

Leaving A Home in Trust for a Person With Disabilities

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I. Introduction.*

Individuals with disabilities and their parents face a multitude of planning concerns. One of the most worrisome is where the individual will live -- what place they will call home -- when the parents have died. Our home is more than the four walls; it is our sanctuary and retreat, reflecting our identity past and present, our command center and base of operations, where we invite visitors and enjoy our privacy. Having our own space is fundamental to our sense of place in the world. There are many housing options available for individuals with disabilities, each with their own possibilities, requirements and obstacles. One model of particular relevance to the special needs planning attorney is leaving the family home in trust for the benefit of the individual with disabilities.

Attorneys often hear from their clients who are parents that they want to leave the family home in trust for their child with intellectual and developmental disabilities (I/DD) so their child can remain in familiar surroundings, have the continuing use of specific enhancements or features for their accessibility and comfort, and receive supports in the home. Families are also motivated to leave their homes in trust for their children with physical disabilities, particularly when extensive modifications for accessibility have been made. This paper focuses mainly on the planning related to individuals with I/DD.

Attorneys need to counsel the clients on these plans, to understand the wishes of the individual with I/DD, address financial feasibility, reveal expectations about the roles that others will play and assumptions about the extent of services available to the person with disabilities from the State, and draft trusts with the flexibility to respond to changing life circumstances, all

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in support of the individual with I/DD living in the setting of their choice, with access to the people, activities and services they choose as they pursue an engaged and fulfilling life.

II. The Right to Live and Receive Treatment in the Community.

“Persons who do not have disabilities have the right to live in the home of their choice, with roommates of their choice, in a neighborhood of their choice.”¹ These basic rights have been long denied to people with disabilities.

Housing for people with disabilities in our country has a troubled past. Only recently has the notion of choice been part of the story. The evolution of housing for people with intellectual disabilities and mental illness from the early days of this country shifts from people living with their families, often hidden from the rest of the community, to the public response beginning in the mid-19th century of establishing institutions for their support and occasionally for their care. Generally, the conditions of these institutions were dangerous, degrading, and often devoid of any therapeutic effort. The public was largely unaware of the nature of these environments until the 1960s and 1970s.

In the early 1960s, the Kennedy administration made improving treatment for mental illness a legislative priority, informed in part by the lived experience of the President’s sister, Rose Marie Kennedy, who was institutionalized. The 1967 documentary film, *Titicut Follies*²,

¹ Varnet, Theresa M. and Spain, Richard, *Home Control Through Trust and Estate Planning*, 1995; revised 1997, 2004; p.3. See also Arc Survey on Housing and Decision making, p. 36

² *Titicut Follies*, 1967; a film by Frederick Wiseman; (Zipporah Films).
<http://www.zipporah.com/films/22>

In 1968, the Massachusetts Superior Court ordered the film be withdrawn from distribution and all copies destroyed; citing the state's concerns about violations of the patients' privacy and dignity. Wiseman appealed to the Massachusetts Supreme Judicial Court, which permitted limited distribution to certain professional audiences and students of their fields. Wiseman appealed unsuccessfully to the U.S. Supreme Court which denied certiorari. *Wiseman v. Massachusetts*, 398 U.S. 960 (1970).

revealing the often brutal and demeaning daily life of inmates of a Massachusetts state hospital for the criminally insane, made a powerful impact though it was barred for years from public distribution by the State of Massachusetts, citing violation of the inmates' privacy. In 1972, Geraldo Rivera's exposé of the Willowbrook State School in Staten Island, New York brought further attention to the deplorable and overcrowded conditions in state facilities where young people with severe intellectual and developmental disabilities (I/DD) and mental illness were housed.

Litigation and advocacy on behalf of institutionalized individuals shone more light on living conditions and lack of therapeutic treatment in institutions. The 1971 case of *Wyatt v. Stickney* is just one example; this case brought by a resident of an Alabama psychiatric hospital focused on the state's responsibilities to individuals who had been civilly committed to provide adequate treatment.³

On the national legislative front, beginning in 1954, the Vocational Rehabilitation Amendments expanded community-based rehabilitation programs for people with disabilities.⁴ The Rehabilitation Act of 1973 made it illegal to discriminate against people with disabilities in federal programs.⁵ The Civil Rights of Institutionalized Persons Act of 1980 enabled the U.S. Department of Justice to enforce protections for individuals in the care of state and local institutions, including facilities for the care and treatment of people with I/DD, and prompted more inquiries into the treatment of abuses in institutional settings.⁶ The Developmental Disabilities Assistance and Bill of Rights Act, enacted in 1984, later reauthorized in 2000,

³ *Wyatt v. Stickney*, 325 F.Supp.781(1971).

⁴ 29 USC §§701-796

⁵ 29 USC § 794

⁶ 42 USC §1997

requires states to guarantee the right to receive treatment in the least restrictive setting for individuals with developmental disabilities.⁷ The Americans with Disabilities Act (ADA), enacted in 1990, aims broadly to eliminate discrimination against people with disabilities in our society.⁸

With the landmark 1999 decision, *Olmstead v. L.C.*, the Supreme Court held that under Title II of the ADA, “States are required to provide community-based treatment for persons with mental disabilities when the State’s treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with disabilities.”⁹ Citing to the ADA, the Court pointed to the opening provisions of the statute which took aim at the discriminatory societal tendency “to isolate and segregate individuals with disabilities” and the aim of the ADA to combat such forms of discrimination that continue to be “a serious and pervasive social problem”¹⁰.

