

HOUSING



Letter of Thanks

Thank you for reading this collection of stories from individuals with intellectual and developmental disabilities, their families, and housing professionals in Tennessee.

The stories were collected through interviews conducted by Vanderbilt University students as part of the 2021-22 *Tennessee Kindred Stories of Disability* project. This annual project gives students who plan to be future educators, advocates, and researchers an opportunity to learn firsthand from individuals with disabilities, families, and disability professionals. The project's culminating booklets are shared with legislators and policymakers each year to educate them about issues that impact their constituents with disabilities.

We would like to thank the individuals who shared their stories this year. As the interviews took place in 2021 during the COVID-19 pandemic, there were added challenges. The interviews were conducted virtually, and we truly appreciate the flexibility of everyone involved. The booklet does not include every story we heard, but all were equally compelling and shared similar themes about housing experiences. The images that accompany the stories were taken by

photographer Jen Vogus and members of the AbleVoices Photography Club. We are so grateful for the partnership with AbleVoices, which provides photography programs for individuals with disabilities as a means for self-expression, empowerment, and advocacy.

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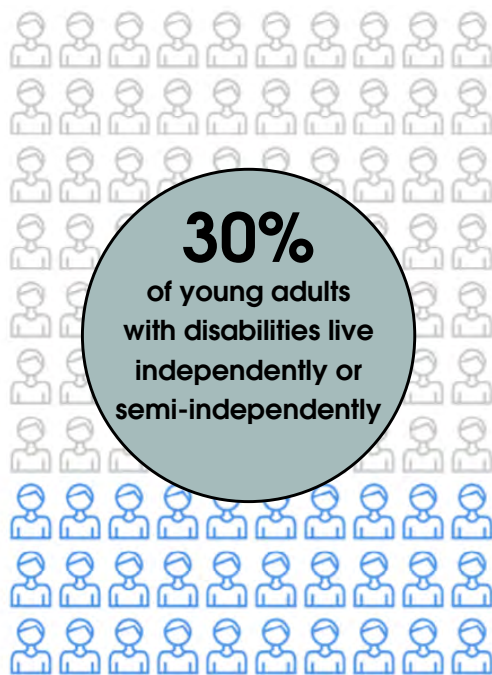
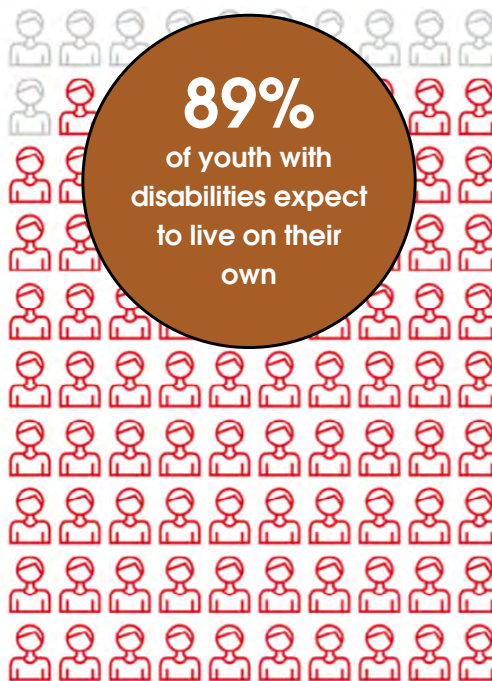
**To view online collections of Kindred Stories, visit
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Introduction

A major concern that adults with intellectual and developmental disabilities and their families face is deciding where the individual is going to live when he or she is an adult. There are many factors that play into this decision. Although more and more housing options become available in today's society, unfortunately, access to these options proves to be challenging for adults with disabilities.

Just like their typically developing peers, individuals with intellectual and developmental disabilities also strive to live independent, meaningful lives. Community living provides that opportunity. Community living and participation is defined as the opportunity to choose where an individual lives, with whom, and other details of his/her housing experience. Being able to participate in community living allows individuals with disabilities the possibility to live a life that they want for themselves. However, major obstacles hinder these individuals from participating in community living. Studies have shown that 89% of youth with disabilities expect to live on their own, however, only 30% of young adults with disabilities live independently or semi-independently.



The stories in this edition of *Kindred Stories of Disability* come from self-advocates, family members of individuals with disabilities, and housing facilitators. Even though individuals with disabilities strive for independent living, most often a variety of challenges prevents them from achieving this goal. Unfortunately, this pattern is replicated across the nation, and countless individuals with disabilities are impacted by limited access to community living.

The most consistent factor preventing individuals with disabilities from accessing community living is **affordability**. According to Technical Assistance Collaborative, also known as TAC, the average income from Supplemental Security Income is only \$794 per month, while the average rent for a one-bedroom apartment is \$1,063. This difference makes it almost impossible for individuals with disabilities to have the chance to live independently, which contributes to the fact that 75% of individuals with disabilities live in a family or friend's home. And unfortunately, affordability is not the only issue families and individuals face when looking at housing options. Lack of supports available, no community engagement, accessibility problems, and many other factors impact their ability to live where they so desire.

