

Creating a Residential Option for Your Child

“One of the biggest fears of parents is that there are care giving options out there in the world that are as good or better than what they’ve been providing. It’s a double-edged sword,” says Jerry Hulick, a Chartered Special Needs Consultant (ChSNC) with the Special Care Planning Team of The Washington Group, a general agency of Massachusetts Mutual Life Insurance Company (MassMutual) located in Fairfax, Virginia “We want our children, whether they have special needs or not, to be as self-sufficient as they possible can. And like a typical child going off to college or moving into a place of their own, we’re happy for them. But we can’t help feeling sad or worried to see them go.”

Today, because of medical advancements and better education opportunities, more people with special needs are able to live independently – or somewhat independently. The result is an increased demand for more housing options, and the market place is responding to that demand. Families are also being proactive, uniting to create homes their children can share, but before we delve into this intriguing option, first a bit about the housing situation in general.

The growing housing market

“The housing industry for people with special needs is evolving in a way similar to what we saw in education,” says Hulick. At one time, very few children with special needs received an education. “Opportunities were limited, but when families began advocating for better public education for their children, changes began to take place,” he explains. Government standards and funding were established, and special education became an expected right rather than a limited option. Now the attention is drawn to improving the housing market, but there are no government mandates like we find in education.

“Lots of models are emerging,” says Hulick. “Here in Virginia, as well as in other parts of the country, there are clusters of homes with four or so residents per household. These might be private-pay facilities or funded by a government program or monies.”

You’ll also find communal-type homes where residents take part in earning income to pay their living expenses through farming, craft making, arts, or another revenue-generating interest they have in common. And in many cases, individuals or couples with special needs live on their own with help from family members.

“The range of possibilities for models is unlimited, as long as you don’t think in a box,” says Hulick. “A multi-person home or a community neighborhood can’t be created with one type of person with special needs in mind and be expected to serve the needs of numerous individuals. Each resident will have his or her own preferences, just as you and I and your own neighbors do. We must work together to create the best situation to meet every resident’s needs.”

Considering your child’s housing needs

If you’re looking for living accommodations for your child, you may need to do extensive research before finding the right place. Perhaps you’ve already done the work and you haven’t found what you want. If you’re now considering establishing a residential option for your child and others, here are some things to keep in mind.

- **Quality of life** – This is your highest priority. The things that will contribute to the quality of life your child will want in a home of his or her own will guide you in creating the environment that will best meet those wants and needs.
- **Rest of life issues** – As you work to establish this home, consider how it will meet your child’s long term needs.
- **Type of residence and locale** – Should it be a house, an apartment in a multi-family house, a unit in an apartment complex, a condo? Should it be in the city, country, or somewhere in between? Does it need to be

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- **Transportation** – Do you need this home to be on a bus line? Does your child need a car or van? Or should transportation be included in the list of tasks the home's service providers perform?
- **Employment** – Will your child work (for pay or in a volunteer position)? What constraints will employment place on creating this home?
- **Social/recreational desires and hobbies** – What's the proximity of this home to your child's family and friends? Are entertainment venues nearby? Will your child want to entertain at home? Does he or she love gardening, yard work, and spending time outdoors?
- **Shopping needs** – How will your child shop for clothes, food, home goods, and sundries? Where are the stores he or she will need to use?
- **Services** – What assistance will your child need on a daily, weekly, or monthly basis? What type of service providers will you need? Will the home accommodate a live-in caregiver?
- **Other residents** – Those who share a home with your child should have similar interests and support needs. Older housing models have suggested no more than four-to-six residents per household.

Finding housemates for your child

"Ideally, you should determine what the model will be for the residence you're creating, then enroll other families whose children have similar needs" suggests Hulick. "Having one lead family manage the home will work better than four or six families trying to come to consensus on the many issues and decisions you will have to face over the years."

If you plan to build or renovate a home

"Not in my back yard (NIMBY) is a sentiment that's seldom heard these days," explains Hulick, "because legislation and local ordinances prevent this objection. However,

there are some county or city ordinances you'll need to deal with regarding home modifications and building codes." Talk with builders who specialize in this type of housing.

Also talk with your medical providers, your special needs attorney, and your financial professional before you begin. "Some home

modifications can be deductible if properly documented and medically scripted," says Hulick. "If you already own a mortgage-free home you're going to use for the residence – for example, perhaps you inherited property from a family member – you may want to consider transferring the home ownership to a trust or special needs trust."



The home might also be owned by you or another family member, but should not be owned by your child (the resident of the home). It's also important to know that funds in a special needs trust should not be used to pay for a home or a mortgage, but another trust could be established for that purpose. When you work with your team of experts you can create a financial strategy that suits the short and long term needs of your family, your child with special needs, and your child's residence.

More financial tips

Here are some additional financial facts for you to consider. Talk to your team to learn how they might work for your family.

- "As the special needs housing industry grows," says Hulick, "government money has been made available." Our current economy may affect funding. Check federal and state government websites or talk with the appropriate department representatives to learn about grants or programs you may be eligible to receive.
- Eligibility for government benefits may change when your child lives on his or her own and earns income. Look into this before making the move.
- When you retire and begin to receive your Social Security benefit, your adult child with special needs also receives a benefit which can supplement his or her monthly income.
- You can use funds from a special needs trust to pay for service providers as part of your residential solution.
- While you're alive, you might help your child pay for personal expenses with your own money. After you die, the benefits from a life insurance policy, with your child's special needs trust or your child's guardian named as beneficiary, can continue to help pay those expenses.
- Don't forget to consider what your rest of life issues will be. Often the financial demands of a person with special needs are given priority over other family members' needs. For example, a parent's retirement fund might be used to pay expenses of a residential option. But when the financial strategy is designed to benefit the entire family, this is less apt to occur.

Persevere and depend on others

If you decide to follow the path of creating a residence for your child, both your work and your reward will be great. Be sure to brainstorm with your team of experts now, throughout the time it takes to establish the home, and at least annually thereafter to discuss concerns, reveal issues that may otherwise go unnoticed, and review options.

Exceptional Parent's article, "Your Search for Safe and Affordable Housing" (December 2010 issue) may also be of interest to you and can be found on the magazine's website (www.eparent.com).

* The Special Care Planner received advanced training and information in estate and tax planning concepts, special needs trusts, government programs, and the emotional dynamics of working with people with disabilities and other special needs and their families. The certificate program was offered by The American College in Bryn Mawr, PA, exclusively for MassMutual financial professionals. State insurance departments recognize that the Special Care Planner certificate program provides essential information on the profession of special care by granting continuing education (CE) credits (varies by state).

A Special Care Planner through MassMutual's SpecialCareSM program can assist parents in drafting Letters of Intent and can help make a difference in the quality of life for an individual with special needs, their caregiver and other family members. Through SpecialCare you will learn valuable financial strategies, identify financial strategy solutions, access vital information, and meet certified specialists who will work with you and your professional advisors – your banker, accountant or financial planner, lawyer, social workers and health care providers – to review your financial picture and offer options to fit the needs of each situation. For more details, visit MassMutual's website at <http://www.MassMutual.com/specialcare>, or call 1-(800)-272-2216.

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