While congressional debate about the ADA spoke strongly against institutionalization, the ADA does not prohibit institutionalization per se, nor does it mandate community living for all people with disabilities.¹¹

Underlying the legal, legislative and advocacy trends was research which “establishes clearly and consistently that people with intellectual and developmental disabilities (I/DD) experience greater personal freedom, more participation in social activities, more frequent associations with

⁷ See Public Law No 106-402, the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

⁸ 42 USC § 12132

⁹ *Olmstead v. L.C.*, 527 U.S. 581 (1999)

¹⁰ *Id.*

¹¹ Kanter, Arlene S., There’s No Place Like Home, *Israel Law Review* 45 (2)2012, pp.183-233, 201.

family and friends when living in the community rather than institutional settings.”¹². Further, the benefits of community living include improvements in individuals’ functional skills (such as self-care and domestic skills, social skills and community living skills), more positive parental attitudes towards community living, and the opportunity for reduced cost to provide care.¹³ Living in the community has also been found to bring specific health benefits in the potential to reduce emergency room visits, incidents of abuse and neglect, and injuries.¹⁴

III. Medicaid Moves Towards Community Settings.

In 1981, Congress expanded the Social Security Act to allow states to provide medical assistance and other services to certain individuals to help those at risk of needing institutional care to reside in the community, and to do so applying different rules for financial and other eligibility criteria. Beginning in 1983, these Home and Community-Based Services (HCBS) opened the door to services that help support individuals living in a variety of community settings. The HCBS waivers allow states to waive certain requirements for Medicaid, specifically state-wideness, comparability, and income and resource rules, to provide a range of selected long term support services (LTSS) targeted to the needs of particular populations, such as those with autism, people with intellectual and developmental disabilities, and older adults, all with the goal to provide alternatives to institutional settings and to foster integration in the community.¹⁵

¹² Lakin, K. Charlie, and Stancliffe, Roger K. “Residential Supports for Persons with Intellectual and Developmental Disabilities” *Mental Retardation and Developmental Disabilities Research Reviews* 13.2 (2007); 152.

¹³ *Id.*, 153.

¹⁴ Freidman, Carli. (2020) The Impact of Home and Community Based Settings (HCBS) Final Settings Rule Outcomes on Health and Safety, *Intellectual and Developmental Disabilities* Vol. 58, No. 6 486-498, 495.

¹⁵ 42 USC §§1115, 1915(c), 1915(i), 1915(j), 1915(k)

State Medicaid programs are required to cover LTSS in nursing homes. Most LTSS services provided through HCBS in the community are optional for the States.¹⁶ As a result, there is wide variation in the services and funding available in different States, and the length of the waiting lists.

The majority of Medicaid funding for people with I/DD goes to HCBS which accounts for about two-thirds of the total.¹⁷ Over 2.5 million individuals received HCBS under state optional plan services, and close to 1.2 million receive optional personal care state plan services in 2018.¹⁸

As a result of expansion of HCBS services and deinstitutionalization, the migration of individuals with I/DD from institutions to the community has been dramatic. The number of people with I/DD living in state-run institutions declined over 80% from a peak of 194,650 in 1967 to 32,909 in 2009.¹⁹ HCBS now accounts for 57% of total Medicaid outlays for LTSS.²⁰

Living in the community does not automatically bring engagement with the community or guarantee that an individual's living arrangement reflects their wishes and preferences. These concerns influenced CMS to introduce new regulations in 2009 to “establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a

¹⁶ <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/index.html>

¹⁷ Braddock, D., Hemp, R., Rizzolo, M.C., Tanix, E.S., Haffer, L., & Wu, J. *The state of the states in intellectual and developmental disabilities: Emerging from the great recession* The American Association on Intellectual and Developmental Disabilities. (2015)

¹⁸ Watts, Molly O'Malley; Musumeci, MaryBeth; Chidambaram, Priya; *Medicaid Home and Community-Based Services Enrollment and Spending*; (Feb.2020); Kaiser Family Foundation; <https://www.kff.org/medicaid/issue-brief/medicaid-home-and-community-based-services-enrollment-and-spending/>. Executive Summary.

¹⁹ National Council on Disability; *Institutions in Brief*. (2012) <https://ncd.gov/publications/2012/DIToolkit/Institutions/inBrief/> site visited 9/24/2021.