The stories in this booklet highlight the trials and tribulations individuals with intellectual and developmental disabilities and their families face in Tennessee as they seek to meet their goals for housing.

Supplemental Security Income is only \$794 per month, while the average rent for a one-bedroom apartment is \$1,063.

Albert

My name is Gabi. I have lived in Tennessee since 1999, and I currently alternate between living in Knoxville and Nashville. I live with my son, Albert, who is 19 years old. Albert was born with a brain malformation that caused epilepsy. He took many medications to stop the seizures, so to help him take fewer medications, a surgeon removed part of his brain. The surgery caused hydrocephalus, leading to the need for a shunt. The shunt stopped the seizures, but issues with the shunt arose. A surgery to fix the shunt led to horror, as a medical error during the surgery caused Albert to become unable to walk. Now, Albert uses a wheelchair, has functional use of only his right arm, and has a very weak body. Because of that, he depends on me for all of his daily living activities. Albert goes to therapy every day for various needs, but he is still dependent on me to help him with his daily activities.

Our current housing situation is complex. We split our time between Knoxville and Nashville. Albert's medical complexities require many visits to his doctors in Nashville, but Albert's father and sister live in Knoxville. Currently, we live in a condo when we are in Knoxville, and we rent a hotel in Nashville.

This situation is not our ideal situation. Our goal is to live in Nashville, because that is where all of the best doctors are to support Albert. Currently, commuting between Knoxville and Nashville is almost impossible to do. Yet, there are significant barriers that prevent us from living in Nashville. Majority

of the housing in Nashville is either not affordable or not accessible. The social security income that Albert receives would not cover rent in Nashville. The affordable and/or free housing available in Nashville have incredibly long wait lists. We have applied to countless places only to be told that nothing is available.

To make housing more challenging, not only is the housing expensive, but it is typically not accessible for Albert. We need a place with medical equipment to support his needs. Ideally, we would love to get out of an apartment and into a house. This would provide space for medical equipment and reduce the amount of travel we must do to get therapy, but this option is not affordable.

I would love for Albert to live in community housing, but it is challenging for me to allow anyone to care for Albert after what happened to him with his medical error. Albert living without me right now is not an option. I cannot leave him with strangers after what happened to him. Maybe when the time comes sometime in the future, but not right now. Also, it seems that all community housing requires a level of independence from people that Albert currently does not have. I wish there were a community housing option that were accessible and affordable that would allow both me and Albert to live with people in similar situations. Yet, until that is an option, Albert and I must continue to live in situations that are not ideal. We need more of



Top: Albert sits outside the garage where all of his belongings are stored until he finds a place to live.

Right: Albert and his mother, Gabriela, stand outside of the hotel where they stay in Nashville.

the community. He will make friends in the community. The question is, how much does the community want Albert? How open is the community to Albert?

We understand the importance of advocacy and policy. We have attended Disability Day on the Hill since 2016. We need legislators to know that this is an issue. It is an issue everywhere, but some places have it harder than others. We need to focus on supporting the development of housing that is safe, affordable, and accessible—little by little, we need to all be working on that together. ■



Ian

My name is Ian. I am a 34-year-old self-advocate. I've lived in Tennessee for most of my life. In high school, I played basketball and went to prom. I had a lot of friends, and I dated a bit. At that time, I wanted to go to college and continue playing ball. I didn't have a clear plan, but I thought that after college I might become a police officer. I also wanted to live on my own.

After graduating, I spent a few months going to TRC (Tennessee Rehabilitation Center). It's a place where they help people learn how to get a job or live on their own. It wasn't the best fit for me though, so I didn't stay there very long. I stayed at home for a while after that, then I had an opportunity at Vanderbilt. They were helping people with disabilities find jobs. That's where I got my first job. I've had a few different jobs since then. I've also lived in a few different places, sometimes with roommates. All those experiences brought me to where I am today.

Rent makes it really difficult for people with disabilities to be where they really need to be.

I currently live in a Friendship House through Our Place Nashville. I've been here for about five years now. About four or five of the residents are graduate students at the Divinity School, and four or five of us have disabilities. We have our own apartment units, but the facility has a community center space, too. I like living in my own apartment. It's nice and quiet.

I also really enjoy that all the residents have dinner together on Monday nights. It's a great time to catch up and see how everyone's week is going. It's nice to know that there are people around me that I can talk to, especially if I ever have any questions or get into a bind. We also get together once a month to talk about the rules and how things are going.

I've had some assistance to be involved in the community, such as volunteer experiences and going to the grocery store twice a week. I have a Best Buddy that I hang out with about once a month, too. I also like working out at the YMCA, visiting family, and going to work.

I've worked at Krispy Kreme for six years now. I work there three days a week. It gets really busy on the weekends. I work early mornings, and I drive myself. My favorite thing about my job is the doughnuts, of course.

The biggest barrier about housing is the cost of rent. I can't pay for my expenses with the money I make at Krispy Kreme. My mom



Top: Ian stands on the balcony outside of his apartment of Friendship House #2. **Right:** Ian stands in the living room of his apartment and shares about the photos of family and friends he hung on the wall.



pays for a lot, and she gives me gift cards to go places. I couldn't live where I live without her. Rent makes it really difficult for people with disabilities to be where they really need to be. Some of my friends still live at home with their parents.

