layoffs, or cannot properly wear PPE. *See* Constantino & Sahin, supra note 168, at 1091.

[171] Chloe Bennett, *Lifepath IDD Caregivers Face Financial Crisis During COVID Due to HHS' Low Wages*, LOCAL PROFILE (Jan. 8, 2021), https://localprofile.com/2021/01/08/lifepath-idd-residents-face-health-crisis-during-covid-due-to-hhs-low-wages/.

B. Changes That Could Be Implemented to Increase the Ability of Individuals with IDD to Live Independently

1. Adjusting Medicare and Medicaid Rules Connected to Wages

The wages for direct support professionals (DSPs) should be increased to a living wage. These workers are vital to independent living: "[e]very day [they] get to come to work and [they] get to help that person live the life they want."[172] In order for many individuals with IDD to live independently, they require in-home personal, medical, or DSPs to assist and support some aspects of their independent living, whether that be in cleaning, transportation, or medicines. Without the guarantee of DSP services, individuals who find an affordable, accessible apartment still cannot comfortably live there.

Across the country, there is a shortage of DSPs due to the difficulties of the COVID-19 pandemic and the low wages. Though "providers are desperate to offer higher wages, inadequate Medicaid reimbursement rates tie their hands."[173] The federal minimum wage has been $7.25 for over a decade, which is not a living wage in any parts of the country.[174] While states can adjust their own minimum wages, Medicaid waiver funding only covers a certain level of reimbursement to the states. For example, the average wage of a DSP in Illinois is $12.43 per hour, and the job has a turnover rate of 54.5%.[175] In practice, families who can afford to will just pay employees themselves, sidestepping Medicaid waitlists and reimbursements. Further, there is a "vast quantity of unpaid services provided by family and friends of individuals in need of" long-term services.[176] An AARP study found the value of unpaid care at just over $11 per hour to total about $450 billion per year in 2009.[177] This is a burden to

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[172] Theresa Vargas, *Help (Desperately) Wanted: One Low-Wage Job Has Become Harder to Fill During the Pandemic, Despite the Nation's High Unemployment Rate*, WASH. POST (Feb. 27, 2021), https://www.washingtonpost.com/local/help-desperately-wanted-one-low-wage-job-has-become-harder-to-fill-during-the-pandemic-despite-the-nations-high-unemployment-rate/2021/02/27/5f9d0b82-786f-11eb-948d-19472e683521_story.html.

[173] *Id.*

[174] One-eighth of the 4.6 million DSPs live in poverty, and three-fourths earn less than the average living wage in their states. Christian Weller et al., *Making Care Work Pay: How a Living Wage for LTSS Workers Benefits All*, HEALTH AFFAIRS BLOG (Dec. 7, 2020), https://www.healthaffairs.org/do/10.1377/hblog20201202.443239/full/; *see* Michelle Cottle, *Who Will Take Care of America's Caregivers?*, N.Y. TIMES (Aug. 12, 2021), https://www.nytimes.com/2021/08/12/opinion/caretakers-elderly-home-health-aides.html.

[175] NAT'L ASS'N STATE DIRS. OF DEVELOPMENTAL DISABILITIES SERVS. & HUM. SERVS. RSCH. INST., NATIONAL CORE INDICATORS STAFF STABILITY SURVEY REPORT 34 (2019). The nationwide average is $12.36 per hour.

[176] Hermer, *supra* note 131, at 80.

[177] LYNN FEINBERG ET AL., AARP PUB. POL'Y INST., VALUING THE INVALUABLE: 2011 UPDATE—THE GROWING CONTRIBUTIONS AND COSTS OF FAMILY CAREGIVING 1 (2011). The same AARP study found that almost 70% of employed caregivers had to seek accommodation at work in order to continue their caregiving responsibilities. *Id.* at 6.

families, an inhibitor to independent living, and an all-around economic concern for the country.[178]

Federal policy has not always helped. During COVID-19, the $600 per week of federal unemployment payments was more than a DSP would receive while working, disincentivizing them to rejoin the workforce when they were most needed.[179] If DSPs did continue working, employees were forced to work multiple jobs at many locations to make ends meet, exposing themselves and the residents with IDD to COVID-19.[180] Therefore, "the lack of funding for a living wage . . . is a threat to not only the people we support but to the employees and their family members."[181] DSPs were essentially in a bind: they could either risk giving COVID-19 to their vulnerable companions by being unable to take the appropriate precautions; they could forfeit their own livelihood by solely living on the low wages; or they could quit their jobs and leave individuals with IDD completed isolated with virtual or no services. There is no clear decision between these harmful situations. Therefore, the lack of personal and medical care services directly plays out in inhibiting transitions to independent living programs. When individuals are so reliant on first obtaining and keeping the services of DSPs, they cannot move out or plan until those services are guaranteed. But, with state budgets and long waiting lists for HCBS waivers, individuals have no clear path. Instead of a system of supporting services that has "respect for and attention to the needs and desires of the individual person," the DSP limitations put on individuals are the "imperatives of the service provider."[182]

