

Top Ten Tips in Creating a Real Home for a Family Member with a Disability

By Frederick M. Misilo, Jr., Esq.

Over 160 people attended the Real Homes, Real Solutions seminar sponsored by the Fletcher Tilton Special Needs Practice Group on March 19, 2011. This seminar presented legal issues, family stories and information from housing finance experts related to creating residential supports for family members with a disability.

From my reflection of the seminar, I'd like to share what I consider to be the ten most important "take-away" points.

1. Future of government resources. There is no dispute that the current economic conditions facing the nation, the states and our local communities will continue. It is estimated that 45 states are expecting budget shortfalls in fiscal year 2012. The recent recession created the largest number of job losses since the Great Depression and the continuation of high unemployment figures bodes a slow and unsteady economic recovery. On the federal budget level, there will be continuing efforts to reduce the burgeoning federal deficit. Individuals with disabilities, recipients of Medicaid benefits, and others who rely on government assistance for health care will face the threat of reductions in appropriations, elimination of some benefits and a conversion to a Medicaid block grant. These threats are real. So, in planning a residential future, significant reliance must be made on private funds. While we must continue to advocate to maintain and increase federal and state appropriations as well as work toward creating more cost-effective models to use government appropriations, families must not overly rely on the hope that government resources will be the sole support of their son or daughter in the future.

2. Importance of starting early with a plan. The parents who have successfully arranged an appropriate home for their son or daughter started planning one to three years before their son or daughter moved in. I am pretty sure that they began internally mulling things over in their minds well before that. The reasons for planning early are self-evident. First, you need to develop consensus within the family about whether your plans make sense and to build an internally driven commitment within the family to keep moving forward. One very obvious trap is what I call the Get -To-It trap. These are the ideas, plans and things that need to be investigated, performed and vetted in order to move forward, but you put them on your To Do list. The problem is that many people never Get-To-It. These are the things that you'll get to... someday. But the list grows and grows while life just happens.

Covey has written about the critical importance of prioritizing those things in our life that at the moment are not urgent but which are very important. The key is to discern those things that are truly urgent and important from the crisis of the day or week that seems urgent but which is, in reality, not all that important. My advice is to schedule some quiet time on a regular basis to write out your thoughts, talk about your plans with your spouse and important other people and to conduct your due diligence. This can be an on-going "Planning Meeting" for you, your family members with invitations going out to others on an as-needed basis.

3. The use of leverage. Broadly speaking, leverage is creating more power through the creative use of resources. For instance, leverage can be three or four families coming together to pool their money to create more buying power so they can purchase a home more easily together than they could on their own. Some families may have more financial resources than others while some others may have more time to contribute. Don't minimize the value of time that may be able to be contributed. In one successful model, two families planned an arrangement where one family purchased a house next to the other family who did not have the financial capital to contribute toward the purchase of the house. But they have something as valuable as money, they have human capital. They live next door and provide a myriad of support to the two young adults living in there. It works. Also, many retirement plans can be leveraged through a loan. Repayments must be made at a marketable interest rate, but remember, you're replenishing your own retirement account by paying down the loan. You will need to check with your retirement plan administrator to see if this is possible with your particular plan. Finally, you should evaluate the advisability of refinancing your principal residence or taking out a home equity loan.

4. Things change, be flexible. Where we live depends on many factors including the location of family and friends, our work, the type of environment we choose to live in and a host of other factors. Things change. We down-size, we retire, we get divorced, etc. And major life events are often accompanied with a change in living environment. In most circumstances, real property in a trust or in a corporate real estate holding entity can be exchanged with very little difficulty so as to accommodate changes in the location of property.