I think people should help raise money for housing. Benefit nights are a way to raise money. We do things like that with Our Place Nashville.

It would have been helpful to learn more specific knowledge (about living on my own) in high school. There are three main things that would have been helpful to learn about: how much rent would cost, what types of jobs would be a good fit, and how to save money. I think if we would have learned those things, things would have gone pretty well – for me and for other people like me. ■

Amelia

My name is Amelia, and I am a mother to four children, ages 27, 25, 23, and 22. Two of my children are on the autism spectrum: my oldest daughter, who is pursuing a master's degree in social work, and my 22-year-old son, Carter, is in his last year of high school.

Carter enjoys playing video games and working at Kroger. However, he does need help with self-management, medication management, and various daily living skills. Due to Carter being in his last year of high school, we are deep into the transition planning period. While the process as a whole can feel overwhelming at times, one area that we are still struggling with is housing.

As of right now, Carter lives at home with me. Since he is still under my roof, I am in charge at home and can make sure that he gets to exercise every day, that he has ways to earn money, and that he stays involved in various activities. Carter and I are best friends, and we have a great time together, but I am almost 58 and starting to worry about having him home indefinitely. Upon realizing that Carter would need housing assistance, I began begging to be moved to Group 6 of the ECF waiver.

Eventually, I was able to get Carter in a group home down the street from my house. I was so excited about this opportunity, but Carter was not. I knew it would be a big change, for both of us, but I was hopeful that being a short walk away would make the transition smoother. However, within five weeks, he was back at home with me. During his time in the group home, he lived with two other young men with autism but, unfortunately, the house was not adequately staffed. There were a lot of times that caregivers didn't even have a car, and the boys could not go anywhere. Medication was laying out unlocked and free for anybody to come along and take. This was especially upsetting for me, since Carter is a pill taker, and after the third time I saw the medication left out on the table, I just said, "You know what? This is not working out." This country has a caregiver shortage because they don't pay the caregivers enough to have a robust workforce of people that are confidently trained and have some experience with people with disabilities or behavioral issues. This shortage was ultimately one of the main reasons that Carter moved back home with me.

The Employment and Community First (ECF) CHOICES program is administered by TennCare and offers services to help people become employed and live as independently as possible in the community.

After learning more about what was provided ... I thought to myself, “Oh, my gosh, nobody can afford that.”

When he's home, I can make sure he gets amazing care. While I do love having him home, I want him to thrive outside of my home on his own. These young boys' home setup was not a perfect scenario, but I know that out there – somewhere – there is a near-perfect scenario. I often think back to one of the first times I learned about a residential school for individuals of all ages with intellectual disabilities in Kentucky. After learning more about what was provided and hearing the cost of tuition, room, and board, I thought to myself, “Oh, my gosh, nobody can afford that.” It was hard to realize that there are incredible places out there that would provide my son with everything a parent could want but is still entirely out of reach for nearly anyone. Trust me, I've thought of a lot of different ways to get there, but it's hard when you're in the day-to-day trenches. It's hard to have the time and the mental space to move forward on any big idea, especially if it's just you.

I've considered moving to another state with the hopes that it would be better, but when you've been in a place 20 years and you have an established life and friends and support, the idea of just picking up and moving to a strange place, knowing no one, and leaving your family behind, to put your loved one in a great situation is a lot to ask. I wish it wasn't that hard, but it is what it is. Don't get me wrong, I do appreciate what's already been available, but I think that it's going to take people in power having a personal investment in the matter to make a change. Unless there's that personal investment in something, the passion, it's not the same. Maybe we need to work on making contact with people that have the power, because it's just words on paper right now. I have a hope that Carter will find a place to live that meets his every want and need, but right now there are barriers. Beyond the barriers, there's a lot of people that can't advocate for themselves. Their voices are going unheard. We need to continue to advocate for quality, meaningful lives for people with disabilities and a vital part of that is housing. ■

Jack

My name is Jack Spencer, and I am 60 years old. I am originally from California. I have lived in the state of Tennessee since 2004. I have many interests, am involved in several volunteer organizations, and enjoy taking part in an array of community projects.

Two of my greatest enjoyments are serving on the State Independent Living Council and being an ADA (Americans with Disabilities Act) adviser to the city of Paris and a few private institutions.

When I was in elementary school, I was diagnosed with learning disabilities. When I was 40 years old, I was in an accident that now requires me to use a wheelchair. I have gained enough strength to transfer from one place to another, but I really cannot walk at all. Up until the time of the accident, I worked several jobs and was never unemployed. Since my accident, however, I have not been able to find steady work. I am currently on disability support, but I do love to volunteer in my community.

