



JUDGE DAVID L. _____
**BAZELON
CENTER**
FOR MENTAL HEALTH LAW

I am

OLMSTEAD

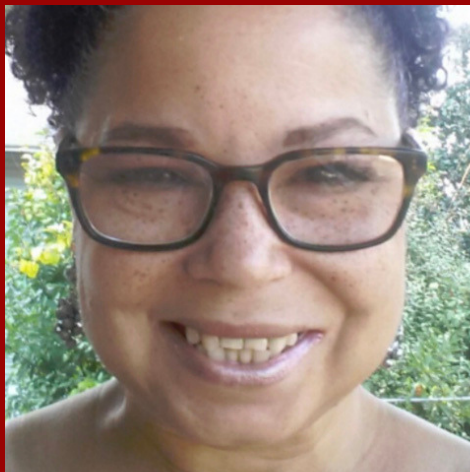


TABLE OF CONTENTS

1 Tashee's Story
4 ... Amanda's Story
8 Hector's Story
12 Gina's Story
17 Irene's Story
21 ... Jennifer's Story
24 Jessica's Story
28 Mary's Story
32 ... Williams' Story

The Bazelon Center for Mental Health Law gratefully acknowledges support for the research leading to the production of these pieces from

The Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
(under contract # HHSP233201600208A)

Tashee Dunsmore's Story

Thanks to her own unremitting perseverance, Tashee Dunsmore is now a certified peer specialist with a bachelors degree in painting and graphic design. Her initial experiences living in a group home full of routine and restrictions frustrated her, but with help from a peer specialist and other community providers, she moved into her own apartment. Becoming a peer specialist and working were crucial to her recovery and today she advocates for all people with mental health needs to be given input, choice, and the ability to have some control over their services and lives.

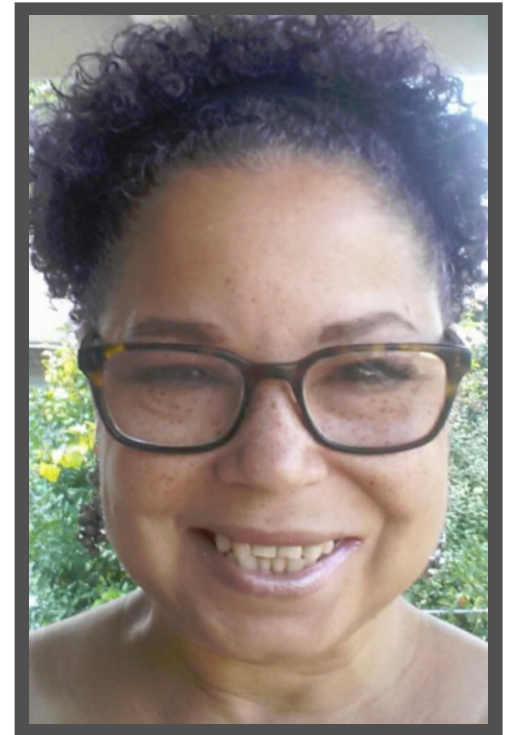


photo courtesy of Tashee Dunsmore

LIFE BEFORE

Tashee found herself hospitalized due to psychosis in 2007. At the time, she was in her 30's and had been living and working in the District of Columbia. She began to experience a psychotic episode and believed that people were conspiring against her. Tashee stopped working and moved in with her parents. In an effort to escape her paranoia, Tashee fled to Mexico where her condition worsened and she attempted suicide. She returned to the United States, choosing to go to Birmingham, Alabama, and was hospitalized there for about six weeks. Subsequently she was discharged to a group home, where she spent the next two and one-half years.

Tashee was miserable during her stay at the group home, a 10-bed facility. The fact that she had a boyfriend there made it more bearable, but she disliked the rigidity of congregate living. Everything had to be done as a group, including the most mundane tasks such as grocery shopping and meals. She had no say concerning what time to wake up, when to clean, and what to eat. Eventually, because Tashee was vegan, the group home allowed her to buy and cook her own food, but this privilege was not offered to anyone else.

Group home rules required residents to be in their rooms by 9 pm, and forbade her from even hugging her boyfriend. She was dissatisfied with most components of her day treatment program, which was mandatory for residents of the group home; the program offered classes that were not particularly useful to her.

The fact that she had a boyfriend there made it more bearable, but she disliked the rigidity of congregate living. Everything had to be done as a group, including the most mundane tasks such as grocery shopping and meals.

Tashee observes that, in addition to the impact of the routine and restrictions that characterize congregate living, the quality of life in a group home is heavily influenced by the staff. Tashee has experienced staff that were kind and understanding and others who were disrespectful and yelled at residents incessantly.

WHAT HELPED TASHEE

Tashee worked for several months while living in the group home. She was employed as a receptionist at a large hotel. However, nearly all of her wages were taken by the group home to pay for her care. Virtually none of the other group home residents worked, and no one was encouraged to do so.

When Tashee tried to enlist the help of group home staff to get her out of the group home, she was unable to do so. Without help from staff, Tashee herself learned about the Shelter Plus Care program, which provided eligible individuals with a rental subsidy and supportive services. She managed to get into this program and, with help from a peer specialist and a clinical director from a community services agency, to secure an apartment.

While she struggled at first in her own apartment, believing that people were surveilling her and that someone had put spiders in her apartment, her new psychiatrist prescribed different medications that were enormously successful in addressing her symptoms.

Tashee also got married, which provided a stabilizing force in her life. She began working as a peer support specialist, and helped individuals transition from a state hospital that was being downsized to group homes.

Tashee loved this work. She designed trainings for group home staff to help them learn to develop better relationships with clients. These trainings, which included role-playing exercises, were very well received.

TASHEE'S LIFE TODAY

She began working as a peer support specialist, and helped individuals transition from a state hospital that was being downsized to group homes. Tashee loved this work.

In her own home, Tashee has enjoyed the freedom to spend her own money on things she wants, cleaning and furnishing her house the way she wants, staying up as long as she wants, eating what she wants, having company when she wishes, and having the freedom to enjoy romantic relationships. She continues to live with her husband, and with the support of the state vocational rehabilitation agency, which paid for her college tuition, books, and art supplies she studied painting and graphic design, receiving her bachelors degree in Art in 2017. She also teaches art at a drop-in center.

Based on her own experiences and those of the many people that she has helped as a peer support specialist, Tashee believes that mental health systems would do well to focus more on serving people in integrated settings and affording them input, choice, and the ability to have some control over their lives. Designing different classes for different levels of functioning that are sufficiently interesting that people want to participate, and encouraging them to do so, is a more effective strategy than mandating participation. The use of peer bridgers, who afford individualized attention and invaluable guidance, should be maximized. Finally, service systems should encourage work as much as participation in day treatment programs.

She continues to live with her husband, and with the support of the state vocational rehabilitation agency, which paid for her college tuition, books, and art supplies she studied painting and graphic design, receiving her bachelors degree in Art in 2017.