²⁰ Watts, Musumeci, Chidambaram, Issue Brief. Figure 2.

setting’ s location, geography, or physical characteristics.”²¹ Known as the HCBS Final Settings Rule, the new regulations published in January 2014 seek to “develop and implement innovative strategies to increase opportunities for Americans with disabilities and older to enjoy meaningful community living.”²² While this rule addressed many aspects of community-based services, it focuses particularly on individual choice and autonomy through the structured person-centered planning process, and the identification of residential settings that are consistent with the goals of fostering individual autonomy and community integration. The changes expressed the intention of the federal Medicaid program to support States in compliance with the ADA and Olmstead, specifically “to provide covered program services to eligible individuals with disabilities in the most integrated setting appropriate to their needs.”²³

The HCBS Final Settings rules present new requirements for the settings in which individuals receiving Medicaid HCBS services will live. The setting must be genuinely integrated within the greater community, offering people the opportunity to seek work in competitive integrated settings, and to connect with the community in ways the individual selects; in sum to have the same opportunities to take advantage of what their community offers as do those without disabilities.²⁴ Individuals are to have the right to choose where, how and with whom they live, to ensure their privacy through having their own key and to control who may visit and when.²⁵ A theme throughout the publication of the Final Rule, in both the comments and responses is the term “meaningful” underscoring the goals to realize true

²¹ Freidman, 487.

²² 79 Fed. Reg. 2948 (Jan.16, 2014), see also 42 CFR Parts 430 *et seq.*

²³ *Id.*, at Section II, A, 8th paragraph, p. 2951.

²⁴ 42 CFR §441.530(a)(1)(i).

²⁵ 42 CFR §441.530(a)(1)(vi)(B),(C),(D).

integration in a community and offer real choices to individuals with disabilities funded by HCBS waiver programs.²⁶

The HCBS Final Settings rule initially provided for a 5-year implementation schedule; this has been extended for the second time, to March 2023 in response to the Covid-19 pandemic.²⁷

IV. Demand for Community-Based Housing Outstrips Supply.

An estimated 17.6% of the U.S. population, roughly 55.2 million people, have a severe disability.²⁸ Of this group, approximately 34% or 18.8 million people are 65 years old or over. A cohort of similar size is following right behind, as the population of people with severe disabilities between the ages of 45-64 is about 33.3% of the total. Not only is the demand for housing for people with disabilities immense, the needs for those who are aging is growing.

People with disabilities reside in a variety of settings. Of those living in community settings, an increasing number reside with fewer people and experience more desirable outcomes, such as more opportunities for personal choice in daily activities, greater freedom from staff control, and less likely to report feeling lonely.²⁹

²⁶ The term “meaningful” appears 33 times in the publication of the Final Rule. 70 Fed. Reg. 2948.

²⁷ CMS State Medicaid Director Letter, SMD #20-003 (July 14, 2020)

²⁸ Taylor, Danielle M. “Americans with Disabilities: 2014”. *Household Economic Studies. Current Population Reports*. P70-152, November 2018; U.S. Department of Commerce; U.S. Census Bureau, 2. *Severe disability for an adult is defined as using a wheelchair, cane, crutches or walker; having an emotional or mental condition that seriously interferes with everyday activities (frequently depressed or anxious, trouble getting along with others, trouble concentrating, or trouble coping with day to day stress), or having Alzheimer’s disease, an intellectual disability, cerebral palsy or other developmental disability; or were blind or deaf; or were unable to perform or needed help performing one or more functional activities (speaking, lifting/carrying 10 pounds, using stairs, walking a quarter mile, or grasping small objects), or Activities of Daily Living (ADLs) [getting around inside the home, transferring, bathing, dressing, eating and toileting]; or Instrumental Activities of Daily Living (IADLs) [going outside the home, keeping track of money and bills, preparing meals, doing light housework, taking prescription medicines correctly, using the telephone]. Severe disability for a child is defined as using a wheelchair, cane, crutches or walker; being blind or deaf, unable to perform or needed assistance with speech or ADLs, or had a developmental delay, an intellectual disability, a developmental disability such as cerebral palsy or autism, or some other developmental condition.*

²⁹ Lakin and Stancliffe, 154.

Annual surveys conducted by the National Association of State Directors of Developmental Disabilities Services documents the trend toward smaller settings. Between 2009 and 2019, the proportion of adults with disabilities living with their parents or relatives grew from 30.7% to 38%, while those living in group homes or apartments managed by agencies, fell slightly from 33.8% to 32%. More people with I/DD are receiving residential supports while living in their own home, which they may rent or own, or which is held in a trust for their benefit. Over the period from 1995-2005, the number of people with I/DD receiving supports in their own home more than doubled.³⁰ More recently, the share of individuals living in their own home or apartment, has grown from 12.9% in 2008-2009 to 18% in 2018-2019.³¹ The percentage of those living in a foster care/shared living increased significantly from 5% to 8%, although the absolute numbers reflect a much smaller population.³²

Despite the desirability of smaller settings for many people with I/DD, the lack of affordable housing is a constant lament for people with disabilities and those with limited income. Making housing more affordable through rental assistance allows tenants greater financial security, more stable housing, and a way out of institutional settings or group homes. Over 1.2 million people with disabilities had federal Housing Choice vouchers in 2018, but lack of federal funding leaves millions of people who are financially eligible unable to access vouchers.³³

Waiting lists for services is another barrier to people seeking to move to smaller settings. Nationwide, over 589,000 people with I/DD were on HCBS waiver waiting lists in over three

³⁰ Lakin and Stancliffe, 154-155.