Until May 2021, I was living alone in an apartment out in Paris, Tennessee. I had paid my rent on time every month for seven years without a problem. About a week before my 60th birthday, I received a knock on the door. It was my landlord notifying me that I had 60 days to move out. He claimed that I was not able to keep up the apartment to the standard to which he

desired. I argued that I did not understand; the apartment had been maintained and mostly cleaned for the past seven years. I had to admit, utilizing a wheelchair and navigating tight spaces such as a bathroom posed some challenges when it came to

maintaining cleanliness, but I did not believe it to be so bad to the point of eviction. Although I truly believed this, and I knew that I had not been in the wrong, I did not want to argue further because I did not want an eviction on my record.



After much stress and worry, a friend of mine who was living with a roommate offered to

allow me to live in their home. About 10 days after that knock on my door from my former landlord, I moved to the small town of Greenfield, Tennessee. I went from living alone in my own apartment to sharing a small, one-bedroom home with two roommates who also have physical disabilities.

After being settled and knowing that I had a roof over my head again, I went back to investigate what happened at my former apartment. I first found out that it was not only me that was threatened with eviction, but three other residents were threatened with eviction. I also discovered that this landlord wanted to raise the rent on all the apartments. Because of one reason or another, he did not believe that we would

be able to afford the rent increase, so he decided to evict instead. Once I knew this, I decided to weigh my options. One option would be to get a lawyer, go to court, and hope that the verdict lands in my favor. I know the basic knowledge that individuals with disabilities have rights, and I could have done more research. But my biggest concern was that if the courts did not side in my favor, I would have an eviction on my record, making it nearly impossible for me to ever find my own housing again. I decided not to fight it.

My dream, even after all of this, is to live alone again. I am a very independent person, always have been. I love my family and even lived with them for a time after my accident, but I've never been married, never had kids. I enjoyed living on my own. Although I am very thankful to my friend for giving me a roof over my head and roommates that can help me with certain things, especially the cleaning, I want to be able to live alone again. The problem, however, is simple: waiting lists are long and there are not enough subsidized houses to go around. I, myself, have been on waiting lists for subsidized housing for six or seven years, even before my eviction. The COVID-19 pandemic has only exacerbated this problem. Sometimes, it feels as if the process is nearly impossible.

My vision for the future would be to create communities of group homes. Some people want to live alone, and some people want

roommates; group homes would be the perfect solution. The key to these kinds of developments, however, is to make them affordable and to have the property to create them. The possibility of creating a mass movement of people with disabilities living independently while still helping each other creates hope. I often think about how, when people see me in a wheelchair, they want to run and open doors for me and grab things off the shelves, which don't get me wrong, I'm very grateful for. I often worry, however, that people look at me and think I am constantly looking for people to offer help. I want people who are not disabled to know that we're able to do these things for ourselves; we, in fact, need to. We need to do these things for ourselves to stay independent, to maintain our own skills. We are not ungrateful in the slightest, at least I am not. But having that conversation is often touchy, but one that I think is very important. We want the greater population to know that we are just as able and capable.

I often find myself reflecting on my life before the accident. Before, I would wake up and go to work. Now, I find myself having

a purpose, giving myself a clear mission in life. A personal mission of mine would be to find a place where I can live independently. A further mission, is to see change in

the world of disability rights. I hope to one day see a world where we do not have to be afraid to fight for our rights. I hope to one day see a community built where we can live independently and govern ourselves. ■

The problem, however, is simple: waiting lists are long and there are not enough subsidized houses to go around.

Carolyn

My name is Carolyn, and I am the co-founder and executive director of Our Place Nashville, a non-profit organization dedicated to optimizing outcomes for individuals with intellectual and developmental disabilities (IDD). These individuals, more commonly known to us as “our friends,” are afforded the opportunity to immerse themselves in community living where independence and a sense of family are formed. A close friend of mine has a son with profound disabilities, and as I watched her navigate the journey of parenting, I began to feel badly that she had to carry such an immense weight while I was spared that hardship. This was a turning point in my life, and I began to realize that I had a moral obligation to fill the existing needs in the world of disability. As I pondered my role in contributing to this community, I focused my attention on housing. It was extremely disheartening to understand the incredible

Without financing to build more affordable housing options and to find staff to provide services in these homes, it is impossible to meet the needs of this vulnerable population.

lack of affordable living options that exist for our friends with IDD, so together with Jaco Hamman, I stepped away from my previous occupation and began working on what would become Our Place Nashville.

The definition of community living is dependent on the individuals who live in that community. Yet the goal always remains to bring people together to form a cohesive unit and enjoy each other in the way that family does. Community living evens the playing field for our friends. It provides them with access to amazing jobs and enables them to participate in and contribute to society at large. Most importantly, community living provides our friends with the opportunity to be ambassadors for individuals with disabilities. Many of the challenges that individuals with IDD face, such as difficulty securing transportation and feelings of isolation, are solved by living in a community of friends. Everyone pitches in to help one another.