The Bazelon Center for Mental Health Law gratefully acknowledges support for the research leading to the production of these pieces from

The Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
(under contract # HHSP233201600208A)

Amanda Farrell's Story

Now a peer specialist, Amanda spent much of her young adulthood bouncing between group homes and the state psychiatric hospital. Finding her own apartment to live in and working gave her a sense of independence and purpose. The most important change for her, however, was becoming a peer specialist, which enables her to make a good living doing what she loves.

LIFE BEFORE

As a young adult, Amanda was very depressed and suicidal due to traumatic experiences that she had undergone as a child. She had been seeing a therapist since the age of 13. The year after she graduated from high school, when she was living with her parents in Wisconsin, her psychiatrist prescribed an antipsychotic for her (even though she had never experienced psychosis).

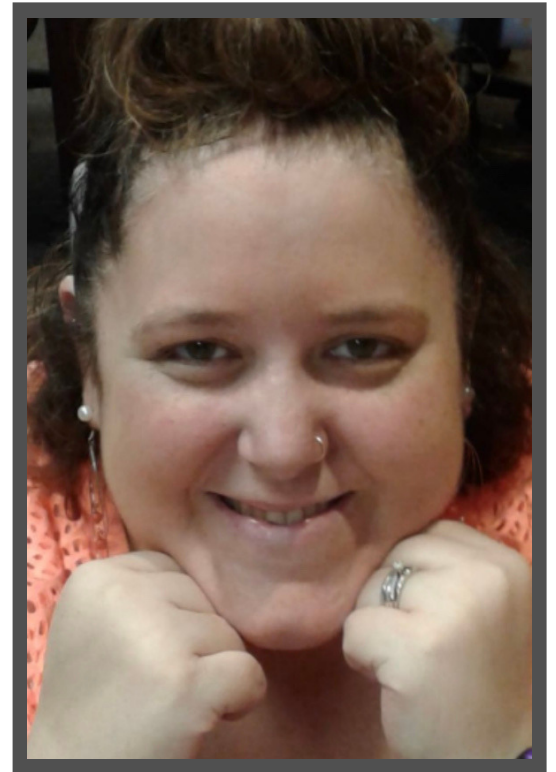


photo courtesy of Jennifer Farrell

The medication caused her to become psychotic; for the first time in her life, she had hallucinations. Three weeks later, she woke up at 5 a.m. with voices telling her to go outside and “get to the church.” She stumbled outside and began wading through a nearby lake toward a church. When exhaustion overtook her, she began floating on her back. After she had been floating for hours, the police found her in a catatonic state and brought her to the hospital.

She was found a danger to herself and involuntarily committed to a psychiatric ward at a hospital. Shortly after, she was discharged to a group home, where she stayed for about six months. At the group home, she was often subject to restrictions for her boisterous behaviors, such as spraying people with hoses. She was denied the freedom to enjoy intimate relationships and was punished when she engaged in them. Sometimes she was forced to sit in a chair all day and copy words from the dictionary. Eventually she was sent to a state psychiatric hospital.

Amanda spent the next six years bouncing back and forth between the state hospital and group homes. During her first admission to the state hospital, she sometimes tried harming herself and was forced to sleep in the hallway on a blanket placed on a cement floor so that staff could watch her. When she was placed on the lowest possible “privilege” level, she would be locked in a geri-chair for hours. During her second admission, she was not permitted to have a regular bedroom and was instead required to live in a seclusion room with a tiny window that she could barely see through. Amanda recounts that staff abused her.

As Amanda puts it, “who has confidence in themselves with goals like taking a shower or staying awake?”

Throughout her hospital admissions and group home stays, Amanda was on multiple psychiatric medications—with sometimes as many as six heavily sedating medications. As a result, she was always physically exhausted and had difficulty functioning. At one point she worked at a packaging job putting cups together, and would have to be woken up every morning to go to work. She had little confidence that she would ever live independently. As Amanda puts it, “who has confidence in themselves with goals like taking a shower or staying awake?”

WHAT HELPED AMANDA

At one point, her caseworker finally began to propose goals for Amanda that reflected her own higher expectations—including getting a driver’s license and getting a job. Shortly after, her involuntary commitment was finally lifted. Her caseworker wanted her to be discharged to an apartment complex where all of the tenants had a mental illness and county staff regularly visited to make sure that individuals were taking their medications. Amanda said “oh no, I want my own apartment!” and began putting in her own applications for apartments. Even if she had to live in a studio so small that it barely had a full-size oven, Amanda was determined to live in her own place.

During her state hospital stay, even as she sat in a room with a window so tiny she could barely see the light, she would daydream about having her own place, and the image that she pictured constantly was herself looking out a window above a kitchen sink, where she could see birds singing and rabbits running in a yard.

When Amanda finally did move into her own apartment, she was thrilled. The idea of doing something as mundane as washing her own dishes seemed amazing to her. When people told her how full of life and joy she seemed, Amanda explained that the fact that she can have her own garage, get into her own vehicle, and leave her house when she wants to makes her happy. “I take nothing for granted,” she says. Her father said “you can tell that Amanda’s actually living now, not falling asleep and drooling.” Amanda got her driver’s license and worked at a number of jobs, including nanny jobs, group home staff jobs, and a job at McDonald’s. Because she had spent such long period institutionalized, however, reintegrating into the community was not always easy. She felt like a six-year old when she watched one of her friends put on makeup.

When people told her how full of life and joy she seemed, Amanda explained that the fact that she can have her own garage, get into her own vehicle, and leave her house when she wants to makes her happy. “I take nothing for granted,” she says.

About six years after her involuntary commitment ended, Amanda met the man who is now her husband, and they married the following year. Amanda describes their marriage as a match made in heaven. Her husband as well as her friends played an important role in helping Amanda move forward. For a while, the county sent people to help her with grocery shopping and other tasks, and to develop a plan to meet her goals, as part of a program called “individualized case services” designed to help people transition to independent living. Her caseworker, who stuck with her throughout her institutionalization, helped her develop her plan and assisted in getting to appointments.

Amanda’s friends taught her how to pay bills. A disability specialist that she met through her church also became a friend and part of the “support team” helped her learn to reintegrate.

Amanda’s life changed dramatically when she got a job as a peer specialist. When she saw a notice for peer specialist training in Appleton, she could not believe it. She and her husband moved to Appleton with her so she could enroll. As she was graduating, Wisconsin’s first peer-run respite center, Iris Place, was opening and Amanda was hired as a certified peer specialist. To Amanda, her job at Iris Place is a miracle; she can make a good living doing what she loves. While she used to get in trouble for sharing her story with clients at the group homes where she worked, now she is able to use her shared experiences to help others.

AMANDA'S LIFE TODAY

According to Amanda, “guiding my own life, making our own decisions about the bills, and about what color the bedroom is going to be, is a joy.”