³¹ *National Core Indicators At-A-Glance* (2008-2009, 2013-2014, 2018-2019). National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI). <https://www.nationalcoreindicators.org>

³² *Id.*

³³ Bailey, Anna; de la Huerga, Raquel; Gartland, Erik; *More Housing Choice Vouchers Needed to Help People with Disabilities Afford Stable Homes in the Community*. (July 6, 2021) Center on Budget and Policy Priorities.

quarters of states.³⁴ The average wait time on a waiting list is 39 months. Without the staff to support individuals in their own home and community, many people with disabilities are stuck in institutional settings as well as community-based settings that are larger than they may desire, for the lack of available or affordable housing of their choice.

As noted above, a substantial percentage of individuals with I/DD currently live in a parent's or relative's home.³⁵ Given the lengthy waiting lists for waiver services particularly for residential care and the lack of affordable housing options, planning for the individual to remain in the family home may make a lot of sense, if the planets align to make it affordable, accessible and desirable for the person in question.

V. What Is Important in Choosing Where to Live?

In 2019, the Arc conducted a national survey regarding housing for people with I/DD, gathering input from people with I/DD and the families of people with I/DD. When asked what factors each group valued most in deciding where the person with I/DD would like, the priorities of the two groups were similar, but not quite the same.³⁶ See Table 1, below.

³⁴ Watts, Musumeci Chidambaram, 15, 20.

³⁵ *National Core Indicators At-A-Glance* (2018-2019)

³⁶ Friedman, C. (2019). *There's No Place Like Home: A national study of how people with intellectual and/or developmental disabilities and their families choose where to live.* The Arc of the United States and The Council on Quality and Leadership. Housing & Decision Making module, p. 21.

Table 1. Most Important Factors in Housing

<p>The top 10 considerations for those with I/DD:</p>	<p>The top 10 considerations for the family members of people with I/DD for housing for their family member with I/DD:</p>
<ol style="list-style-type: none"> 1. Cost 2. Location 3. Safety, security, and freedom from crime. 4. Close to shopping, places of worship, libraries, doctors, restaurants. 5. Transportation 6. Close to family 7. Close to work, school, day services, and/or other services. 8. Neighborhood. 9. Nice home in good condition. 10. Accessibility. 	<ol style="list-style-type: none"> 1. Safety, security, and freedom from crime. 2. Close to family. 3. Quality of services and supports. 4. Quality and stability of staff. 5. Location. 6. Cost. 7. Activities and things to do. 8. Close to work, school, day services, and/or other services. 9. Close to shopping, places of worship, libraries, doctors, restaurants. 10. Transportation.

The survey also captured views on the crucial role played by support staff, the importance of a positive and respectful relationship with direct support professionals, and concerns about the negative impact of high staff turnover, poor training and lack of respect from staff that were sources of dissatisfaction in living arrangements. When asked about their dream living scenario, persons with I/DD mentioned features such as the ability to have a pet, for their home to be more accessible (e.g., to reach what is in one’s closet without assistance), being able to live with their romantic partner, living as an integral member of the home and community, being valued, respected and loved.³⁷ This survey showcases the articulate and nuanced wishes and priorities

³⁷ *Id.* Housing & Decision Making module, pp. 26-27

expressed by individuals with I/DD in describing how and where they want to live, and provides a helpful guide for individuals and families to discuss options, plans, and trade-offs.

VI. What Will it Cost to Take Care of the Home?

The threshold question for clients wanting to leave the family home in trust for the benefit of their child with disabilities is: are there sufficient funds to take care of the property during the child's residency and to achieve the clients' other quality of life and legacy goals?

This assessment will be improved by considering not only the routine expenses, such as a mortgage, property taxes, home owners insurance, utilities, and community association or condominium fees, but also the cost of major repairs and replacement of appliances. A common rule of thumb for projecting the costs of home repairs is 1%-3% of the value of the home annually.³⁸ Older homes, and those located in climates that affect the durability of roofing, exterior paint and structural materials, are on the higher end of the scale. Consumer Reports estimates the life span of most home appliances at 10 years; major systems such as heating and air-conditioning may need replacement every 15-18 years; roofs and decks have variable life-spans, largely dependent on the materials and climate.^{39, 40}

As residents age in place, additional modifications may be needed for safety and to accommodate wheelchairs and walkers. Costs for these types of modifications vary widely, by type, location and materials. For example, nationally, the average cost to make a home

³⁸ Williams, Terri. *Rule of Thumb: How Much to Budget for Home Maintenance* (updated May 9, 2021) <https://www.thebalance.com/home-maintenance-budget-453820>. Site visited 9/25/2021. See also Weston, Liz. *The Huge Hidden Costs of Owning A Home*, (April 25, 2016) <https://www.nerdwallet.com/article/mortgages/the-real-cost-of-your-house>, site visited 9/25/2021

³⁹ <https://www.consumerreports.org/appliances/how-long-will-your-appliances-last/> (June 20, 2019) site visited 9/25/2021.

⁴⁰ Williams; Weston.

accessible for a person with disabilities is \$4,353, with a broad range between \$130 and \$19,000.⁴¹ Some common alterations include widening doorways (\$700-\$2,500 each), installing an exterior ramp (\$1,000-\$4,000), and building an accessible bathroom (\$3,000-\$15,000).⁴²

A study by the U.S. Department of Housing and Urban Development assessed the accessibility of the nation's housing stock, and found that about a third of housing in the U.S. is potentially modifiable for a person with a mobility disability, less than 5% is accessible for people with moderate mobility difficulties, and less than 1% is accessible for wheelchair users.⁴³ Even if there are funds for such modifications, the majority of home properties may not be modifiable to begin with.