The greatest challenge that I see working at Our Place Nashville lies in the lack of funding for housing and services specific to individuals with IDD. Without financing to build more affordable housing options and staff to provide services in these homes, it is impossible to meet the needs of this vulnerable population. Our community living center is dependent on the generosity of donors and fundraising events. The COVID-19 pandemic has forced us to put many of these fundraisers on hold. Our friends rely



Top: Carolyn sits at the kitchen table and talks with Sloane and Ernie, two residents of Friendship House #4. **Right:** Carolyn stands outside the front door of Friendship House #4.



on housing in urban areas with public transportation to thrive, and as Nashville grows and develops, it becomes increasingly more difficult to find community living options. It is critical that our friends have the ability go out into the Nashville community and educate people on their specific needs and challenges. Without community living as an option, our society will potentially miss out on a whole generation of capable and inspiring advocates for individuals with IDD.

I encourage our government and community leaders to be honest, recognize the needs of our community of friends, and then do anything possible to make sure those needs are met. At the end of the day, we all should ask ourselves, "What would we do if we were in their shoes? How would we want to be treated?" Then the reality of the situation becomes much more relatable, and that is where transformative change begins. ■

Julie

My name is Julie, and I am a single mother of two children. My son, Bryan, is 24 years old and has autism. Bryan and I live together in an apartment in Mt. Juliet. We moved about four years ago from Illinois. Because Bryan will never be able to drive a car, I chose an apartment in an area where he could walk to the places he likes to go. I want him to be as independent as possible. Bryan likes to play video games, is a very social person, and has a heart of gold. In our current living situation, he's lacking community engagement and opportunities to become a self-advocate. His goal is to someday have his own place to live in an assisted living community, but we have encountered challenges along the way.

When Bryan turned 22 years old and aged out of the school system, things suddenly shifted. He had been receiving services that helped him in many ways as well as provided ways to support me so that I could help him, too. Now there is no clear

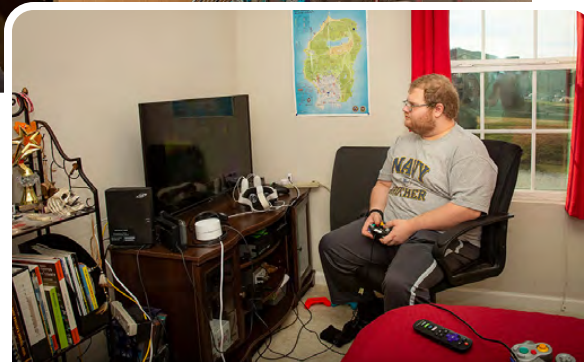
path. Our school district did a wonderful job of being proactive and pointing us to a state-operated training center for Bryan to attend after he graduated. They felt this would be the best next step for him, and we had a plan designed for him once the program was over. He would spend 18 months there, where he could take classes, live on campus, and gain valuable life skills. Once completed, he would be placed in an assisted living situation. All of this was put into place by the school district. However, everything fell apart after the start of the global pandemic. Because of COVID-19 and a lack of funding and staff, Bryan has been unable to start this next chapter.

We have been given little information as to when he will be able to move onto campus and start this program. Communication from the facility to students and their conservators has been practically non-existent. The most painful part was in September of this year, when everyone we knew across the country was back in school, from kindergarten to college, except Bryan. My son has been denied that opportunity. He is fully vaccinated and willing to wear a mask and cannot understand why everyone but him is allowed to attend school classes in person. Without the life skills experiences from this program, he cannot move forward to look for employment and eventually live successfully in his own apartment. Not being on campus means Bryan isn't getting the social interaction and community engagement he really needs to thrive.

We are missing the scaffolding of services that he needs so that he can work toward living more independently.



Top: Julie's son, Bryan sits at his desk in his bedroom, where he spends most of each day. **Right:** Bryan plays video games in his room to pass the time until he can receive services to help him live more independently.



We were directed to contact another state-run service to look for housing and filled out a lengthy questionnaire. We were told that Bryan was on the waiting list, but that it would be at least two years until he was able to receive any services. It was communicated that the funding was gone and, because he wasn't in a crisis situation in his current living situation, he did not qualify for assisted living. There has been no acknowledgement of what has been taken away and why.

Conservators and families are left out of the conversations and kept in the dark. The silence has been deafening.

We are currently in a holding pattern but are working with Disability Rights Tennessee. It feels like we're at a deficit now. Bryan is already 24 years old, and we may need to wait two more years for any services that can help him move closer to attaining his housing and life goals.

I have to jump through a hundred hoops all by myself, trying to find the right person with the right information, and it's just not there. There is no clear path.

This was the first time I've ever felt like my son is truly being discriminated against. Other people are getting what they need, but what Bryan needs to live a better life is quietly being taken away. The support has diminished without any conversation with conservators. It's just gone.

The front door to this programming and how to get there is invisible. I have to jump through a hundred hoops all by myself, trying to find the right person with the right information, and it's just not there. There is no clear path. The reality is that I am 55 years old. I have been the sole caregiver for my son for 24 years and there is no end in sight. I'm at a point where not only is Bryan not getting what he needs, but my life can never be mine unless the right programming is there to help Bryan. He is ready to take the next step to live more independently, but it takes a village. It feels selfish to talk about myself and my needs, but I won't be here forever, and I want to make sure I can give Bryan what he needs so he can live as independently as possible, and I can feel confident that he'll be okay. That is the biggest fear for most parents who have a child with disabilities: the fear of the day when they're not here anymore.

