

# Independent Living for a Family Member with a Lifelong Disability

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While many persons with disabilities live at home with their families by choice, others do so because of long waiting lists for traditional residential programs. Families of persons challenged with disabilities are often unaware of the various housing options and in-home supports which enable persons with special needs to live independently. This handout explores alternatives to the traditional provider based group homes and congregate care settings that were, until recently, the only options available. Recent changes in Federal Home and Community Based Services (HC) housing policies have made it possible for persons with disabilities to have housing options similar to what persons *without* disabilities want for themselves.

Lifelong planning for a child's future can expand available choices. Whether a person rents or owns his or her home, there is a sense of belonging and security in choosing where and with whom to live. This article will explore the importance of financial planning, and how families can partner their private resources with governmental benefits and agencies to plan the best future for their child.

## PLANNING FOR THE FUTURE - FIRST STEPS FOR FAMILIES

It is never too early to start planning. Most of us have learned that we should begin a savings plan in our twenties. When a family has a member with a lifelong disability, planning should begin in the early teens. Under the IDEA, schools must begin transition planning for adulthood when the child reaches age 14. This is a good time to start planning where and with whom s/he will live when the parents are no longer able to care for him, or earlier if the individual desires independence at an earlier age.

By the time an individual is in high school, families have an idea of the types of services a family member may need in adulthood to be independent, and preferences regarding type of home.

Families need to understand that planning for their child's future is a long term commitment, just like planning for their own retirement. One's "life plan" needs to be reviewed and revised from time to time. It is important to remain flexible and open to change. What an individual *thought* they may want when they were age 18 may be very different from what the same individual wants at age 30.

There are a number of planning steps families should take:

- Become familiar with public, private, local, state and federal programs and agencies that offer supports and services.
- Determine the preferences of the family member with a disability. While one person may prefer to live on his/her own, other persons may crave companionship and want roommates or to stay in a family setting.
- Consider guardianship or the need for powers of attorney.
- Calculate the amount and type of resources needed to supplement care and support services available from the government.
- Meet with a financial planner who is familiar with government benefits to discuss how the family's assets can be preserved and invested to maximize child's housing choices.
- Determine the costs associated with different housing options to decide what is and is not affordable.
- Meet with an attorney knowledgeable about special needs law. (Special Needs law includes consent issues, guardianship and less intrusive alternatives to guardianship, special needs trusts, eligibility for needs-based or sliding fee benefits and residential options that may be available for a person with a lifelong disability).

If a family is planning to purchase a home or a condo, the family will want to explore ownership options. All of this information should be preserved and revisited every few years to determine if the initial plan still meets the family's needs.

Because most families are not in a financial position to fund long term lifelong care privately, knowledge of benefits, and residential options they support can enhance quality of life and expand one's choices as to where and with whom one lives.

Benefits fall within three basic categories: Needs-based Benefits, Sliding Scale Fee Benefits, and Entitlement Benefits.

**Needs-based Benefits** include Supplemental Security Income (SSI) and Medicaid, which is often referred to as the ticket to Home and Community Based Services (HCBS) in most states. To be eligible, the disabled individual must have limited income and resources (\$2,000 or less in assets, income less than 133% of poverty level for Medicaid, and income less than \$1,090 in 2016 for SSI).

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**Sliding Scale Fee Benefits** include Supplemental Nutrition Assistance Programs such as SNAP/food stamps, heating or fuel assistance, Section 8 Vouchers, Public Housing and Health Care Benefits (called CommonHealth in MA) for the working disabled. To be eligible, one must be marginally poor. Each program has its own criteria, but the common element is that these are programs for low-income working or disabled poor.

**Entitlement Benefits** include Social Security Disability Income (SSDI), Medicare, and Individuals with Disability Education Act. Entitlement depends on being categorically eligible. In the case of SSDI and Medicare, one must have worked and paid into SSA. Or one's parents must have paid into SSA and the disabled adult must qualify for Childhood Disability Benefits (CDB) as a Disabled Adult Child (DAC).

In order for a disabled child to receive DAC benefits:

- The parent must have retired, become disabled or died.
- The child must have been disabled prior to age 22.
- The child must be continuously incapable of Substantial Gainful Activity.
- The child must be single.

