

Leaving a Home in Trust
for a Person With
Disabilities

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ON SPECIAL NEEDS PLANNING AND SPECIAL NEEDS TRUSTS

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Evolution in housing for people with
disabilities.

Institutions give way to community integration.

The right to live in the community now articulated in law, public policy, Medicaid and public opinion.

In the community, smaller settings highly desirable and now mandated.

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Medicaid Home and Community-Based
Waivers (HCBS)

Providing support for people with disabilities to live and receive services in the community.

States vary in offering waivers.

CMS Final Settings Rule.

Supported Living Services v. Residential Services.

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Where do adults with I/DD live now?

- 38% With parents or other family members
- 32% In community-based group residential settings
- 18% In their own home or apartment
- 7% In foster care or host home
- 4% In ICF/ID or other institutional setting
- 2% Other

Source: National Core Indicators At-A-Glance (2018-2019) National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute.

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What's most important in choosing where to live?

THOSE WITH I/DD:

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.

FAMILY MEMBERS OF PEOPLE WITH I/DD ON HOUSING FOR THEIR FAMILY MEMBER WITH I/DD:

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.

Source: Friedman, C. & The Arc of the United States, There's No Place Like Home. 2019

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What's holding up moving out?

Chronic shortage of affordable housing.

Chronic shortage of staff.

Waiting lists for HCBS waivers.

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Financial analysis for leaving a home in trust

Capture the actual operating, repair and replacement costs of the household.

Life expectancy and aging of both clients and person with disabilities.

Nature of family wealth.

Other lifetime and legacy planning goals.

Financial advisors can assist in modeling.

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What help will the State provide for the house?

HCBS waiver programs will not provide any assistance with the carrying or operating expenses of the property for those living in their own homes.

Other State agencies or charitable organizations may provide some assistance with accessibility improvements, property tax credits for people with low income.

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Others living in the home.

Roommates receiving services.

Others providing services, care or sharing the costs.

Compensation – from Medicaid or from the trust.

Tax free living arrangements.

Zoning requirements.

Expectations of family members.

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Drafting for flexibility.

Clients' legacy goals and priorities.

Person with disabilities' goals and priorities.

Anticipate changes: aging, environment, finances, declining independence, loss of services.

Allow maximum flexibility in ability but not duty to provide residence.

Trustee selection, now and future.

Disasters happen.

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Counseling the clients.

How does the person with disabilities define their own good life?

Does the home meet the wants and needs of the person with disabilities?

Are services available to meet the person's needs in the home without family supports?

Discuss expectations with other family members.

Build the circle of support: friends, family, co-workers, staff, agencies, neighbors, medical and other health care providers, trustees.

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