In the short term, the 6.2% increase in federal Medicaid matching funds authorized by the May 2020 CARES Act should be made permanent.[183] This increase in matching funds would allow states and providers to raise wages and attract DSPs.[184] As finding, retaining, and paying for DSPs are the main barriers to individuals moving out and living independently, this permanent increase would be a good start to filling the vacant positions due to COVID-19 in the short term. In the long term, Congress should pass some version of President Biden's $775 billion plan to rebuild a 21st century workforce. The plan would

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[178] The contributions of unpaid family caregivers were approximately $450 billion in 2009. *Id.* at 1.

[179] *See* Bennett, *supra* note 171; PCPID, *America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities, and the U.S. Economy* 8 (2017), https://www.nadsp.org/wp-content/uploads/2018/02/PCPID-2017_-Americas-Direct-Support-Workforce-Crisis-low-res.pdf.

[180] *Id.*

[181] Bennett, *supra* note 171.

[182] Korman, *supra* note 78, at 32.

[183] *See* Coronavirus Aid, Relief, and Economic Security Act, Pub. L. No. 116–136, 134 Stat. 281 (2020).

[184] *Id.*

both fund existing DSPs, as well as support the high amount of informal caregiving through tax and Social Security credits for informal caregivers.[185]

2. Increasing Waiver Programs: Case Study of Money Follows the Person Leaving Individuals with IDD Behind

Congress should expand waiver programs such as Money Follows the Person and HCBS funding. However, even these successful federal programs historically leave individuals with IDD behind. The example of the heralded Money Follows the Person program—the ultimate person-centered approach—displays the discrepancies in transitioning individuals with IDD. Any plan passed to increase such waivers should explicitly keep individuals with IDD in mind.

i. Recent Adjustments to Money Follows the Person

In many cases, individuals with IDD are left behind by states implementing waiver and affirmative housing programs. For example, a popular Medicaid program, Money Follows the Person ("MFP"), enables state Medicaid programs to move people with disabilities from institutions into the community.[186] The federal spending bill, approved in late December 2020,[187] funded the MFP program for $450 million through September 2023.[188] It also reduced the time to be eligible for MFP funding from ninety to sixty days at an institution.[189] MFP allows states to use funds to transition individuals in nursing homes or long-term care institutions to community residences. Thus, states'

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[185] *The Biden Plan for Mobilizing American Talent and Heart to Create a 21st Century Caregiving and Education Workforce*, BIDEN HARRIS: DEMOCRATS, https://joebiden.com/caregiving/ (last visited Oct. 16, 2021). In a preliminary analysis, the Biden administration's plan would result in the creation of more than one million jobs in home health. LENORE PALLADINO & CHIRAG LALA, POL. ECON. RSCH. INST., THE ECONOMIC EFFECTS OF INVESTING IN QUALITY CARE JOBS AND PAID FAMILY AND MEDICAL LEAVE 2 (June 2021), https://peri.umass.edu/component/k2/item/1465-the-economic-effects-of-investing-in-quality-care-jobs-and-paid-family-and-medical-leave.

[186] *See* Kristie Liao & Victoria Peebles, *Money Follows the Person: State Transitions as of December 31, 2019*, CTR. FOR MEDICAID & CHIP SERVS., https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/mfp-2019-transitions-brief.pdf (last visited Oct. 16, 2021). Under the Deficit Reduction Act of 2005, Congress created the Money Follows the Person Rebalancing Demonstration to assist states flexibility in providing HCBS. *Id.*

[187] *See* Consolidated Appropriations Act, 2021, H.R. 133, 116th Cong. (2020).