When it comes to housing supports, Medicaid is the most crucial governmental benefit. As stated above, Medicaid is the ticket to services. Without Medicaid, one cannot qualify for HCBS Medicaid Waiver programs which fund the majority of residential placements and in-home supports for persons with disabilities.

There are several types of Medicaid programs. These include Standard Medicaid, Health Care Benefits for Working Disabled (sometimes called "buy in" Medicaid) and Expanded Medicaid under the Affordable Care Act. There is also a special Medicaid eligibility for Home-based Services under DHS or for Rehabilitation Services (MA Rehab in MA).

Medicaid-funded Home and Community Based Services (HCBS) provides supports and services to individuals living in the community. It is crucial that families educate themselves about Medicaid Waiver Programs (See HCBSadvocacy.org for status of waiver programs in each state). There are long waiting lists in most states for HCBS programs so it is important to apply early. One should not wait until one is in desperate need for residential supports to apply. Apply early - as early as age 18. Once one has filed, it is important to monitor the status of your request for HCBS at annual Individual Service Plan meetings (ISP), for the following reasons:

- States are expanding Medicaid waiver programs as they stretch dollars previously spent on ICFDDs and large congregate care settings which tend to be more expensive.
- HCBS regulations were updated in January 2014 with an emphasis on community integration and providing supports in natural settings.

As Tip O'Neill used to say, "all politics are local." The ramifications of our current economic and political climate

can make a huge difference in what is available in your region. There is huge pressure among federal, state and local governments to cut budgets and not raise taxes to fund services. Attempts to reform Social Security to eliminate CDB/DAC benefits could result in loss of this entitlement benefit. There have also been attempts to place new Medicaid waivers into Block Grants which would cap state or federal spending on this program. Attempts to limit benefits for certain groups could result in persons with milder disabilities falling through the cracks. There is a rising number of persons in need as baby boomers age and can no longer provide care for a disabled child. Without expansion of services, this will result in dilution of services as fewer dollars are available to pay for increasing numbers of persons requiring help.

The watering down of services heightens the importance of Special Needs Trusts. The SNT helps retain eligibility for Medicaid when a parent or grandparent dies, by providing private funds (usually from an inheritance) to supplement the goods and services available through Medicaid and other benefits. A properly written third party Special Needs Trust—which is funded directly from a bequest in a will or life insurance—does not require a payback to the government, and allows funds or assets remaining in the trust to flow to other family members or favorite charities when the primary beneficiary dies. This is not a session on special needs planning, but information on SNTs and other planning vehicles is included. Develop a financial plan so the SNT has the funds to maximize options. Couple it with the use of ABLE accounts and investment advice from a knowledgeable financial planner so that funds grow to meet current and future needs.

In planning for the future of one's child, developing a Person-Centered Plan is helpful in determining where and with whom your adult child will live. Does s/he prefer to live alone or with others? Does s/he want to be close to family? How much support is needed? What are his or her transportation needs? Where are parents/siblings going to live or retire? What work, volunteer or leisure activities are available in the area? Are there other families to partner with? What is the time schedule for reaching independence? These are all questions one should ask before a move takes place.

The answers to the above questions will determine what type of home will best suit the adult child's needs. There is a range of residential options. Is it best for the adult child to live in the family home, sibling's home, a group home, a friend's home, his or her own home? What are the natural or private-pay supports available? A person may receive intermittent supports in one's own home provided by Medicaid waiver funds such as PCA, homemaker services, Meals on Wheels....

Shared living or Adult Foster Care, which may provide 24/7 supervision (with Medicaid waiver funds) in the caregiver's home is a growing and popular option.

Shared living or Adult Foster Care in a rented apartment or own home controlled by the adult child or the child's trust

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(Medicaid waiver funds caregiver) is another option similar to the above. Having control over the abode is an advantage if the caregiver burns out, so only the caregiver moves, while the individual remains in the familiar setting.

Some individuals prefer to live alone with one or two roommates in a rental or owned home. Families need to consider which is available and most appropriate: private pay and natural supports or Medicaid waiver supports.

Traditional group homes with 4-8 housemates and 24/7 staffing are still available, but there may be longer waiting lists for this type of program.