Funds left in trust are also intended for other purposes, like clothing, hobbies, recreation, education, travel, personal services not covered by waiver programs, replacement of furniture and redecorating, pet care and veterinary bills, professional services like case management, legal and accounting expenses, advocacy, and paying the trustee. Clients may also intend that others will benefit from the trust in the future when the primary beneficiary dies.

Parents should also consider the value of their time presently devoted to supporting and assisting their child and taking care of the home property. When the parents are gone, these tasks will remain. While increased staffing or other services under a waiver program may fill

⁴¹ <https://www.homeadvisor.com/cost/environmental-safety/remodel-for-disability-accommodation/#:~:text=Remodeling%20for%20Disability%20Accessibility,or%20as%20little%20as%20%24130>, site visited 9/25/2021.

⁴² *Id.*

⁴³ Bo'sher, Luke; Chan, Sewin; Ellen, Ingrid Gould; Karfunkel, Brian; Liao, His-Ling. *Accessibility of America's Housing Stock: Analysis of the 2011 American Housing Survey*. (March 19, 2015), U.S. Department of Housing and Urban Development, Office of Policy Development and Research.

some of these gaps (e.g., transportation may be covered), HCBS waivers will not pay the mortgage or other expenses related to maintaining or take care of the home property.

The Trustee may find that other resources to help with the cost of maintaining a home are limited. Some waiver programs and other state funded sources may provide some assistance related to the home, such as personal emergency response systems, home and/or vehicle accessibility, and certain assistive technology, but access to these programs is not guaranteed. States may offer reduced property tax rates for individuals with disabilities, even if the property is held in trust.⁴⁴ The individual with I/DD will have their own income which may provide for contribution to household expenses, but individuals who are waiver eligible already have limited income, and these funds may be committed to contribute to the cost of care for waiver services as well as the individual's personal expenses.

A rigorous review of the actual and projected costs of operating and maintaining the home should be conducted to enable calculation of the funds over time needed to take care of the property. Clients might consider having a home inspection to get a more accurate picture of the remaining life of various appliances and insight into future repair or replacement needs. A sample list of expenses is found at Attachment 1.

Clients should consult with a financial advisor who can assist in modeling the growth and use of assets during the clients' lifetime as well as their child's, as well as the impact of taxes. As more wealth is concentrated in retirement accounts, the tax impact in planning for a child with disabilities must be considered.⁴⁵

⁴⁴ See, e.g., Md. Code Ann., Tax-Property, §9-104(9)(ii)

⁴⁵ *Report on the Economic Well-Being of Households in 2020*. U.S. Federal Reserve. May, 2021. <https://www.federalreserve.gov/publications/2021-economic-well-being-of-us-households-in-2020-retirement.htm>

VII. Services Available Through HCBS Waiver Programs for Individuals with I/DD Living in Their Own Home.

Individuals with I/DD residing in their own home may be eligible for staffing supports under the HCBS category of Supported Living, which has also been known in the past as Community Supported Living Arrangements and Personal Supports. Within this rubric are services including: coordination, training, supports and/or supervision related to an individual's self-advocacy, adaptive skills, community engagement, daily living, health-related matters, personal care, protection and oversight, social and leisure skills, and transportation and travel training.⁴⁶ These services may be provided on a range of intensity, from drop-in to more time intensive assistance, reflecting the needs established in the individual's person-centered plan of care, with the goals of assisting individuals to live independently and provide opportunities to help the individual shape the direction of their lives.⁴⁷

Other waiver services available to an individual may include personal care assistants; day habilitation; mental health and other health and social services; supported employment services, such as assistance to locate and obtain paid employment or self-employment, assistance with maintaining employment in group or individual work settings; community integration services to assist the individual in participating in community activities; and transportation. Each waiver eligible resident of a home has the right to choose their own providers for Supported Living and other services, not all must be served by the same provider.

⁴⁶<https://health.maryland.gov/dda/Residential1/Proposed%20Residential%20Services/Supported%20Living%20Draft%20Proposal.pdf>. Site visited 9/26/2021.

⁴⁷*Id.*

Transportation is an important consideration, given the importance of community integration. Particularly if the individual's home is not convenient to public transportation, access to a vehicle is crucial to get to the individual to work or a day program, shopping and other activities. Supported living does not include the provision of transportation. If the individual is receiving "meaningful day" community development services or supported employment services under a HCBS waiver program, in addition to their supported living services, then transportation may be included. For those receiving residential services (that is, for individuals who are living in a residence operated by an agency provider) often a vehicle is provided for the household through waiver funding. For those in a home owned by their trust, other arrangements for transportation may be necessary, adding the cost of a maintenance and repair of a vehicle to the overall cost calculations.