[188] Michelle Diament, *Program Helping People Leave Institutions Renewed After Years in Limbo*, DISABILITY SCOOP (Jan. 11, 2021), https://www.disabilityscoop.com/2021/01/11/program-helping-people-leave-institutions-renewed-after-years-in-limbo/29143/. Additionally, Money Follows the Person was amended to allow for individuals to qualify for community transition after spending sixty days at an institution, down from the previous ninety-day requirement. *Id.*

[189] *Id.*

Medicaid funds essentially "follow the person."[190] Lastly, compared to HCBS waivers, MFP does not require budget neutrality.[191]

Former CMS Administrator Seema Verna encouraged states to use available MFP funds in September 2020 and stated COVID-19 "expose[d] America's overreliance on institutional long-term care facilities."[192] However, without the adjustments to DSP wages and increases in affordable, accessible housing, the program will not be as successful for individuals with IDD. As CMS itself reported through the MFP program, states "have learned how difficult transitions can be when affordable and accessible housing is scarce and communities' capacity to provide home and community-based" services are insufficient.[193] Similarly, nearly every state cites insufficient affordable, accessible housing as one of the most significant barriers to the program.[194]

ii. How MFP Transitioning Operated in Practice

States are allowed to choose the groups and types of facilities for their MFP efforts.[195] Looking at the 2019 data, individuals with physical disabilities and older adults made up over 75% of all transitions.[196] Individuals with IDD and mental illness only represented 12% and 4%, respectively.[197] Further, only five states accounted for almost half of the transitions in the MFP program in the country from 2008–2019.[198] The discrepancies between who and where MFP transitions have taken place are stark.

The Medicaid and Medicare cost savings from transitioning for individuals with IDD is staggering. CMS reported that monthly expenditures in the first year of transition declined $4,013 per month, per individual, for a total savings of $48,156 for each person transitioned.[199] MFP participants were found to be less likely to be re-institutionalized after their transition.[200] Without housing that is specifically in mind for those with IDD—not just those with

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[190] Denise F. Hoffman et al., *The Missing Link: Examining the Impact of Housing Vouchers and Community-Based Services and Supports on Transitions from Nursing Facilities to the Community*, 27 J. DISABILITY POL'Y STUD. 243, 243 (2017).

[191] Gaughan, *supra* note 126, at 412.

[192] Michelle Diament, *Trump Administration Pushing Program That Moves People Out of Institutions*, DISABILITY SCOOP (Sept. 25, 2020), https://www.disabilityscoop.com/2020/09/25/trump-administration-pushing-program-that-moves-people-out-of-institutions/29010/.

[193] HARGAN, *supra* note 56, at 16.

[194] Hoffman et al., *supra* note 190, at 244.

[195] Liao & Peebles, *supra* note 186, at 1.

[196] *Id.* at 2.

[197] *Id.*

[198] *Id.* at 3 (Connecticut, Ohio, Tennessee, Texas, Washington). In 2019, Illinois, Virginia, Tennessee, New Hampshire, Kansas, D.C., and Delaware reported zero transitions. *Id.* at 4–5.

[199] HARGAN, *supra* note 56, at 12. In comparison, the cost savings for those with physical disabilities was $1,783 on average. *Id.*

[200] *See id.* at 23 (only 6% re-institutionalized within 180 days, compared to 15% of "[o]ther transitioners").

physical disabilities—programs like MFP will continue to transition those with physical disabilities over those with IDD.

iii. Increasing and Extending MFP and HCBS Waivers

Congress should make Money Follows the Person permanent. MFP, which does not have the same budget-neutrality requirement for states as HCBS, should be permanently extended and further funded. It should also include and address specific goals for transitioning individuals with IDD. COVID-19 has shown the disastrous consequences of the lack of person-centered housing options for individuals with IDD. If states and the Federal Government continue to cut funding for such waiver programs, the reality would include more individuals placed in group homes or state-run institutions, which is another public health and budget disaster in the making.

Further, these programs are popular. In 2013, Medicaid HCBS spending finally surpassed institutional care spending.[201] For IDD specifically, as of 2018, HCBS spending constituted 79% of Medicaid expenditures.[202] Therefore, to continue the success, waiver programs such as MFP must prioritize keeping individuals out of institutional settings: it is more cost-effective and successful to prevent individuals from IDD from institutionalization in the first instance. Transition itself has an upfront cost. Further, individuals who start receiving services in an institutional setting "have longer institutional stays" compared with those who start in a community setting.[203] The differential is massive: only 1% of younger adults with disabilities had a long institutional stay if they began in a community setting, compared with 50% of those who started in an institutional setting.[204] Preventing individuals with IDD from having to go into an institutional setting in the first place will save taxpayers money: the cost of a Medicaid-funded nursing home bed can range between $50,000 to $80,000 per individual, while the annual costs of a bed in a state-run institution can exceed $200,000 per year.[205]

In order to achieve this goal, Congress should pass a version of President Biden's $775 billion plan to rebuild the 21st century workforce. The plan includes $450 billion to expand HCBS by providing a higher federal Medicaid match for participating states, which would lead to higher wages for DSPs.[206] It also allows caregivers to earn Social Security credits for the time they are out of the workforce providing care for family members; this is especially key, as

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[201] *See* CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 20, at 8, Figure 1.3.