I believe there should be a highly structured program for people with cognitive disabilities once they graduate from high school. Families should be able to go to the State of Tennessee website and find clear information on independent living options. This should be the front door. Maybe there should be minimum requirements, and people can fill out applications to determine what an individual's first steps should be and how they can be accomplished, moving them toward their desired living goal. A professional can do an evaluation to decide what each person needs and then helps families walk through the process, step by step, defining a clear path that works well for everyone.

I think lawmakers can help us by making an effort to reach out to organizations that are supporting people with disabilities. Instead of making a policy based on their personal world view, they can engage with different groups and let the people speak for themselves, or let their conservators speak on their behalf. It's critical that we hear from adults on the autism spectrum and adults with other disabilities who are going to be impacted by legislative decisions. I'm not just advocating for Bryan; I'm advocating for his peers and their families. I'm also speaking up for the caregivers who have rights, too. We rarely step up and say, "What about me?"

If Bryan were not autistic, he wouldn't be Bryan. He may not ever be able to fully support himself financially, but he can do something. He has the ability to contribute to his own personal care at some level as well as live a bigger life and contribute more to society. He has so much to share with the world. ■

Bryant

My name is Bryant, and I am 24 years old. I am from Franklin, and now I live in the dorm at Lipscomb University. I am a first-year student in Lipscomb's IDEAL Program, and I live with one roommate, a second-year student in the IDEAL Program. Some of my hobbies are sports and photography. I love the Boston Celtics, and I really like getting to watch volleyball and basketball games at Lipscomb. I also love having a job! When I was in high school, I worked at a few different places: Columbia State, Williamson Medical Center, and Chick-Fil-A. Now, I have an on-campus internship with campus security during the week, and I work at Publix on the weekends.

I moved into the dorm at the beginning of this semester, and this is the first time that I have lived somewhere outside of my family's home. Growing up, I wanted to live at home with my parents when I was older. When I was accepted into the IDEAL Program, I started to think about living in the dorm. I like the freedom and responsibility of living in the dorm. It's really important to me to be independent and living in the dorm is a way that I can be more independent. I like being able to cook my own food, clean, and wash my own clothes. I like being able to drive myself to work and back home to visit my family on the weekends.

I also really love the things I get to do because I am living in the dorm at Lipscomb. I've learned how to keep track of my own schedule and make sure that

I'm on time to my classes. I am getting the chance to gain more experience working through the IDEAL Program. This year, I am doing an on-campus internship with campus security. Next year, I will get to do an off-campus internship. I also love getting to hang out with my friends. My roommate and I get along really well. We watch Disney movies and talk about school. I have a great group of friends in the IDEAL Program. We go to class together, eat together, and go to Lipscomb sporting events together. We've even had events such as karaoke and campfires at the dorm hall!

When I consider my future goals, they are all centered on being independent. I really love my job at Publix, but my dream job would be in sports photography. I would love to someday take photos for the Nashville Sounds or Titans football. Living on my own is also very important to me. I would love to live in an apartment or house and have my own bedroom and bathroom. I would even enjoy living with friends. I think it would be really fun to learn to cook food together and have movie nights. My dream home would have a garage for my truck, and I would also love to have a porch outside with a fireplace and television for watching football and basketball games!

I have enjoyed my time in Lipscomb's dorm so far, but I look forward to having my big bed again. It can also be challenging to live in a space with a lot of noise. It's often loud in the dorm, and loud noises can