The most important thing for Amanda about living on her own is having independence. She takes great pride in being a good tenant and taking care of her home. While at earlier points in her life, Amanda lived surrounded by clutter, now her house is immaculate. She loves being able to paint and decorate, and to make things match. Sometimes just being able to take care of things and multi-task makes her feel like a superstar in her own mind. She enjoys paying bills, even though it is hard. Before she began working at Iris Place, she never had enough earned income to pay the bills without help from SSI and from her husband. Being able to write out a check to cover her own rent was a very big deal. It felt terrific. According to Amanda, “guiding my own life, making our own decisions about the bills, and about what color the bedroom is going to be, is a joy.”

The Bazelon Center for Mental Health Law gratefully acknowledges support for the research leading to the production of these pieces from

The Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
(under contract # HHSP233201600208A)

Hector Ramirez's Story

Hector Ramirez is a university professor, an advocate, and a respected figure in California's disability rights community. These achievements might surprise those who knew him during his childhood, which he spent institutionalized at a psychiatric hospital. Separated from his family and isolated from the outside world, Hector struggled to develop an appropriate sense of independence. For many years, he was treated as having significant limitations, and few who knew him expressed any meaningful expectations for his future. The opportunity to return to his family as an adolescent marked a momentous change in Hector's life, and he has continued to succeed in the community ever since.



photo taken from disabilityrights.org

LIFE BEFORE

Hector was diagnosed with childhood schizophrenia at a very young age. At age four, the state's child welfare agency removed him from his home, believing that his mother was not able to properly care for him. He was first placed in a group home, an experience that he remembers as extremely distressing. He did not cope well in that setting because he missed his family so strongly. After only three months, he was moved to a psychiatric hospital, an even more restrictive and isolated placement. He would remain at the hospital for the next eight years.

Hector's years at the hospital were largely unpleasant. Because he was so young when he was placed there, he did not fully understand why he had been institutionalized. Hector felt abandoned by his family, and he believed that he had been placed in the hospital as punishment for being himself. Being cut off from the outside world at such a young age prevented Hector from developing a realistic understanding of the world. He also felt that the hospital setting denied him a normal sense of dignity and self-determination, as he had few opportunities to make age-appropriate decisions about his daily life.

His family visited when they could, but they were not able to come as often as Hector might have wished because, in his words, they “had to do what they had to do to survive” as they carried on their own lives in the outside world. They made sure to visit on birthdays and holidays, but even those visits felt structured and artificial.

The hospital also lacked a meaningful education program for its young residents. The staff seemed to focus more on behavior management than intellectual progress. Hector and his peers spent most of their time on hobbies and arts and crafts projects seemingly designed to keep the children busy and out of trouble. The hospital did not develop educational plans that were based on the individual strengths and needs of each child or that would prepare them for an independent adult life.

His family visited when they could, but they were not able to come as often as Hector might have wished because, in his words, they “had to do what they had to do to survive” as they carried on their own lives in the outside world.

WHAT HELPED HECTOR

During his time at the hospital, Hector was lucky to make a connection with one particular therapist who recognized his potential. She helped Hector to file a petition to be released from the hospital. Because of her advocacy, other people, including the judge at the conservatorship hearing, began to understand that Hector could speak for himself. Hector succeeded in his court petition and, at twelve years old, he moved out of the hospital and returned to his community.

Hector’s freshman year of high school was his first time attending a public school. The school initially placed him in a segregated special education class, then moved him to integrated but remedial courses. Over the next four years, Hector gradually overcame his educational deficits from his years in the hospital, making his way up to honors classes by his senior year.

For the first time, Hector had the opportunity to form relationships with his classmates who were not aware of his prior “special education” label. Hector enjoyed getting to know classmates from diverse backgrounds and feeling that he belonged in the school community. He took advantage of extracurricular offerings and joined the football team and the choir. Hector also spent a lot of time at the school library, which he found “amazing” compared to the limited resources available at the hospital.

Over the next four years, Hector gradually overcame his educational deficits from his years in the hospital, making his way up to honors classes by his senior year.

After graduating from high school, Hector was excited to go on to college. Unfortunately, this first attempt at higher education was unsuccessful because Hector was still not fully aware of, or comfortable exerting, his legal rights. He did not understand the extent of the accommodations that might be available to him, and he resisted resuming “special education” services because of his negative associations with his experiences at the hospital. He dropped out of college, but reenrolled almost four years later.

Hector’s second attempt at college was successful. At a conference hosted by the disability advocacy organization RespectAbility, he had learned that the protections of the Americans with Disabilities Act were not limited to people with physical disabilities but also extended to people like himself who had mental disabilities. Armed with this knowledge, he was able to request the reasonable accommodations he needed to succeed in his classes.

The people who had known Hector as a child never expected him to graduate from college or pursue a challenging career. In fact, he says, most people who interacted with him and his fellow residents did not expect much at all from them, except to eventually land back in an institution. Hector was lucky to have a supportive family, including a mother who constantly encouraged him to advocate for himself.

HECTOR'S LIFE TODAY

Hector and his peers are also living longer than previous generations of people with mental disabilities did – and longer than anyone expected them to live when they were first diagnosed as children. Hector describes the experience of aging with a mental disability as a “new frontier” that presents new challenges. He has observed that older individuals with disabilities often face additional barriers to accessing services, and he fears that some individuals will return to an institutional setting because they are not able to access the services that should be available in the community. He is also concerned about the effects that budget cuts and policy changes could have on the continued availability of mental health services. Hector has continued to advocate for people with disabilities and has served on the Los Angeles County Mental Health Commission. Today, Hector serves as a board member of Disability Rights California, the agency mandated by federal law to protect and advocate for the rights of Californians with disabilities.

Still, the effects of his early years at the hospital continue to linger. Even now, at the age of forty-two, intrusive memories from the hospital occasionally wake Hector up in the middle of the night. His relationship with his family was also permanently altered. After a childhood of seeing his relatives only during defined visiting hours, Hector still finds it strange to spend unstructured time with his family just “hanging out.” Despite all of his personal and professional accomplishments, he – as well as his family members – continue to worry that everything could fall apart again. After the lack of autonomy he experienced as a child, Hector says, these fears will likely remain in the back of his mind for the rest of his life.

Today, Hector serves as a board member of Disability Rights California, the agency mandated by federal law to protect and advocate for the rights of Californians with disabilities.