[202] *Id.* at 8.

[203] KATE STEWART & CAROL V. IRVIN, MATHEMATICA POL'Y RSCH., DOES EARLY USE OF COMMUNITY-BASED LONG-TERM SERVICES AND SUPPORTS LEAD TO LESS USE OF INSTITUTIONAL CARE? 9 (2018), https://www.medicaid.gov/sites/default/files/2019-12/hcbsasadiversiontoiltc.pdf.

[204] *Id.* at 10.

[205] O'HARA & YATES, *supra* note 92, at 9.

[206] Weller et al., *supra* note 174.

over 50% of individuals with IDD reside with family members.[207] Further, there is draft legislation for a HCBS Access Act that would require Medicaid to provide minimum home and community-based services to everyone who is eligible and allow people with IDD to move across state lines without forfeiting their services.[208] It is not a cliché to say this bill would be a "game changer" for the over 800,000 people on waiting lists for HCBS across the country.[209]

3. Acknowledging the Holistic Approach to Person-Centered Housing

In 1970, at the peak of institutionalization, one writer commented "[o]ne may separate the residential institution from the concepts that gave birth to it . . . [I]t is clear that the basic rationalizations justifying [the] practice are being modified."[210] While the context of his statement was in the peak of the institutionalization era, the basic sentiment has a morsel of truth: individuals with IDD, policymakers, and advocates can always be engaging in an active discussion of what *is* working, what are the rationales, and what are the needs. There is no one-size-fits-all approach. With individuals with IDD facing increased barriers and being transitioned less often than their peers due to their medical and independent living needs, lack of DSP supports, and absence of affordable housing, this honest and critical conversation is even more necessary. The goals of "community" for each individual are different and should be factored into their person-centered choice.

Acknowledging the downsides to deinstitutionalization for the IDD community can strengthen the partnerships and create better outcomes. Ultimately, all individuals need social and community settings to thrive. But there are other considerations to being integrated in a community than just what setting in which one resides. To most individuals and families, there are concerns over transportation to jobs, community centers such as libraries and YMCAs, and meaningful social and community interactions. All of these aspects of social determinants of health—housing, community, well-being, employment, and transportation—should be considered when completing a

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[207] *See* Sheryl A. Larson et al., IN-HOME AND RESIDENTIAL LONG-TERM SUPPORTS AND SERVICES FOR PERSONS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES: STATUS AND TRENDS 2017 11 (2020), https://ici-s.umn.edu/files/aCHyYaFjMi/risp_2017; Weller, *supra* note 174.

[208] HCBS Access Act of 2021 ("HAA"), S. 151, 117th Congress (2021), *available at* https://debbiedingell.house.gov/uploadedfiles/hcbs_access_act.pdf; Press Release, NAHC, NAHC Advises Congress on Key HCBS Legislation (Apr. 30, 2021), https://report.nahc.org/tag/hcbs-access-act-of-2021/.

[209] Michelle Diament, *Waiting Lists May Be Eliminated for Disability Services Provided by Medicaid*, DISABILITY SCOOP, (Mar. 22, 2021), https://www.disabilityscoop.com/2021/03/22/waiting-lists-may-be-eliminated-for-disability-services-provided-by-medicaid/29252/?fbclid=IwAR0ZvKpdMy7gbxW8ZqaOUI4-X-YY_fq-_Oulh-wI6Q_YFK4S-h29FQHx6iU.

[210] Alfred A. Baumeister, *The American Residential Institution: Its History and Character*, *in* ALFRED BAUMEISTER & EARL BUTTERFIELD, RESIDENTIAL FACILITIES FOR THE MENTALLY RETARDED 26 (1970).

successful transition, not just whether an individual is physically in their own apartment building. One of the greatest concerns some advocates and policymakers hear from individuals who moved out of institutions is the loneliness experienced once they are out of a social environment.[211] As social science has revealed, humans seek meaningful connection. Families and individuals concerned with the potential for isolation leads to many individuals with IDD to reside at home or in other congregate settings. Living alone in an apartment independently without the community supports will not alone create the champion of deinstitutionalization that advocates envision.

