



A Place Of Her Own

By [James McCarten, Esq.](#)

First and foremost, I am Diane's husband and Kathryn's father. After that, I am an attorney and a "tax nerd," which is the title bestowed on me with much love, affection and humor by my daughter, Kathryn. Kathryn is almost 24 and has autism. Her mother and I want as independent and fulfilling a life for her as she can have. Recently, that has begun to hit home much more closely than it ever has before; Kathryn is focusing in on what it will take for her to be able to move out of the house and into a place of her own.

That's a phrase we're hearing a lot these days, "a place of my own," and boy, does that leave me conflicted. On one hand, I am proud of Kathryn and her goal of becoming independent. On the other hand, as her father and being intimately familiar with some of her challenges, especially her overriding preoccupation with being included by peers her own age (despite her lack of success in that area and often without an understanding of the consequences of her actions), I worry about her safety, happiness and general well-being. I cannot help worrying about her, but I also know that I need to give her room to become her own person as an adult, which means giving her the opportunity to try; she can't succeed if she doesn't get to try and, maybe, to fail. She has seen her older sisters move out into their own apartments, later moving into their own homes and Kathryn wants and expects to also have that experience. She deserves that experience. But how do her mother and I minimize the downsides so that any mistakes do not destroy her spirit and drive to be as independent as possible?

So when Kathryn talks about wanting to live in a place of her own, her mother and I can't help but recall some of Kathryn's inconsistencies: for example, her ability to cook a whole meal for the family with only a little guidance from her mother, but yet a week later fill the house with smoke by overcooking popcorn in the microwave (having punched in too many minutes and beginning to watch TV before the popcorn was ready); her ability to do her own laundry, but not before she has gotten to the point where she has nothing clean to wear; finally, the fact that she will remember to let her dog out before going to bed, take her meds on her own, and maybe remember to lock the front door after letting the dog back in the house about half the time. She still needs regular reminders on many day-to-day skills. All paradoxes of Kathryn being Kathryn that concern her mother and me.

As Kathryn has gotten older, her mother and I have started to try to better help her understand her realistic choices. It really started because Kathryn finally decided she

needed to learn how to drive. Just as we have had to help Kathryn learn about the costs associated with owning a car (gas, upkeep, tires, insurance), and the fact that a 15 to 20 hour per week part-time job does not provide enough income to afford the out-of-pockets above, much less purchase the tricked-out pick-up truck she wants. In that same fashion, we are having to teach Kathryn, by first learning ourselves, about the types of living arrangements available to Kathryn and their costs; in other words, the financial and practical pros and cons of each option available to her to “have a place of her own.”

As if the process weren't difficult enough, in the middle of our education, the Centers for Medicare and Medicaid Services (CMS) issued its new regulations requiring that home and community-based waiver services (HCBS) should only be provided to those qualified individuals living in community-like settings. Restated just a bit, if the residential setting is separate from the general community and only for individuals with disabilities or otherwise appears institutional or isolating, she will not be able to receive the Medicaid waiver supports that are likely to be necessary for her to live independently. The implementation of that regulation is having a huge impact on our education and the housing options available to Kathryn and other young adults with developmental and/or intellectual disabilities who also need HCBS supports to live “in a place of their own.”

So, this write up is to share some of the important information we are learning from our journey with Kathryn to explore housing options, and the first installment will describe the types of independent housing traditionally available for individuals with disabilities. The second installment will then examine the new CMS (Centers for Medicare and Medicaid Services) community-based regulations and their impact on Kathryn's housing options. The final article of this series will consolidate the best of the surveys and suggestions we've come across in trying to determine the best housing options for Kathryn.

The Need to Plan for Independent Living Options

Professionals and parents alike recognize that individuals with special needs typically have trouble handling transitions. Whether it's as small a change as going to a different restaurant than was mentioned yesterday or as major as an unexpected trip to the dentist, predictability and a regular schedule play a large part in making each day pleasant and allowing it to go smoothly for Kathryn. With a transition as significant as moving to a new home (and we have moved several times), it takes patience and preparation to ensure that Kathryn is ready for the changes that a new abode will bring without suffering through too many autistic meltdowns. More importantly, as we are now experiencing with our parent's generation, there is a strong likelihood that we may eventually become unable to care for our child as we age, whether due to physical or other age-related infirmities. Parents may even pass away before being able to help prepare their adult child for the transition from

their home and care to some other abode. The loss of a parent is powerful and emotionally traumatic for those without special needs. Now consider the impact on a person who does not handle transitions well, especially when his/her parent has been the only caregiver and emotional support they have ever known. In addition to the sense of personal loss, all that has been familiar and comforting to the child—home, room, regular schedule, neighbors, church and perhaps even pets— may be lost at the same moment without any preparation. Without question, parents themselves need to be involved in making arrangements for, and easing their child into, independent living before it becomes absolutely necessary and while the parents and the child have some control over their choices.