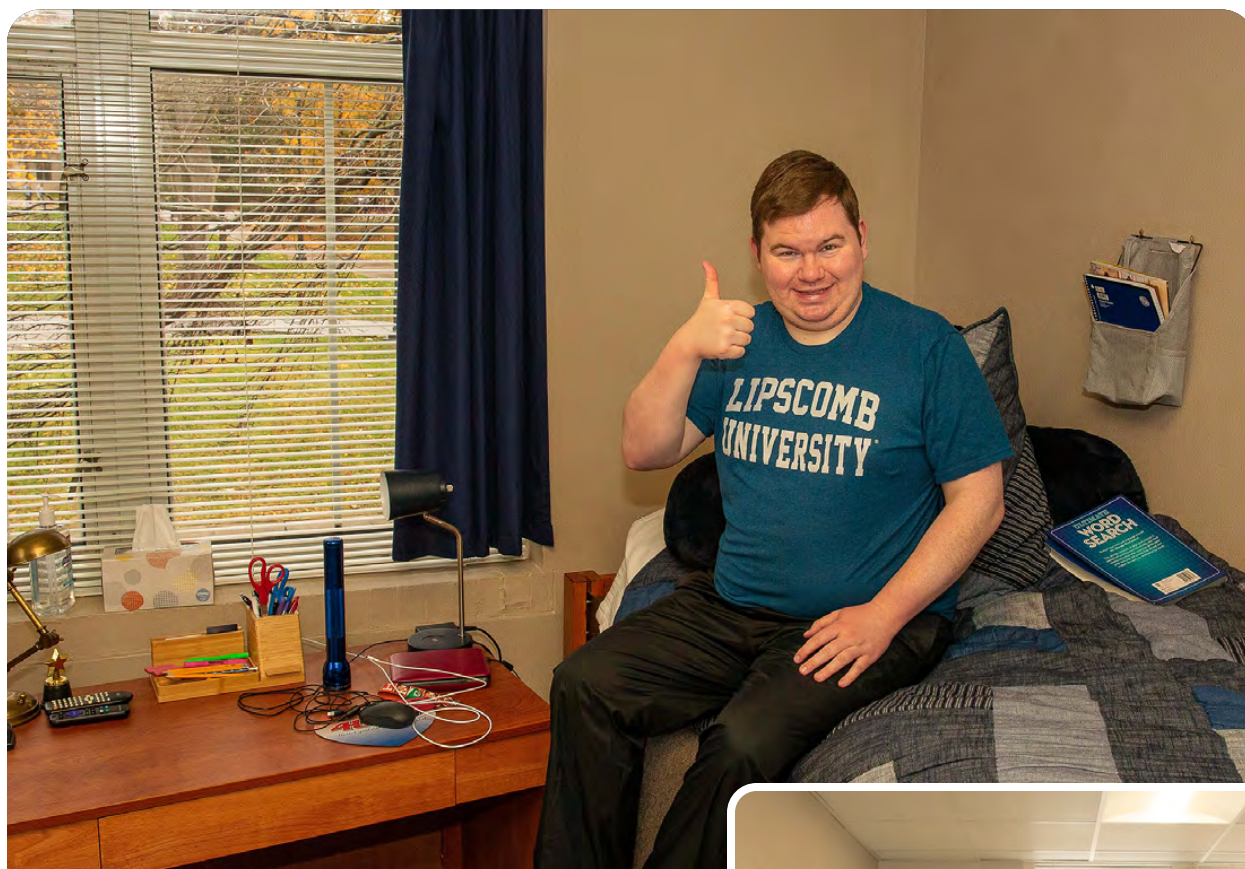
When I consider my future goals, they are all centered on being independent.

be overwhelming for me. Ultimately, it is important to me to continue in my journey towards independence, eventually living in my own place and being able to choose my living situation. I never want to be in a government placement or forced to live somewhere that I do not feel comfortable.

One thing that would have benefitted my first experience living on my own would be opportunities to practice independent living beforehand. Before Lipscomb, my schooling helped me strengthen many skills I would need after graduating, but I would love to see schools do more to help students practice independent living, preparing students for this transition. For example, a “retreat-like” option for students before they graduate could be a promising way for students to receive guidance and growth in independence. While I have had a really positive experience in Lipscomb’s IDEAL Program, there have still been challenges. There are many aspects of community living that can be challenging, such as laundry, cleaning, and asking for help with things like repairs. I have also learned a lot about managing my time throughout the day now

that I am living on my own, and having more practice could have helped me with this. Schools could help students by supporting them through practice, while tracking and monitoring their progress. Then they could help evaluate strengths and weaknesses for students.

Overall, my experience at Lipscomb has been especially positive. This has been a great place for me to begin my journey towards independence, and I am so grateful for the support I have received through Lipscomb’s IDEAL Program. Community engagement and availability of necessary support can often be issues for individuals looking to transition into community living, but this is something that I have had a great experience with through Lipscomb. This opportunity has helped me grow in skills I can carry with me forever, and I think it has helped prepare me for my future goals in independent living. I hope that more colleges and universities will take steps towards providing student programming that can meet the needs of students with disabilities and set them up for success. ■



Top: Bryant sits in his Lipscomb University dorm room that he shares with his roommate.

Right: Bryant enjoys doing laundry on his own in the dorm whenever he needs to.



Sadie

In the future, I feel like there is the potential of having more and more recipients in homes like ours – supported living homes with staff who respect and care about the clients they serve. Our goal in community living is to give *person-centered care*, meaning that individuals with disabilities living in supported homes have opportunities to make choices about their lives, from what they want to eat to choosing new roommates. They're involved in every aspect of their care, including their ISP (Individual Support Plan) goals.

The recent changes in funding have been a barrier to having more individuals with disabilities in person-centered community living arrangements that meet their needs. We have to plan their placement carefully based on client needs and income so that appropriate housing options will be available to them.

I've been director of Residential Services for a while, but I've been working in houses due to lack of staff, along with our organization's executive director.

Another challenge, aside from funding, is prospective clients' needs. Some adults with disabilities may need more structure or a more restrictive home setting than we can provide. If someone's needs exceed the level of support we provide, that restricts them from living in the community, because it may impact the others in the home. Some clients also have medical issues, and we do not have skilled nurses working in our homes. Instead, we must train our clients in self-care so they can give themselves insulin shots or check their heart rate.

We also need services that can deal with mental health in combination with other disabilities so we can grow and work with more clients. Currently, there aren't any therapeutic community living programs that can really tackle mental health issues along with other disabilities. Even though some disabilities should be primary, a person's mental health is usually overshadowed by their disability. Our current interventions don't solve the mental health issue, so we need some real treatment professionals who are trained in trauma and how it impacts our adults with disabilities. A therapeutic supported living home or agency with trained professionals would greatly benefit adults with disabilities who have experienced trauma. These supports would enable them to become more successful and could also help in deescalating crises as they arise.