5. Identify housing dollars separate from support and service dollars.

The acquisition and regular maintenance of real estate can be budgeted and planned for in a fairly easy fashion. The source of funds to purchase may come from savings, a loan from a retirement account, a gift from family members, proceeds from a home equity loan, etc. The regular carrying cost of the home can be paid from anticipated rental income, a planned escrow account or other anticipated revenue. I suggest you consider creating an annual budget for estimated housing costs as a planning tool. Two important sources of government funding for residential support for individuals with disabilities are the Section 8 voucher program and the Alternate Housing Voucher Program (AHVP). Both programs are administered through housing assistance agencies and local housing authorities. Applications for rental vouchers can be obtained and filed at local housing authorities. Even with an anticipated long waiting list, I suggest that an application be filed if there is a tangible possibility of your son or daughter moving out of your home. Under federal regulations governing the use and administration of Section 8 housing vouchers, a person with a disability who has been granted a voucher is entitled to a reasonable accommodation in how the voucher is used. This means that the customary “arms-length” requirement between landlord and tenant can be modified. So, a family owned or controlled rental unit can be leased to a family member with a disability who has a voucher. In some circumstances, a special needs trust can be the landlord and the beneficiary of the trust can be the tenant.

6. Know the support and service needs of individuals.

A complete understanding of the service and support needs of each individual must be arrived at as part of the planning process. While this may seem obvious, there is one general tendency I’ve noticed over the years. Parents often overestimate their son’s or daughter’s daily living skills. Often, parents discount the value of a regular routine, the presence of familiar family members and the often overlooked presence of verbal and non-verbal cueing that is natural in a home environment. It may be worthwhile expense to retain the services of a qualified professional to assist you in accurately evaluating the level of services and supports your son or daughter as well as other prospective residents will need when they move in to their new home. Accurately assessing the service and support needs of each individual is essential in estimating the anticipated costs of meeting those needs through appropriate staffing.

7. Identify support and service dollars. Obviously, if your son or daughter and other prospective residents are eligible for adult services from a state agency, you should speak with the appropriate person assigned to his or her case about your intentions. This person can be helpful in providing a realistic expectation about prioritization and allocation of resources. Also, personal care assistance (PCA) funded through the Division of Medical Assistance can be a source of support dollars. A determination of whether PCA is appropriate and the extent of the PCA support should be made as soon as possible. Finally, each resident’s Supplemental Security Income (SSI), Disabled Adult Child (DAC) benefits and other recurrent monthly income will be available to fund a portion of the supports to be provided. It is customary that seventy-five (75%) of the recurrent monthly income of each resident be paid as a form of a service fee. Also, for many families, privately paying for services and supports has become a daunting but necessary reality.

8. Importance of good advisors. The activities of maintaining a home for a son or daughter with a disability can involve, for instance, the purchase of real estate, creating a landlord/tenant relationship, having service and supports being provided on a regular by paid staff, maintenance and upkeep, etc. An attorney should be involved in many of these areas including selection of the appropriate legal entity to own the real estate, creating sensible service agreement for settings that are non-DDS or non-DMH regulated, understanding and complying with applicable labor/employment practices, identifying potential sources of liability and taking steps to minimize and/or avoid such liability is essential. The skills and talents of experienced staff who can manage a residential setting can be a valuable asset. There are a number of highly skilled administrators with years of experience in managing residential services and supports for individuals with disabilities available to serve either on a short-term consulting or long-term management fee basis. Of course, having a reliable handyman, plumber, and electrician on speed-dial can save time and lower your blood pressure when the inevitable yet unexpected housekeeping crisis hits.

9. Integration of the housing model into your estate plan.

You must plan for how the home will be managed when you are unable to be involved due to death or disability. A comprehensive, special needs plan is an essential part of developing a home for your son or daughter with a disability. The fundamental documents must provide for the distribution of assets to the appropriate persons and trusts in the proportions desired. Durable powers of attorney with critical Medicaid planning language and health care proxies are essential. The use of a special needs trust to hold assets for the benefit of a son or daughter with a disability to pay for future services and supports is the centerpiece of this plan. These essential documents must be coupled with a realistic financial plan adequate to provide for supplemental services and supports throughout the lifetime of a son or daughter with a disability.

10. Important personal qualities: patience and persistence. There is no cookie cutter approach to developing an effective and successful home for your son or daughter with a disability. It is easy to get disillusioned because solutions are slow to develop. There are many moving parts. Some dead-ends. The parents I've had the privilege to work with on these types of situations have demonstrated an enormous amount of patience and persistence. They share a common characteristic that expects more from themselves than from any one else, including the government. There is also a sense that "I know best" and "I'm going to keep trying". These personal characteristics of patience and persistence imbued with a sense of optimism are important to move from the vision of a home to a real home.

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