



Assisted Housing Options for Adults With Special Needs

For many families, providing adequate housing for a child with special needs can be fairly straightforward, particularly if the child remains in the primary residence with one or both parents. As the child gets older, there are considerations that need to be dealt with to ensure stability as they enter into adulthood and their aging parents might be facing issues related to their own health.

Housing is the single most important issue facing adults with special needs and requires advanced planning and action. Depending on the variety of the needs and specifics of the individual, finding and keeping adequate housing can be the most stressful situation, before money, services and even health issues. Without adequate housing, adults with special needs can suffer exponentially, especially during a booming housing market where prices and demand are high, and inventory is low.

In some ways housing needs are reflective of the person's station in life, and fluid as a result. We think of parents always wanting to be the primary source of housing as a caregiver, and as children age, depending on their specific needs, the change in housing status and what is required might dictate something else here.

While the majority of parents would prefer the child to stay in the family home, the reality is that if a child has significant physical needs an evaluation might result in the child needing to live in a full-time location where they can be provided 24/7 care.

As the child gets older, the realization that most supplemental programs (federally supplied) will stop after age 21 can be a rude awakening for parents. Discovering that services and programs once relied on will no longer exist can have a significant impact on the family, and potentially disrupt the physical and mental health of the individual with special needs.

The good news is that often by the time the child is 22 years old, most parents have already met with an SNA member and have the planning in place about structure with finances, so that if the child is on public benefits, they won't lose them. While they still have to deal with the question of housing, it can provide parents added reassurance to know that with the help of a qualified individual, there can be creative arrangements for the adult with special needs.

Once the parents start having significant health issues, and as they age, it's critical that plans are decided in advance to decide about the housing issues the adult with special

needs will be facing. Sometimes they're able to remain in the family home, with siblings or someone close to the family staying with them. If the house is sold at some point, it can provide a source of revenue for the trust, which will help supplement other services for the individual.

Prior to the parents passing away, some states such as New Jersey and North Carolina will have the individual with special needs on a track for group housing, but there is typically between a 5-10 year waiting list. If both parents die, there is an emergency wait list, but it might take only a year or so for the individual to be placed in a group home. So frequently there is a 12 to 24-month window of scrambling of what to do if there were no plans in place.

It's not uncommon for particularly high-functioning individuals to transition into apartment living or a group setting, before the parents are too elderly, or as the parents have their own medical issues to try and ease the change in housing. A lot of the decisions at this stage are purely dictated by what funds are available.

In comparison with other siblings, planning for the housing of the adult child with special needs will be more advanced, requiring an adequate inheritance to ensure they will be taken care of for the remainder of their life. Housing will likely be the primary financial concern, and unless a trust has a significant amount of cash reserve, there can be a struggle about where and with whom the individual should reside. If, for example, both parents pass away and the individual with special needs still has a 30-year life expectancy, perhaps keeping the family house is not the best use of trust funds in the long term.

There are often not enough services available, and even with Medicaid paying for certain things, one recommendation is that both (healthy) parents should have life insurance, to fund housing and have some flexibility to buy time and make good decisions, in light of changing life situations.

While every situation is unique to their family, a common concern is that often the medical and/or housing needs of the parent will create issues for the individual with special needs. If a parent moves into a nursing home, and there is no guardianship or SSI for the individual with special needs, there can be a sense of desperation and panic because those critical conversations never happened. It can sometimes be a generational issue, where adults aged 45 and up didn't address these types of issues, but younger generations have perhaps been more aware of the need to make plans in advance. A sibling might call an attorney and inform them that their parent always took care of the child with down syndrome, but now that parent has passed away and they don't know what to do.

Additionally, it can be traumatic for the adult with special needs when they lose a parent, and this additional stress can exacerbate their mental health. The coronavirus made these situations even more distressing, and many service programs were shut down.

While group housing can be an option, setting up a home with several residents and a social worker checking in, this type of housing environment is expensive, and without careful planning in advance, the reality is that this type of housing is often not a realistic option for most families. As housing prices have skyrocketed in many parts of the country, finding affordable housing remains a challenge for most families, and finding a shared arrangement, or participating in a waiver program for people with developmental disabilities can help cover the living costs.

Above all, the most important thing is that parents of an individual with special needs are planning and having these really hard conversations while everything is relatively calm. Too frequently we have this conversation when mom or dad is having a medical crisis. Then everyone is panicked but a lot of times they wait too long and choices are more limited. The longer the delay the more limited the options are, so it's critical that families start having these necessary conversations well in advance.

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