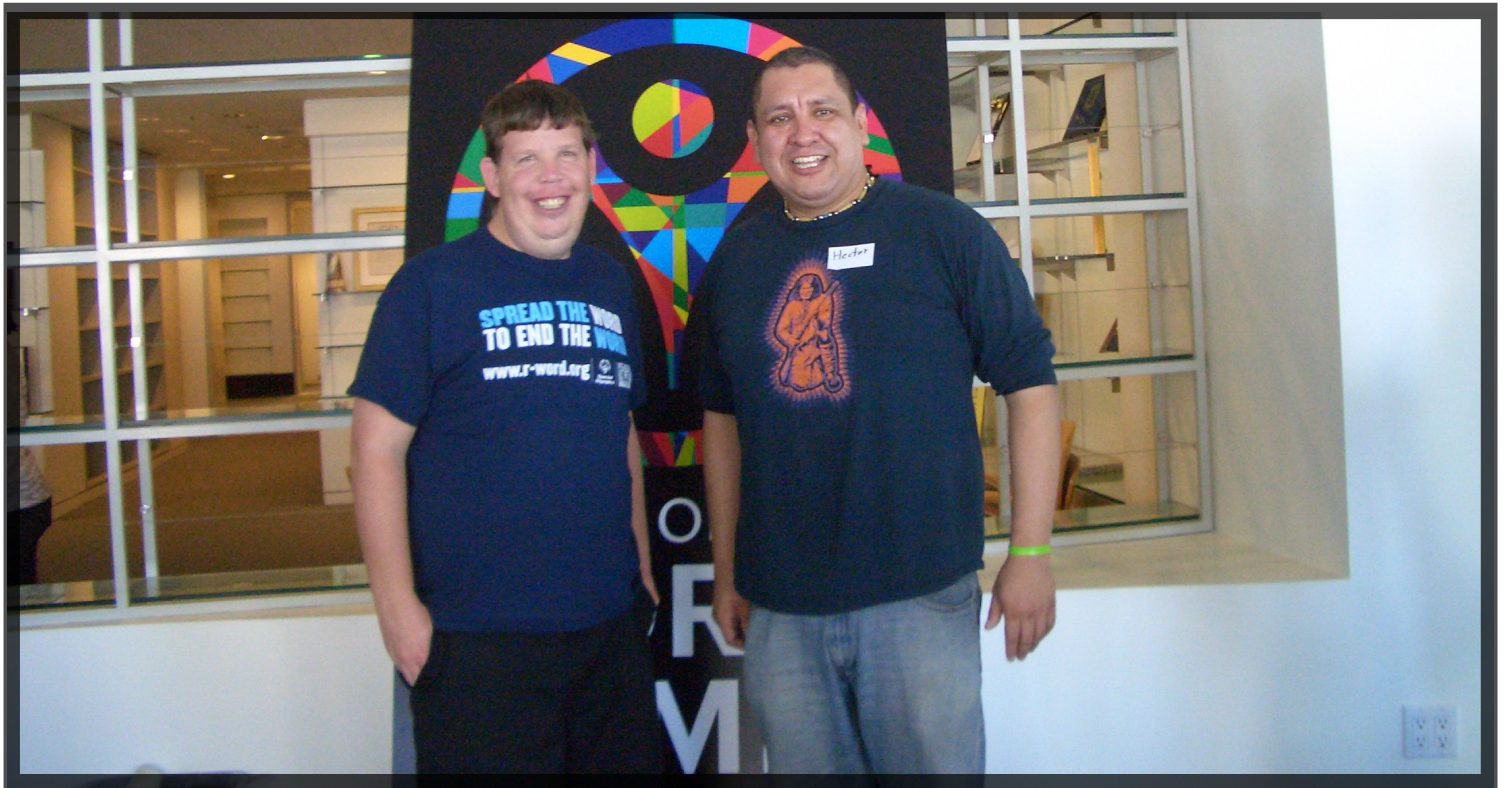


photo taken from awards.wegohealth.com

The Bazelon Center for Mental Health Law gratefully acknowledges support for the research leading to the production of these pieces from
The Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
(under contract # HHSP233201600208A)

Gina Calhoun's Story

Gina spent seventeen years of her life in and out of psychiatric hospitals, including a years-long stay at a state hospital in Pennsylvania. These experiences, along with months spent in group homes and on outpatient commitment, had a long-lasting impact on her. The inability to exercise control over her own life created tremendous frustration and distanced her from the mental health service system, even leading her to run away and escape from the state hospital at one point. Taking charge of her own life through work, relationships, and the opportunity to live independently has made an enormous difference in her life. Gina has not been hospitalized in approximately thirteen years, and thrives in a happy marriage and productive career.



photo courtesy of Gina Calhoun

LIFE BEFORE

About 20 years ago, Gina was struggling and found herself involuntarily committed to a private psychiatric hospital in Pittsburgh. Upon being discharged on “outpatient commitment” status, she was placed in a group home that did little to help her recover. The one thing that Gina found helpful during this period was the volunteer work that she had insisted upon doing rather than participating in a day treatment program. She volunteered at a ministry and taught children who had been expelled from school. Her creative approach to teaching and the appreciation that she received from her students made her feel valued. When the period of outpatient commitment ended, she began to struggle again and was involuntarily committed to another private hospital, where she stayed for almost a year.

At that point, the hospital staff told her “you’ve been here for far too long, and we don’t know what to do with you but you are not ready to be discharged.” Gina was transferred to the state hospital, where she remained for somewhere between two and five years. While she hoped that the hospital might offer structure that would help her recover, she found little in her hospitalization to promote recovery.

When she first arrived at the hospital, she was placed in a room with a bed, a dresser, and a makeshift closet, along with seven or eight other young women.

The hospital offered little activity and much of her time was spent in the day room doing things like playing “Skip Bo.” She was bored and frustrated. Having grown up in the woods, Gina describes herself as an “outdoor girl,” and the inability to go outside was an enormous source of frustration. Because smokers were allowed outside to smoke regardless of what “privilege level” the hospital had granted them, she began smoking. Finding that walking was a useful wellness tool, she walked the halls of the hospital. Staff thought that she was anxious.

Having grown up in the woods, Gina describes herself as an “outdoor girl,” and the inability to go outside was an enormous source of frustration.

WHAT HELPED GINA

One day, a fight broke out at the hospital and Gina was hit in the head with a garbage can. She needed stitches for her injuries. At that point, Gina knew that she had had enough. When staff allowed her to go to a Friday night dance, she escaped from the hospital grounds, wandering through a creek and wilderness until she was free.

A trucker in Carlisle, Pennsylvania picked up Gina and drove her to New York City, where she woke up in a medical hospital after passing out. After managing to get on a bus to return to her parents in Pennsylvania, Gina went home for a day and then, concerned that she would be picked up and returned to the state hospital, she lived in an old car for a period of time before going home again. Contrary to her fears, however, state officials did not seek to return her to the hospital, but instead asked her to give testimony in support of their efforts to close the state hospital where she had previously been institutionalized.

What helped Gina finally begin to recover was work. During a period of outpatient commitment, she was told to attend a partial hospitalization/day treatment program. Knowing that she needed something different, Gina refused to attend, prompting the county to explore other options for her. When Gina expressed an interest in work, county workers expressed great skepticism, saying, “Gina, by not showing up at the day program, you demonstrate no personal responsibility.”

You can't stay out of the hospital and you have no work history. What makes you think you can hold a job?" Gina persisted, explaining, "My goal does not revolve around going to the day program and hospitals; my goal is to work, therefore I will be more committed to the process."