As is evident, the range of services that might be available to an individual is broad; and may involve more than one provider agency. The terminology distinguishing types of services can be confusing, and changes over time. The detailed rules are also subject to change over time. The difficulty in navigating the complex systems which provide support for people with disabilities, even for families who have been active advocates for years, has been well documented.⁴⁸

Special needs planning attorneys should counsel their clients and the individual with disabilities to educate themselves about the services that may be needed in the future and to meet with service providers to discuss how these services could be made available in the family home.

⁴⁸ Carlson, Sarah R., Wilt, Courtney L., "Learning about and qualifying for Home and Community-Based Services Waivers: Families' perspectives and experiences"; *Journal of Vocational Rehabilitation* 53 (2020) 17–28, DOI:10.3233/JVR-201082; see also, Friedman, Carli, "Stakeholders' Home and Community Based Services Settings Rule Knowledge", *Research and Practice for Persons with Severe Disabilities* 43(2018)54-61.

Because public benefits, services and policies change over time, clients should be advised to revisit the care plan for their child’s future periodically, just as they are advised to revisit their own estate plan. Given the complexity and dynamic quality of HCBS waiver services in particular, clients and their children may find it helpful to engage a consultant specializing in such programs to aid in this periodic review. Trustees should be advised to conduct similar reviews periodically, to stay abreast of changes in programs and the needs of their beneficiaries.

A key feature of supported living is fostering and developing natural supports that are meaningful to the individual.⁴⁹ Natural supports refers to informal, unpaid relationships that help to support the individual with I/DD and to ground the person in their community.⁵⁰ This may be family members, neighbors, and other people met through jobs, volunteering, or spiritual communities. The growing understanding of the importance of natural supports and/or benefactors has led to efforts to structure “circles of support” made up of people committed to assisting the person in achieving personal life goals.”⁵¹ HCBS regulations call for the person-centered plan to reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including natural supports.⁵²

Trustees should be mindful of the value of these relationships, and support the beneficiary’s opportunities to develop them. Especially for those individuals who may not have living or nearby family members, creating and maintaining a circle of supportive and caring people is essential for truly being part of a community. This will take effort on the part of the individual,

⁴⁹ Lakin and Stancliffe, 154.

⁵⁰ See e.g., <https://www.arcind.org/supports-services/natural-supports/> The Arc of Indiana, site visited 9/26/2021.

⁵¹ Lakin and Stancliffe, 154.

⁵² 42 CFR §441.725(b)(5).

their agencies and staff, their trustee, family and friends, and our society as a whole, to initiate and sustain meaningful connections. It takes work. As one blogger relates:

“It is no surprise to those of us in the disability advocacy community that neighborhoods today are not cultivating community relationships let alone integrating those who have intellectual or developmental disabilities (I/DD). For years, organizations, like those in the Coalition for Community Choice (CCC), have been working to convince policymakers that being part of a meaningful community must extend further than simply being located in a neurotypical residential neighborhood.”⁵³

Family members may be eligible to be paid as care-givers under HCBS waivers when services are self-directed by the individual. States may impose limitations on the payment of individuals, e.g., a State may not allow a legal guardian or other legal representative of the individual who is directing services for the individual to be paid as a care-giver, due to the inherent conflict of interest.⁵⁴

VIII. Who Else is Living In The Home?

Clients and their child with disabilities should consider whether others will live in the home with the child, and think ahead about the financial arrangements. If clients are leaving a family home in trust (as opposed to a smaller, downsized residence), it is likely there may be enough space for family members, roommates or caregivers to live there. Additional residents can help contribute to operating costs by paying rent or other expenses, or performing regular maintenance, and so relieve pressure on the trust assets. The other residents may also be live-in caregivers; they may receive food and/or lodging rent-free in exchange for services; as an

⁵³ Audige, Marko, blog post (August 23, 2018); <http://www.coalitionforcommunitychoice.org/2018/08/study-50-americans-dont-recall-name-lady-across-street/>. Posted in Advocacy, Housing.

⁵⁴ Edwards, Elizabeth, *Q&A - Relatives as Paid Providers*, National Health Law Program, (December 5, 2014).

added incentive for this type of arrangement, the value of the food and lodging may also be tax-free.⁵⁵

Clients, their child with disabilities, other family members and proposed caregivers should be advised to discuss openly their expectations of family members living in the home and providing supports or care for the child with disabilities. The expectations should be clear about what tasks or financial contributions that person will take make, if any, and what compensation they may receive. If a trustee employs caregivers, they should take steps to ensure that taxes are properly withheld and paid, and the trust is insured; alternatively a trustee may arrange to outsource these employment responsibilities. As addressed in the following section, family members (whether residing with the beneficiary or not) may be able to be paid as caregivers through waiver programs.

There needs to be a contingency plan for the eventual departure of the beneficiary or the other residents as life changes occur over time, including marriage, job changes, advancing age or declining health. These changes may trigger the need of plans for the home and the beneficiary's continued residence.

If the trustee plans to rent a room to a roommate unrelated to the trust beneficiary, to have a caregiver (and perhaps the caregiver's spouse and family, too) reside in the home, registration and licensing of the property may be required by local or county housing codes. The licensing requirements may include inspection and safety provisions, such as smoke and carbon monoxide detectors, or documentation of lead paint abatement.⁵⁶ For example, Baltimore County, Maryland exempts from rental property registration and licensing an owner-occupied property in

⁵⁵ 26 CFR §1.119-1.