The need to help manage what may be the child's most important transition is why special needs lawyers, medical professionals and social work professionals spend so much time and energy advising families to plan ahead and begin the process while parents are still able to participate in, educate and assist their adult children with special needs in managing these changes. Even with all that has been written on the subject, statistics tell us that seven out of every 10 adults with a disability still live at home with their parents and other family caregivers. See [*The 2016 Easter Seals Living With Disabilities Study*](#). While the following overview of housing options is meant to provide parents and professionals with an introduction to what is available for adults with special needs, determining what's best for a specific individual will depend upon that person's need for support, finances and their preferences, as well as those of their family.

Separate Living Arrangements at Home

One of Kathryn's goals when she talks about having a place of her own is to have an area completely separate from her mother and me where she can have more control, including, for example, deciding when to clean, how loud to play her music or the television and being able to choose to leave her dirty clothes on the floor of her closet or her bedroom.

Therefore, one of the options we have discussed with Kathryn is the idea of an in-law suite or a separate apartment over the garage. This would accommodate Kathryn's wish to exercise more control over certain aspects of her life, while still allowing us to help by monitoring her medications, controlling when the Internet is available (being able to shut it down at 10 o'clock), providing her access to our washer and dryer, and providing meals, to the extent she wants to join us. Putting a small kitchenette in an in-home apartment would allow Kathryn the freedom to decide what foods to keep available for snacking and meals. Further avoiding stove and oven issues, it might be that a microwave is all she would need for cooking. But whether it is Kathryn or your child, the real focus has to be on the supports the adult child needs in order to live alone successfully. Maybe there's even enough space

in that separate apartment for a roommate so that the living experience becomes more of a supported living experience than just being a little more removed from her parents.

True Independent Living

If Kathryn proves capable of living independently, and needs fewer direct supports and less regular oversight, a separate apartment or condominium might be the answer. If Kathryn is renting in an apartment complex or a house in a different neighborhood, what kinds of supports will she need and who will provide them? Where should that “place of her own” be? Perhaps the first question really needs to be: What transportation can Kathryn use? If Kathryn is unable to drive but can use the bus, is there a bus system convenient to the apartment? Is the apartment located within safe walking distance of employment opportunities and shopping? What about neighbors? Is the apartment complex safe for her? A separate apartment presumes that your child is relatively self-sufficient and does not need the supports of a personal attendant for daily activities.

Shared Living Arrangements

When faced with these decisions, many families have chosen to create their own shared living arrangement for their adult child with disabilities. A shared living arrangement is often an apartment or a house with the capacity for one or more roommates who are chosen for their ability to provide the primary lessor, your adult child with special needs, support, peer guidance and some level of oversight. This is an option chosen by families who can afford to absorb the cost of a two- or three- bedroom facility and guide the search for proper roommates. If the home is in a college town,, think how wonderful it would be to find a student, a rough peer for your young adult, who was already familiar with the special needs and challenges of an individual with a disability because that student was studying special education, social work, medicine or some other related academic program. The amount of rent charged the roommates is usually negotiated based upon the amount of support they will provide, which becomes part of the rental agreement. Supports might include shared experiences such as shopping, evening walks, an occasional movie, sports events or other social activities.

Group Homes for Adults with Disabilities

When people with disabilities cannot live independently but do not require a great deal of advanced care, [a group home may be a good choice](#). In general, group homes are individual residences in traditional neighborhoods where each person has his/her own bedroom. Sometimes, but not often, larger living accommodations may be available. The types and variety of group homes are as numerous as any of us can imagine. The residence can be staffed with counselors or other full-time employees paid to assist those who live there. If

those living in the home don't need a high level of care, counselors may only be at the facility from shortly before breakfast till after dinner. One of the positives, which can also be a challenge for certain residents, is the close-knit social setting. Think in terms of dormitory living, including noise levels and shared bathrooms. Finally, group home arrangements may be either state- funded or private pay. The availability of HCBS waiver supports often significantly affects the choice of living arrangements. It is important to note that rent HCBS covers only support services, not rent.