Gina was referred to the vocational rehabilitation agency, which found her not ready to work. But a staff person suggested she try a local transitional employment service agency. Gina got a six-month job working for the U.S. Census, going door to door to encourage people who had not returned census forms to fill them out. She wanted to try a job with a beginning, a middle, and an end. Gina loved the job. She discovered that she was very good at persuading people, and really enjoyed talking with and meeting different people. The sense of accomplishment from doing her job well, as well as the receipt of a paycheck, provided validation.

When her work was done, she received a letter and a bonus check in the mail for having the most forms completed in the final phase of the census collection. The letter stated, "Your persistence and persuasiveness paid off; you made a difference in two communities." Gina noted the stark contrast between how she was perceived as a Census employee and how she was perceived as a hospital patient.

The six months during which she was employed by the Census Bureau represented the longest she had stayed out of the hospital in quite some time. While she was hospitalized several times after her job with the census, the stays were shorter.

The letter stated, "Your persistence and persuasiveness paid off; you made a difference in two communities."

Gina's parents helped her secure an efficiency apartment in Waynesboro, Pennsylvania. Among the reasons that she chose this location were its proximity to her parents and its distance from the hub of mental health services. At first, she was in an apartment with mental health staff visiting her several times a week. The constant turnover of case managers made it difficult for her to develop relationships with them, and she ultimately decided not to continue receiving the services that she had. Because the housing was contingent upon accepting services, she was unable to keep her apartment. Gina moved to a different apartment without staff. She negotiated a reduced rent for herself in exchange for helping to clean the hallways.

Once in her new apartment, she was still able to access mental health services, but had more choices about her services and felt more in control of her life—a critical element for Gina. Her new case manager was willing to listen and be creative, helping her explore her goals, including living on her own, rather than attempting to make symptom management the focus of her services. Having services that aligned with her values, driven by her choices, enabled her to thrive.

Gina was hired by the Mental Health Association of Franklin & Fulton County, and led its Community Support Program. She then became a peer support worker helping people transition from Harrisburg State Hospital to the community. This life-transforming experience was tremendously affirming.

GINA'S LIFE TODAY

Gina has been successfully working in various capacities for more than a decade. Six years ago, she got married—and in a gesture celebrating the control she had regained over her life, she and her husband chose to have their wedding ceremony at the state hospital where they had met.

Many aspects of Gina's hospitalization had a lasting impact on her. The constant lack of privacy left her with persistent anxiety about the need for personal space; to this day, it is difficult for Gina to have guests stay over in her house. In addition, the hospital environment made it difficult for Gina to develop trust—fears that others would violate her space, and experiences with others taking her belongings made trusting others a challenge.

Even now, Gina finds it very hard to develop trust with anyone. Her experience of being held in five-point restraints at a private hospital was traumatizing. In addition to the fear of being locked in a room and tied down to a table, her first experience in such restraints left her with two cracked ribs. To add insult to injury, Gina felt blamed by hospital staff for being restrained.

By contrast, living independently and working brought hope and dramatic change. Supporting herself, Gina felt liberation. She no longer felt like she needed to hide things, and rejoiced in small pleasures like being able to keep a ten dollar bill pinned to her bulletin board just in case she needed it. While some things, like grocery shopping, felt overwhelming after having been hospitalized for so long, she relied on the natural supports provided by her family, her church, and others.

The support of her parents and her sister, and their visits to her, were enormously important to her and helped her blossom. The preacher in her church approached her and asked what she liked to do. When she told him that she liked to dance, he convinced her to start a Jumping for Jesus aerobics class. The safety of having her own private living space and the value of having a job mean the world to her.

“Our service systems should begin with the mindset of supporting people to find the right environmental fixes to meet their needs, and hold the highest expectations for everyone.”

One of the most important things that Gina has taken from her experiences is the importance of having the expectation that all people can live as active citizens of their community. Gina notes that “in our public mental health system, we segregate. We judge who is going to make it in the community and who is not. But we don’t have a crystal ball. Our service systems should begin with the mindset of supporting people to find the right environmental fixes to meet their needs, and hold the highest expectations for everyone. Not everyone may choose to take the journey, but giving people a chance to do so is important, and would allow people to respond very differently, and positively, to the mental health service system.”

Irene Kaplan's Story

After spending sixteen years living at an adult home in New York, Irene Kaplan says she would not wish a similar experience on her worst enemy. For Irene, the environment in the home was one of intimidation, mistreatment, and loss of control. She felt the staff treated her like a child, inculcated a feeling of dependency, and imposed an “artificial system” for when and how to carry out everyday tasks. Nevertheless, now that she again lives independently in her own apartment, she has succeeded in regaining her ability to live her life as she chooses. Since she left the adult home in 2009, Irene has dedicated herself to reforming the state’s mental health system to ensure that no one has to live in an adult home unless it is their own choice.



photo taken from ciadny.org

LIFE BEFORE

Irene entered the adult home system out of desperation and a lack of alternatives. She had lost her apartment and was experiencing a period of homelessness and illness. During her time on the streets, she suffered a series of respiratory infections and was robbed of her Social Security Insurance checks. Compared to her life on the streets, a short stay at the adult home seemed to guarantee at least that she would have shelter, regular meals, and access to her SSI benefits.

Even as she moved into the adult home, though, Irene knew that securing these comforts would entail tradeoffs. The quality of the food was, in her opinion, “lousy” compared to her own cooking, and she sacrificed the ability to decide what to eat. She did not observe any effort by the staff to take into account the nutritional needs of individual residents, many of whom had health conditions such as diabetes, food allergies, or, like Irene, high cholesterol. The residents were unable to choose healthier meal options that would have helped them to manage these health concerns.

Irene and her fellow residents were unable to choose healthier meal options that would have helped them to manage [their] health concerns.

Irene had to cede control over her surroundings and her roommates. Irene says one roommate physically assaulted her. Another was a “hothouse blossom” who insisted on keeping the bedroom very warm and prevented Irene from opening a window to let fresh air into the room. This roommate also snored, causing Irene to lie awake at night and sleep only during the day.

Irene wanted to move into her own apartment because in the home “everything was done for me, but not to my satisfaction.” The staff applied the same rules to all residents. For example, even though Irene regularly left the home to visit her doctor and pharmacy, she was not free to come and go as she pleased: if she returned late, the door would be locked and she would have to wait for a staff member to come let her in. It took three months and legal intervention before Irene could install a personal landline in her room as an alternative to going through the home’s switchboard.

WHAT HELPED IRENE

A few years after she moved into the adult home, Irene was approached by a member of the Coalition of Institutionalized Aged and Disabled (CIAD), a consumer-led organization that advocates for the rights of individuals living in nursing homes and adult homes. The advocate’s message of independence and self-advocacy strengthened Irene’s conviction that she could one day return to an independent life in the community.