Further, the stakes in getting it right are high: without proper person-centered housing, the options for IDD individuals are institutionalization in nursing homes or ICFs with the potential for abuse. Almost 70% of perpetrators that violently victimize individuals with disabilities are intimate partners, relatives, or other acquaintances.[212] This again highlights the need for community supports, since "[i]f you're shutting down that person's ability to go to their [community participation services] provider and you're shutting down that person's ability to go to their supported employment provider . . . you may be, in fact, restricting them to be at home all day with their abuser."[213]

We should open up the conversation surrounding independent living for individuals with IDD to one that is more realistic regarding the options available and the services with which they can be paired. For example, Pennsylvania acknowledges seven housing settings for adults with autism: remaining at home, family living, renting an apartment or home, purchasing a home, shared housing, intentional communities, or licensed facilities,[214] and the state's acknowledgement of these diverse settings allows for better family planning and utilization of state funding. Some families' partnerships with deinstitutionalization advocates ended in the 1970s and 1980s since they "challenge[d] what they thought were bad institutions—not the idea of institutionalization itself."[215] Ostracizing those families and advocates again in the current wave of policymaking will not lead to better outcomes for individuals with IDD. While this Note does not argue for a return to institutional

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[211] Dara Baldwin et al., *Reactors Panel on Policy Implications and Research Needs*, *in* DEVELOPING AFFORDABLE AND ACCESSIBLE COMMUNITY-BASED HOUSING FOR VULNERABLE ADULTS: A PROCEEDING OF A WORKSHOP 76 (2017).

[212] Erika Harrell, *Crimes Against Persons with Disabilities 2009-2014 – Statistical Tables*, U.S. DEP'T OF JUST., tbl. 8 (Nov. 2016), https://bjs.ojp.gov/content/pub/pdf/capd0914st.pdf; *see also Abuse and Exploitation of People with Developmental Disabilities*, DISABILITY JUSTICE, https://disabilityjustice.org/justice-denied/abuse-and-exploitation/ (last visited Dec. 20, 2021) ("In addition, abuse is typically more severe, is more likely to occur multiple times and is more likely to be repeated for a longer period of time.").

[213] Courtenay H. Bond, *For Adults with Intellectual Disabilities, COVID-19 Poses Many Challenges*, INQUIRER (Sept. 18, 2020), https://www.inquirer.com/health/coronavirus/intellectual-disabilities-covid-19-risk-challenges-mental-health-20200918.html (alterations in original).

[214] DIANA T. MYERS, PA. DEP'T PUB. WELFARE, HOUSING OPTIONS FOR ADULTS WITH AUTISM SPECTRUM DISORDER 3 (Apr. 2010).

[215] Bagenstos, *supra* note 152, at 18 (emphasis omitted).

living—in fact, it argues the opposite—for individuals with IDD who have high medical or independent-living support needs, there actually could be greater success when advocates engage in a critical conversation that the ideal of transitioning to an independent apartment may not be the optimal choice made by the many individuals with IDD, especially with current funding and services structures. There is no one-size-fits-all approach. So improving intentional communities—such as group homes and community programs—and speaking to individuals on their goals surrounding community should not be left out of the conversation. At the forefront, more flexible waiver programs can make these person-centered decisions a reality.

CONCLUSION

The current housing crisis for individuals with IDD brewed with the nexus of affordability, accessibility, discrimination, and, importantly, the difficulty in marrying services funding to person-centered needs. These difficulties disproportionately affect those with IDD in comparison to the general population and even to others within the disability community. Individuals, advocates, and policymakers should focus on three hinge points that would greatly increase the ability for person-centered housing for individuals with IDD: wages, waivers, and flexibility. Increasing wages for DSPs would help recruit and retain workers of this profession who are absolutely vital for individuals with IDD to live independently with some supports. Increasing funding and eliminating budget neutrality requirements for waiver programs such as HCBS and MFP would assist in eliminating the 800,000-plus waitlist in this country for such services and allow for truly person-centered decision-making for individuals with IDD to live in a setting which best matches their needs and desires. Finally, advocates and policymakers should be open to acknowledging that there is no one-size-fits-all approach to housing for individuals with IDD who have independent living needs that are often unique in comparison to individuals with mobility, hearing, and vision disabilities. Though we do not want to return to large, isolated institutions of the past, the voices of the individuals with IDD—not our own fiscal and subjective biases—should pave the way forward for intentional housing for individuals with IDD in the 21st century.