In Georgia, where I live, as in many states, health care licensing is required for all group homes. Under Georgia's health care facilities administration, two categories of group homes are recognized: community living arrangements (CLAs) and personal care homes (PCHs. A personal care home provides room, food service and certain personal services for two or more adults with disabilities not related to the owner or administrator by blood or by marriage. PCHs must be licensed by the Georgia Department of Community Health (DCH). It is, therefore, possible for two unrelated families to inadvertently create a private PCH by merely agreeing to rent an apartment or buy a home together for their adult children with special needs and split the costs of providing the services needed by roommates. A Community Living Arrangement is effectively a PCH where the residents are financially supported entirely by the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD). DBHDD attempts to limit both PCH and CLA group homes to no more than three or four "clients" (adults with special needs) at any one time, although some CLAs have up to six, and on occasion more, individuals living there.

Assisted Living Facilities

In Georgia, a specific sub-type of PCH is one which provides additional services, such as the administration of medication and direct assistance with other essentials of daily living; for example, eating, bathing, grooming, dressing and toileting. These are known as assisted living communities and can serve 25 or more residents. In some ways, these assisted living communities resemble assisted living facilities for the elderly, and with public policy now demanding greater community access for individuals with a disability, are not in favor and are becoming harder to find.

In addition to assisted living communities, Georgia has a few intermediate care facilities, which are residential facilities for individuals with intellectual or developmental disabilities that severely impact the essentials of their daily living. Only if the facility is run by DCH or one of its contractors are the costs of such care covered by Medicaid, and those facilities tend to resemble traditional nursing homes.

Private Choice Communities

These communities are usually much larger than typical group homes, are often found in rural settings (though sometimes in suburban or urban neighborhoods) and usually include one or more central buildings containing such amenities as classrooms, art and community activity areas, a gymnasium, quiet room and clinic. Housing frequently consists of separate cottages or larger homes with or without full-time staff assigned to serve as a “house mother/father,” depending upon the needs of the residents. These facilities will often offer group activities, outings and shared chores such as gardening, kitchen duty and common area upkeep. Activities may include horseback riding, swimming, tennis and exercise classes, as well as shopping trips, evening movies and the like. What is most important for parents and individuals with disabilities to understand is that these facilities are almost exclusively private pay. Because of the institutional nature of the arrangement, residents seldom qualify for Medicaid or other government supports. For those individuals with special needs whose families have seen them thrive in these communities, the new Medicaid community-based settings rule is particularly frustrating—especially when Medicaid funding was being made available prior to the issuance of the community settings rule.

Skilled Nursing Facilities

Individuals who require skilled medical care 24/7 may need to live in a skilled nursing facility if it is impossible or unsafe to provide such care in the individual’s private residence or a group home. Institutional facilities like nursing homes are the last resort for most families and for most Medicaid agencies. For those with severe special needs, it may be the most appropriate option, so that family members do not become full-time caregivers, which can be extremely isolating for all involved.

Host Homes

In certain circumstances, where someone with special needs requires continuous care throughout the day, an unrelated family may be reimbursed for their time and for opening their home to the individual. Host homes must be licensed by the state and/or approved by the Medicaid agency, but when appropriate, the cost is covered by the state Medicaid program.

Finding the right independent living arrangement for a family member with special needs requires patience and study to finally determine what arrangement will be the best fit. As a parent or guardian, it means doing your homework, a topic that will be covered in more detail in a subsequent article, including a physical visit and inspection of prospective living accommodations with your family member.

Just as important as finding the right “place,” is understanding how that living arrangement is going to be funded. If relying on their own resources, the family will have freedom of choice and full control over the facilities and services provided. However, if they must supplement their resources with Medicaid services, their choices will be more limited.

Please heed the advice of professionals and begin the transition process long before an emergency occurs, precipitating and a complete, sudden and unexpected change in the life of your child with special needs.

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