⁵⁶ See, e.g., https://resources.baltimorecountymd.gov/Documents/Permits/rental_registration/rentalhousingapp.pdf

which one unrelated adult resides and without limit on other individuals who are related to the owner as grandparents, parents, children or grandchildren.⁵⁷ Similarly exempted is the arrangement with an individual paid caregiver residing with the owner.⁵⁸ Critical to these exemptions is the “owner-occupied” condition. If the property is owned by a trust, registration, licensing and inspection are necessary in this jurisdiction. Fines can be imposed for the failure to comply.

Trustees should be aware that waiver programs may also require protections for other waiver recipients who reside in the home, such as a lease or tenancy agreement that offers the same tenancy rights they would have in a public housing option.⁵⁹

An alternative arrangement that a trustee might consider is to rent the home property to an individual who serves as a foster parent to the adult beneficiary. In this type of model, the individual with disabilities lives with an individual or family that is vetted and paid by the State as a foster parent to host the adult with disabilities in the foster parent’s home. This model provides for round-the-clock responsibility for the health and welfare of the individual with disabilities.⁶⁰ Note that this arrangement is funded through a different waiver program, called Shared Living, which has different requirements than Supported Living.

All of these examples illustrate the complexity of the living arrangement for the individual with disabilities who needs others to share the home, for their support and comfort.

⁵⁷ Baltimore County Code, Building and Housing, Rental Housing Licenses, Section 35-6-103 (2015), as amended April 2, 2018.

⁵⁸ https://resources.baltimorecountymd.gov/Documents/Permits/rental_registration/exemptionaffidavitrentalreg.pdf

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⁵⁹ <https://health.maryland.gov/dda/Residential1/Proposed%20Residential%20Services/Supported%20Living%20Draft%20Proposal.pdf>. Service Requirements, A.7.

⁶⁰ Medicaid Home and Community-Based Services (HCBS) Taxonomy Category and Subcategory Definitions.

Relationships are complicated and change over time, and the impact of these changes may have a direct impact on the continuity, security and success of the arrangement.

IX. Drafting for Flexibility

Clients may focus on their home as the ideal place for their child with disabilities to remain, but on further questioning may acknowledge that their true goal is to provide for a safe, secure, and desirable residence for their child. While the family home may be the preferred choice at the time a trust is drafted, countless circumstances can change that preference, such as the home becoming too costly to maintain, the client or beneficiary no longer wishing to reside there, changes in the client's or beneficiary's ability to live independently, and declines due to aging or illness that make the home less accessible. The trust should be drafted to allow the trustee maximum flexibility to respond to the client's and beneficiary's changing needs, which may ultimately call for another home purchase, a rental, assisted living, retirement community or residential care through a HCBS waiver program. Similarly, if the client contemplates other family members residing in the home with the child with disabilities, the trust should allow for the inevitable changes that may arise for these individuals. The attorney should discuss with the client how the trustee is to prioritize the needs of the child with disabilities and the other family members and reflect this in the language of the trust.

Title to the home should also be discussed, with the same goal of flexibility, to allow for the property to be sold during the child's lifetime, as may be needed due to any number of changes in circumstances, such as the home becoming too costly to maintain, the beneficiary no longer wishing to reside there, changes in the beneficiary's ability to live independently, and declines due to aging or illness that make the home less accessible. If the individual owns the property at death in fee simple, the home will pass into the individual's probate estate and may be subject to

a claim by the state Medicaid program, in contrast to the property being owned in the trust, which will pass outside of probate.

An ownership interest in one's one home is an excluded resource for most public assistance programs.⁶¹ If a trust holds legal title to the beneficiary's home property, the beneficiary has an equitable ownership interest. For a beneficiary on Supplemental Security Income (SSI), receipt of rent-free shelter from their own trust is not considered in-kind support and maintenance and so does not trigger a reduction of the SSI benefit.⁶² However, if certain other shelter expenses (mortgage, property insurance if required by the mortgage holder, property taxes, rent, heating fuel, gas, electricity, water, sewer or garbage removal) are being paid from a trust this will cause up to a one-third reduction in the monthly SSI benefit.⁶³

A revocable trust is the recommended vehicle for such long term arrangements, allowing the greatest flexibility. If an irrevocable trust is preferred for other compelling reasons, then at a minimum the trust should include the power for someone to change the trustee appointments, to modify the trust in the event of changes in law related to public benefits and if allowed by state law, to be decanted into a new trust.

X. Selection of the trustee.

As with any special needs trust, the selection of the trustee is critical. Our clients want the best of all worlds in their trustee: someone who genuinely cares about their family member, is honest and true, a good financial manager, responsive at all times, an advocate for the beneficiary's rights and needs, knowledgeable about public benefits, and immortal. Introducing

⁶¹ For Supplemental Security Income, for example, see 42 USC §1382b(a)(1).

⁶² POMS SI 01120.200 F.2.