Irene spoke out against the state’s mental health system, which in her view operated the adult homes as a “dumping ground for unwanted people” whose families could no longer care for them. Irene proudly testified during the trial in *Disability Advocates Inc. v. Paterson*, the landmark *Olmstead* case that reformed New York’s mental health system to ensure the availability of community-based services for adults with mental illness. During her testimony, when the judge asked Irene how she felt about leaving the home, she replied, simply, “freedom.”

During her testimony, when the judge asked Irene how she felt about leaving the home, she replied simply, “freedom.”

While the *Disability Advocates* case was pending, New York created a small program to provide supported housing to 60 people living in adult homes. As a result, sixteen years after she had entered the home, Irene was finally able to move into an apartment in Brooklyn through this program. She was able to choose an apartment with a location that she felt provided safety and convenience. Irene also liked the unit itself, which felt airy and quiet and offered views of greenery and the sky through the windows.

Irene has been able to organize her apartment as she wished. She was pleased to have the space to expand her book collection beyond what she had been able to keep in the adult home. She also enjoys the peace of living alone with her cat, with few distractions while she reads or watches television – a strong contrast to the frequent interruptions at the adult home.

She also used her transition as a motivation to stop smoking: in fulfillment of her promise to herself that she would quit smoking when she left the adult home, she smoked her last cigarette the day she moved into her apartment.

For Irene, it was easy to resume her familiar routines in the community. Even though her experiences in the adult home had sapped her self-confidence, she was comfortable shopping and cooking for herself again within a few days of her move into her own apartment. She values the ability to decide for herself what to prepare for each meal – whether it will be steak, chicken, or simply a bowl of cereal.

Although she hadn't known the area well before she moved in, she quickly grew to like her new neighborhood. She has also enjoyed getting to know her neighbors, who are always eager to hold the door or lend a hand when they see Irene with her walker. One of Irene's neighbors is also a former adult home resident, and Irene has enjoyed the freedom to speak and joke freely with her neighbor about their shared experiences, which the women were reluctant to do while they were living in the home. She feels lucky that everything she needs is a short walk away from her apartment, including a medical clinic across the street and her eye doctor around the corner.

She is glad to have the opportunity to make her own decisions about where to go for everything from medical care to shopping. A home health aide comes to help her with laundry, deliver groceries, pick up her prescriptions, and perform other tasks around her apartment that are difficult for Irene because of her mobility issues.

Irene has also regained the ability to control her own finances. During her time in the adult home, she received only a small allowance of a little over a hundred dollars a month, much of which she spent on snacks and meals when she didn't like the home's offerings. Now she can spend her money as she finds appropriate. She has enjoyed having the means to acquire some furnishings for her apartment, many more books, a television, and a second-hand computer and tablet that have provided access to the Internet. She also used her transition as a motivation to stop smoking: in fulfillment of her promise to herself that she would quit smoking when she left the adult home, she smoked her last cigarette the day she moved into her apartment.

IRENE'S LIFE TODAY

Irene has continued her advocacy work with CIAD to this day. She has found a sense of purpose in her role as a peer advisor, which allows her to educate adult home resident about their rights. She has also traveled to the state capital to meet with legislators and raise awareness about the adult home system. Her message to lawmakers is clear: “the adult home system is not a place to spend the rest of your life unless you choose it for yourself.”

Irene tells decision makers that the state's mental health system needs to be revamped to provide people with more choices and the supports they need to remain in their own homes in the community. CIAD, she says, “gets things done” through their advocacy and outreach work. After experiencing a loss of control and independence during her years in the adult home, this ability to pursue systemic change is invaluable to Irene.



photo taken from ciadny.org

Jennifer Vonbrandt's Story

Today, Jennifer sees herself as a beautiful young woman with a lot of courage. Her courage is what enabled her to take steps towards recovery and she has now been living in her own apartment for four years. Jennifer overcame years spent cycling in and out of hospitals and group homes to successfully live on her own with the help of a crisis and recovery center and thanks to her bravery. Part of her motivation was the impact that her cycling was having on her young daughter—who is now 17 and working on securing a job and a driver’s license. Jennifer enjoys the freedom and independence of her current life.



photo courtesy of Jennifer Vonbrandt

LIFE BEFORE

Jennifer experienced her first psychiatric commitment when she was a teenager. She was confined in a state hospital for approximately a year. During that time, she used to bang her head against a brick wall and sometimes would hit doctors. In an effort to kill herself, she would drink hairspray, rubbing alcohol, and cleaning solutions. Jennifer was desperate to leave the hospital, and constantly wondered “When am I going to get out of here?” She asked many times to be released, but was told that she was not ready. Jennifer experienced abuse during her hospitalization—part of a set of incidents leading to a federal investigation and media coverage. Visits to her family did not go well; in part, the medications that she was taking made her drowsy and listless. One Thanksgiving, she could hardly keep her head up, and her mother asked, “What’s wrong with my daughter?”

Jennifer then spent another two years in and out of community hospitals, the state hospital, and group homes. Privacy was scarce. At the state hospital, she had three other roommates sharing one room. People would steal others’ belongings, and Jennifer even had her false teeth stolen.

Staff watched her shower, watched her dress, and followed her wherever she went.

The images she had seen of people being restrained and screaming haunted her. Abuse also occurred. During one incident, she was punched and had her hair pulled by staff, and a rag stuffed in her mouth made it hard for her to breathe. Three large men sat on top of her. A supervisor discovered what was happening and put an end to this behavior.

Jennifer was desperate to leave the hospital, and constantly wondered “When am I going to get out of here?”

WHAT HELPED JENNIFER

At some point, state hospital staff told Jennifer she needed to make a change in her life so that she would stop coming back. Around that time, she was sent to a crisis and recovery center, which she found extremely helpful and which linked her with supported housing. Her transition to her own apartment was not easy, as she was scared to leave the hospital and live on her own. She did not feel like she knew how to function on her own. But she was also excited about getting her independence. One of the things that gave her the courage to try living independently was thinking about the impact on her daughter—who was in pre-school or kindergarten at the time—of Jennifer’s cycling in and out of hospitals throughout her life. While she continued to have some hospitalizations at first, medication changes helped and Jennifer eventually settled into supported housing.

JENNIFER'S LIFE TODAY

Jennifer is very happy to be living in her own home. She has been living in her current apartment for four years. Staff comes to help her with medications, and to help her with grocery shopping and clothes shopping. Jennifer attends a Clubhouse, where she participates in groups. She volunteers every week at an animal shelter; she loves her work there, and is particularly attached to one cat who loves to be petted. She keeps a journal that she writes in every morning and night.