Top: Sadie help residents, Barry and Justin, with their lunch. **Right:** Sadie stands outside on the front porch of a Prospect supported living home.



The last barrier we're experiencing right now is short staffing. I've been director of Residential Services for a while, but I've been working in houses due to lack of staff, along with our organization's executive director. Our priority is to ensure our clients receive proper care and can continue to enjoy their community. Therefore, our administrative team has spent a great deal of time in our homes recently. Retaining staff is difficult, because jobs in other fields can offer much more money than we have

available through our funding sources. And our staff must have a heart for this work. It's not a glamorous job, and you have to be willing to work through some difficult situations at times. This population is so appreciative of everything we do for them, and it's so rewarding. It's a heartfelt job, and I know we're making a difference by helping our clients live as independently as they can. ■

Kezia

My name is Kezia, and I am 32 years old. I have lived in Tennessee pretty much my whole life. I lived in Knoxville most of my life, and now I live in Nashville. When I was in high school, I thought about being a writer, being a poet, and doing art, and ultimately, I settled on wanting to be a tour coordinator for the music industry. Currently, I work at the hospital, but I also advocate for people like myself in my free time. I do a lot of advocating, and I'm hoping to be a paid advocate someday. I'm not going to say it's going to happen immediately; I'm just going to say I hope to be one someday.

For me personally, community living is about wanting to be independent. You want to be able to pay your own bills. You want to be able to say, "Hey, I bought this, and I didn't have anyone help me. I didn't rely on anybody, and this solidly mine." I feel

For people who are interested in community living, I want to tell them, don't give up.

that community living is great, but there's so much more we could possibly do. A lot of people, like myself, just want to be able to live on their own, but how? How can we make it possible for us as individuals to own a house? With disability and Supplemental Security Income (SSI) laws, it is very difficult.

Currently, I live in a house with two housemates. The house is owned by Caregivers, a home care company. My roommates and I do a lot of stuff together: we go bowling every Friday, and we go out on the weekends. My favorite thing about my current living situation is that I don't have to answer to anybody. I am my own boss, and I can do whatever I want. I would like to be living in a townhouse in New York or California with my cats.

For people who are interested in community living, I want to tell them, don't give up. There's always a time and a place for everything. You can be independent. You just have to convince not just yourself that you can, but your family, too. You have to try, because if you don't, you'll never know if you can. ■



Top: Kezia sits at the kitchen table of her house with her cat, Handsome. She enjoys arranging flowers to brighten up the room. **Right:** Kezia often cooks meals for her and her roommates.



Resources

Tennessee Disability Pathfinder helps people with disabilities, family members, educators, and other professionals find and access resources, support, and services through a telephone helpline and an online resource directory. TNPathfinder.org

Vanderbilt Kennedy Center, Tennessee Council on Developmental Disabilities, Tennessee Departments of Health, Intellectual and Developmental Disabilities, Education, Human Services/Division of Rehabilitation Services, and Mental Health and Substance Abuse Services.

The **Housing and Services Resource Center** was created for people who work in the organizations and systems that provide housing resources and homelessness services, behavioral and mental health services, independent living services and other supportive services, and others who are working to help people live successfully and stably in the community. acl.gov/HousingAndServices

Administration for Community Living

The **Residential Information Systems Project** (RISP) is a longitudinal study of long-term supports and services (LTSS) for people with intellectual and developmental disabilities (IDD). An annual survey of state IDD agencies is used to gather information about the settings in which LTSS recipients live, federal and state funding sources, residential setting type and size, recipient age and expenditures. risp.umn.edu

University of Minnesota

About Us

Vanderbilt Kennedy Center for Excellence in Developmental Disabilities

Provides innovative leadership in education, research, and services to people with disabilities, the community, and families. All activities promote the independence, self-determination, productivity, integration, and inclusion of individuals with developmental disabilities and provide supports for families. vkc.vumc.org/ucedd, (615) 322-8240 or toll free (866) 936-8852

The Arc Tennessee

A statewide advocacy organization that empowers people with intellectual and developmental disabilities and their families to actively participate in the community throughout their lifetime. thearc.org, (615) 248-5878 or toll free (800) 835-7077

About the Photographer

Jen Vogus is a photographer, educator, and parent advocate. She is also the founder of AbleVoices (ablevoices.org), a nonprofit organization that teaches photography to individuals with disabilities as a means for self-expression, empowerment, and advocacy. Jen is a graduate of the Tennessee Council on Developmental Disabilities' Partners in Policymaking Leadership Institute and a board member of The Arc Tennessee. Vogus was assisted during the photo shoots by AbleVoices Photography Club members Wilson Brim, Sami Zinni, Alex Balkon, Steven Greiner and Brock Bordeau.



A lot of people, like myself, just want to be able to live on their own, but how? With disability and Supplemental Security Income (SSI) laws, it is very difficult.

Tennessee Kindred Stories of Disability
vkc.vumc.org/kindred