⁶³ POMS SI000835.465 D.1.

management of real property to the trustee's job makes this selection even more important, bringing with it responsibilities to maintain the property, pay property taxes and other lienable expenses, comply with local government codes, and manage the relationship with other residents. These are duties of a regular and persistent nature, requiring detailed records, prompt payments, scheduling and an ability to respond to emergencies. If the trustee is not equipped to handle these responsibilities, much may be delegated to a property manager; this in turn will add to the cost of the trust administration. The trustee must still engage with the property manager to stay informed of the condition and status of the residence.

A trustee holding real property must have a long view. The beneficiary will age, and over time may need different accommodations or assistance. Neighborhoods change; the immediate area may become unsafe or property values may increase so much that it is prudent to sell and acquire another residence. The property condition may decline or be damaged suddenly. Recently, major fires and floods have damaged and destroyed real property in many areas of the country. People with disabilities have been impacted disproportionately in these events due to obstacles to their timely evacuation and loss of power for those reliant on electrically powered machines for breathing, cooling and other necessities.⁶⁴ Disaster planning should be part of the periodic review of the trust and the beneficiary's needs.

Depending on the total value of the trust assets, a corporate trustee may be an option. Often these trustees have the resources of a property management team on board. There are non-profit trust companies that focus on serving people with disabilities; an increasing number now will hold and manage real property in trust, whether first or third party. The clients'

⁶⁴ Morris, Amanda. "In Wildfires' Turmoil, Evacuation is a Struggle for Disabled People", *New York Times*, September 13, 2021, print edition.

circumstances may recommend having two trusts, one to hold and manage the real property and another to hold the other trust assets, to take advantage to trustees with different strengths who can work together effectively.

The trust model discussed here, a third party trust as part of the parents' estate plan, contemplates life in the future. The trust may not be funded for years; during that time named trustees may fall out of favor, assets may become depleted and fall below the required minimum for a named corporate trustee, and corporate entities may change or change their trust portfolio priorities. In addition to the periodic planning review recommended above, the trust should include multiple options for appointment of successor trustees, such as naming individuals or entities with the authority to appoint trustees in the future.

XI. Conclusion.

Planning for our children's future is a labor of love and anxiety, especially for parents of a child with disabilities. Chief among the concerns is where the child will live when the parents are gone. Many parents want to leave the family home in trust for their child, and take comfort in the thought that their child will always have a familiar and beloved residence to shelter them. Special needs planning attorneys can help their clients work through the practicalities of this plan, considering the life-long financial requirements, the need for and availability of public benefits and support services, and the need for flexibility to respond to life and environmental changes; they must also counsel their clients to involve their child with disabilities in developing this plan, to ensure that it reflects the child's wishes. The attorney can have a continuing role in making this plan a reality, by assisting clients to periodically evaluate the plan to assess its continuing feasibility and make adjustments along the way, as well as to keep informed about the services and supports available through Medicaid HCBS waiver services.

Over the last seventy years, our country has dramatically changed its view on the rights of people with disabilities to make their own life choices. With years of advocacy, through improvement in our laws and policies, we have evolved ambitious goals for those with disabilities to experience true integration in our society and define their own good life. Creating flexible trusts to hold a home can play an enduring role in achieving these goals.

Attachment 2

Sample Trust Language for residence for the beneficiary

- A. It is my intention that my child, _____, (“the beneficiary”) live in a safe and secure home, and that the Trust provide a source of funds for achieving this if such can be accomplished consistent with _____’s wishes, [his/her] anticipated needs over time, [his/her] life expectancy, and the availability of different housing options for [him/her].
- B. The Trustee may acquire, maintain, invest in or rent any residence for the use and benefit of the beneficiary, whether or not the residence is income producing and without regard to the proportion that the value of the residence may bear to the total value of the trust property and even if retaining the residence involves financial risks that trustees would not ordinarily incur.
- C. The Trustee may pay or make arrangements for others to pay or contribute to the carrying costs of the residence, including, but not limited to, rent, mortgage, taxes, assessments, insurance, expenses of maintaining the residence in suitable repair, and other expenses relating to the operation of the residence for the benefit of the beneficiary.
- D. The Trustee may engage caretakers for the residence and property.
- E. The Trustee may allow others, such as caregivers or roommates, to reside in the residence with or without charging rent, as the Trustee, in their sole and absolute discretion, shall determine appropriate.
- F. The Trustee may seek information from and consult with the beneficiary, [his/her] medical and other health care providers, [his/her] personal support staff, and any others involved in [his/her] care and supports, and any other sources of information that the Trustee may deem appropriate in making their decisions regarding the safety and practicability of retaining the residence for the beneficiary. The Trustee shall also consider any information provided in any Letter of Intent that I or any member of my family may have prepared regarding my child.
- G. The Trustee may sell the residence and retain the proceeds in the Trust or retain the residence for income producing purposes for as long as the Trustee may choose, if the Trustee determines that the Trust can no longer afford to maintain the residence for my child and achieve the other purposes of the Trust, or that my child cannot reside there safely or that my child, having moved from the residence will not subsequently return, or for any other reason that the Trustee may determine appropriate, in their sole and absolute discretion. The Trustee shall have no duty to convert any residence to productive property.
- H. The Trustee shall have no liability for any depreciation or loss as a result of the retention of any residence retained or acquired under the authority of this Section.
- I. The exercise of all powers and authorities described in this section shall in the sole and absolute discretion of the Trustee.