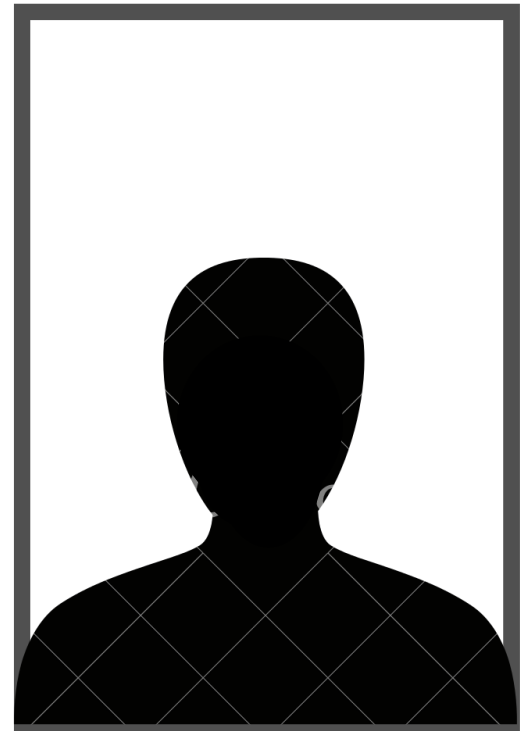
Jennifer enjoys the freedom and independence that she now has. Looking back on her life in the hospital, she observes that the environment felt like a prison, and her life felt hopeless. Now she sees herself in a different light—as a beautiful young woman with a lot of courage.

She takes pride in being able to do the ordinary things for herself that “normal human beings” do, like bathing and cooking. While she was too scared to learn to cook or use a washing machine during her days living in group homes, she now cooks many different types of meals, and washes her own clothes. The most important things about having her independence are the ability to be herself without having people judge her, and the absence of bars on the windows and freedom to let air in. Jennifer’s daughter is now 17 and working on securing a job and a driver’s license. Jennifer is very proud of her life now.

The most important things about having her independence are the ability to be herself without having people judge her, and the absence of bars on the windows and freedom to let air in.

Jessica Thomas' Story

Jessica Thomas was in and out of medical and psychiatric hospitals dozens of times between 2006 and 2009 – she stopped counting at thirty – following a physical assault by a family member. She struggled to describe the symptoms of her head injury in a way that medical professionals would understand; more often, she says, the doctors from whom she sought treatment thought she was delusional. Eventually, Jessica received an appropriate diagnosis and treatment that seemed effective, but the traumas she experienced during her involuntary hospitalizations continue to affect her daily life.



LIFE BEFORE

Jessica's story began in August 2006 when a family member physically assaulted her. She visited a medical hospital, where the doctors diagnosed a concussion and a sprained elbow, knee, and ankle and sent her home. She visited two other hospitals a short time later after she re-restrained her ankle in a fall and was also experiencing severe head pain. One hospital diagnosed her with post-concussion syndrome, provided her with pain medications, and sent her home; the other gave her some information about head injuries and also sent her home. Jessica then returned to the first hospital she had visited to seek help for her head pain. The medical professionals there believed she was suicidal – which Jessica denied – and transferred her to the psychiatric unit for an involuntary admission for three days. There, Jessica says, doctors diagnosed her as psychotic and delusional because they did not believe her claims of physical abuse by two family members.

Jessica was next transferred to a different hospital to treat her medical condition, which causes her to become dizzy, fall down, and shake due to low blood pressure. Her mother visited her in the hospital and said that Jessica threw an object at her.

Jessica was released, but the hospital did not provide a discharge plan beyond allowing a family she knew to take her in.

After about three weeks, Jessica was released, but the hospital did not provide a discharge plan beyond allowing a family she knew to take her in. At some point during her stay with the family, Jessica went to a crisis center and explained that her head hurt and felt like it was leaking. The crisis center believed she was delusional and she was sent back to the first hospital for another involuntary admission. Upon release from the hospital, she did a short period of partial hospitalization, then returned to the family, who dropped her off at a homeless shelter. Jessica lived at the shelter for about a month, until another family agreed to have her live with them. A few months later, she went to live with her mother.

Several months later, Jessica's mother brought her to a new hospital, where a doctor diagnosed her feeling of her head leaking as paresthesia linked to Asperger syndrome. She transferred to a psychiatric hospital and agreed to stay for an evaluation, hoping to learn more about her new diagnoses. But the hospital discovered Jessica's history of involuntary admissions and alleged violence and transferred her to yet another psychiatric hospital, where she remained for several months. Jessica's experiences at this hospital were highly distressing: the staff restrained her, refused to give her menstrual pads, and did not respond when another patient assaulted her.

Jessica was released to live with her father. She had begun to experience symptoms of Post-Traumatic Stress Disorder related to her hospitalizations, then experienced a crisis. Jessica was hospitalized again and has no memory of the next several months she spent in the hospital, although her family has told her that she was experiencing psychosis, appeared catatonic, and stopped eating. Her father requested that she receive Electroconvulsive Therapy (ECT). Jessica found the ECT effective, and while she lost memory as a result, she gradually began to regain the ability to form new memories. The hospital staff focused on bringing her weight back up to a healthy range. She also remembers taking walks with hospital staff around the hospital grounds and working with a music therapist.

WHAT HELPED JESSICA

Nine months after this hospitalization began, Jessica was released to a group home and participated first in a day treatment program, then in a clubhouse program.

She received a housing subsidy, food stamps, and Social Security benefits. She soon landed a part-time job and has continued to work, either full- or part-time, ever since.

Initially, a parent handled her finances, but she regained control of her finances after a year and now lives independently. Jessica is working part-time and taking classes in a certificate program, and hopes to find a full-time position in her field once she graduates.

Jessica continues to manage her doctor's appointments and medications. She is also eager to begin therapy to help with her anxiety; Jessica recently had an initial meeting with a therapist and is excited to begin regular sessions soon.


Jessica appreciates the balance of living independently but knowing that the caseworker will be available whenever she needs some additional help.

Jessica enjoys living in her own subsidized apartment. She does all of her grocery shopping, laundry, and housekeeping herself, and she handles any maintenance issues that come up with her apartment or car. As a requirement of her housing program, she meets with a caseworker twice a month. Jessica appreciates the balance of living independently but knowing that the caseworker will be available whenever she needs some additional help. These days, Jessica and the caseworker primarily focus on stress management and continued community integration, such as getting back to church and finding a gym. Jessica has also met with education and employment specialists who have helped her plan her next steps in those areas of her life.

Jessica is proud to have the ability to take care of herself and her home and to advocate for herself with her health insurance company and medical professionals.

JESSICA'S LIFE TODAY

It has been almost eight years since Jessica was last hospitalized. Nevertheless, the effects of her many hospitalizations continue to linger. She still experiences PTSD symptoms on a regular basis, including intrusive and flooding thoughts and nightmares.



She also finds it difficult to trust people after her experiences and tends to keep to herself, but she is happy with her life. She is proud to have the ability to take care of herself and her home and to advocate for herself with her health insurance company and medical professionals. She is looking forward to completing her education and moving forward in her career.