Non-traditional group residences, which may be private pay (co-op or condo style arrangement with other families), are an option. Legal advice and agreements are needed in arrangements like this. Services may vary depending on the needs of individuals sharing the home and their eligibility for MAHealth.

Private congregate care settings still exist. They are usually very expensive, and not always a good value. One needs to monitor care closely in private congregate care settings as a change in management can change the facility's tone and quality of care.

Last is the traditional Intermediate Care Facility for Disabled (ICFDD or ICFMI) which requires intensive medical needs, usually within large congregate care settings (institutions/nursing homes).

There are numerous ownership options which include the following:

- Corporate (LLC, C-Corp, S-Corp, Ltd. Partnership or Non-Profit)
- Parent or Sibling ownership of a Condominium
- A Co-operative
- A unit can be owned by a real estate or nominee trust, or by a first- or third-party Special Needs Trust.
- The individual with a Disability can also own the unit, but keep in mind there may be an estate recovery lien placed on the home should the individual receive MAHealth and die after the age of 55.
- In some cases, two or more individuals have owned a condo or home together. If this occurs, you will need to have agreements in advance as to how a share will be sold and what control the remaining owner has over a future buyer.

There are numerous financing programs to reduce the cost of housing, reduce the cost of the property, reduce the cost of financing the property, or subsidize the availability of cash to make the purchase affordable.

Federal Programs available to assist with purchasing a home include:

- The Federal Deposit Insurance Corporation (FDIC) provides a list of foreclosed properties that are for sale.

- Home Mortgage Fund Providers Fannie Mae and Freddie Mac Corporations work with lenders to provide mortgage loans to individuals with limited incomes.
- Housing and Urban Development (HUD) allows low income individuals to purchase properties below market price.

Federal Programs are available to assist with renting a home. These include: the Housing Choice Voucher Program (HCVP-Section 8) which provides a housing subsidy. The low-income tenant pays only 30-40% of income in rent, with remaining rent covered by a voucher paid directly to the landlord.

Federal financial assistance programs, which provide supports within the community, include:

- DDS/DHS Medicaid Waiver Funds
- Adult Foster Care (AFC)
- Shared Living
- Personal Care Assistance (PCA)
- Medicaid, SSI, SSDI benefits
- Earnings of resident(s)
- Parent or other private supplements from individuals or special needs trusts.

When determining which Federal programs may be most appropriate, there are a number of factors to consider:

How many occupants will share the home?

How much staff will be needed?

Will staff be paid or volunteer family and friends?

Is 24/7 care needed or just intermittent supports?

How many people will invest in the home or condo?

What type of financing will be needed?

If more than one party is purchasing the home or condo, residents or investors will need an agreement as to how to sell one's share or seek new roommate.

In answering the questions above, a person-centered plan will be of tremendous value. A Person Centered Plan—which reflects the individual's and family's hopes, dreams and wishes—includes a Legal Plan, a Special Needs Trust, and a discussion of guardianship or alternatives such as Powers of Attorney. Consideration must be given to how assets will be protected from theft, waste and misuse. The legal plan should ensure future decisions are made by informed and competent persons. Meeting with a competent financial planner is recommended as well. A well thought-out financial plan will ensure there are adequate funds to put strategic plan in motion

Given the shortage of public funds, families may want to consider developing a Public/Private Partnership, which uses public money to fill in the gaps of public funds.

The individual should remain eligible for all Governmental Benefits available to maximize public funds used, and limit the amount of private dollars needed. Private sources of funds to

supplement the cost of housing and care can come from the purchase of a Survivorship Life Insurance Policy, a savings plan/ABLE Act, and an estate plan that provides a larger percentage of the estate for the Adult Child with Special Needs left to a third party special needs trust.

In summary, families should:

- Start early and remain flexible as needs/wants change.
- Meet with a Special Needs Attorney to develop a legal plan to maximize private funds to supplement government benefits (Special Needs Trust to preserve Medicaid eligibility).
- Keep the legal plan updated to reflect the individual's and family's changing circumstances.
- Make sure the strategic plan reflects the individual's wants and needs.
- Identify supports and services available.
- Identify housing resources and options available.
- Seek advice from a Financial Planner to maximize your child's choices.

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