The Bazelon Center for Mental Health Law gratefully acknowledges support for the research leading to the production of these pieces from
The Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
(under contract # HHSP233201600208A)

Mary Salinas' Story

Mary Salinas recently moved into her own apartment after living in institutional settings for about three and a half years. She had agreed to move into the assisted living facility following a brief hospitalization because she did not feel that she had any other options. After a few years, she applied for, and received, a public housing unit that has allowed her to regain her independence, privacy, and control over her daily life.



LIFE BEFORE

Mary, now in her sixties, has received treatment for depression for most of her life. Approximately three and a half years ago, she was admitted into a psychiatric hospital for the first time. At that time in her life, Mary was essentially homeless. She had recently moved back to Colorado from Oregon and had been staying with a friend, but the arrangement did not work out. She had lost touch with most of her other local friends, and she needed a place to live that would allow her to keep her cat.

After about two weeks, a caseworker suggested that Mary move into an assisted living facility. The caseworker made the process easy for Mary, handling the admission paperwork and arranging for Medicaid coverage, but she did not discuss any community-based alternatives. The assisted living facility was the only option that was presented to Mary. She recalls that she had been having difficulty concentrating and remembering things while she was in the hospital and generally felt “out of it.” She thought it best to follow the caseworker’s recommendation.

Mary moved into an assisted living facility located outside of town. While the staff were considerate and the food was decent, it was not where Mary would have chosen to live. This facility was rather large, with thirty-two residents, and Mary found it hard to live with so many other people. She generally got along with the other residents but preferred to stay by herself much of the time. She was glad to have her own room shared only with her cat.

After about a year and a half, Mary moved to another assisted living facility that was located in the city. The facility's new owner told Mary that she was hoping to make a lot of money by operating the facility. The owner restricted the residents' access to food and placed chains on the refrigerator to prevent the residents from eating outside of the designated meal times. Mary was distressed when one of the other residents left the facility to return to a psychiatric institution. She was further persuaded to leave when her doctor advised her to look for another facility.

This facility was rather large, with thirty-two residents, and Mary found it hard to live with so many other people. She generally got along with the other residents but preferred to stay by herself much of the time. She was glad to have her own room shared only with her cat.

Mary decided to return to the first assisted living facility. Although it did not have the same problems as the second one, she was still uncomfortable being around so many people all of the time and organizing her life around the facility's regimented schedule. Mary began to spend less and less time at the facility as she stayed busy with group therapy, volunteering in the community, and attending church functions. She was able to get around in the community using transportation services provided through Medicaid.

WHAT HELPED MARY

Looking for a way out of the facility, Mary applied for public housing assistance. The housing authority estimated a one to two year wait, but she was pleasantly surprised when the housing authority located an available unit in an elderly low-income housing community after only five months. She was not familiar with the neighborhood before she moved in, but she found it to be a clean and upscale area with many conveniences, like a grocery store only four blocks away from her building.

After her time in the assisted living facilities, Mary enjoys the small pleasures of her independent life. She values the ability to have a glass of milk whenever she wants, to decide for herself what to eat for each meal, and to have dessert even if she has not cleaned her plate – all choices that she was denied in the assisted living facilities. She also values her privacy. In the facilities, she says, she was always surrounded by other people. When she went outside, she had to sit with all of the other residents.

Even inside her private room, she was constantly aware of the presence of the other residents and staff all around her. She always asked guests to take her out when they visited, rather than staying in her room. Now, she says, she has “all the privacy in the world.” She feels comfortable inviting friends over to her apartment, and she can sit outside by herself in the garden.

Now, [Mary] says, she has “all the privacy in the world.” She feels comfortable inviting friends over to her apartment, and she can sit outside by herself in the garden.

During her first two years in the assisted living facilities, Mary had returned to the hospital five times. She has not been hospitalized in the past year and aims to avoid any further hospitalizations now that she is on her own. She continues to see her therapist, who strongly supports Mary’s desire to stay in the community. She also attends peer-run group therapy meetings, and she appreciates knowing that the peers watch over her; for example, if she misses a meeting, a peer will call or stop by her apartment to make sure she’s okay.

MARY'S LIFE TODAY

Recently, Mary’s arthritis has worsened, making it more difficult for her to get around. An aide now comes to her apartment to help with groceries and laundry. Mary still decides what the aide should buy, and she says it’s always “kind of fun” to look over the aide’s purchases.

Mary has declined additional home health services that have been offered, preferring to cook and clean for herself as long as she is able. She says she wouldn’t feel comfortable sitting “like a queen” as she watched other people clean her home; she grew up taking care of herself and working hard, so she insists on doing what she can around the apartment.

Other natural supports in the community have also been important to Mary, including her minister, who has offered to bring her to discussion groups at the church. She volunteers at a day center where people experiencing homelessness can come to take a shower, do laundry, and collect mail. She decided to pursue this type of volunteer work because of her own experiences with homelessness. Mary’s job at the center is to hand out the mail, so she’s been able to continue her work even as her arthritis has worsened.

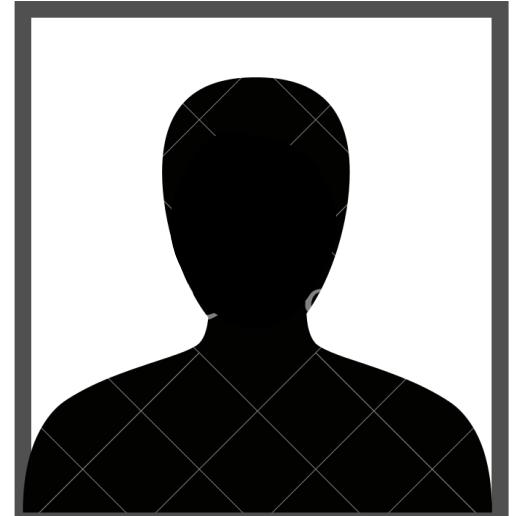
Mary still experiences depression, as she has throughout her adult life. At times, the pressures of daily life – replenishing household supplies, figuring out how to fix a broken watch – weigh upon her. Nevertheless, it feels “normal” and “natural” to take care of herself once again. She is proud of her independence, and she finds it helpful to stay busy and to stay in touch with others who have had similar experiences. Between group therapy, volunteering, and church, she is always able to meet these needs in the community.

She volunteers at a day center where people experiencing homelessness can come to take a shower, do laundry, and collect mail. She decided to pursue this type of volunteer work because of her own experiences with homelessness.

William Simon's Story

William describes his first few months at the hospital as “just a day to day existence.” The hospital did not provide any services or treatments aimed at helping the patients recover or gain skills, and William was not allowed to leave the premises. He and the other patients simply existed in the hospital – sitting around, watching television, or maybe reading a book, if they could find one.

William notes that the patients had no say in organizing their daily life in the hospital.



They had no choice but to comply with the staff’s directions about when they could eat, sleep, or shower. The staff constantly monitored their activities, and the patients were not allowed to opt out of any part of the hospital’s schedule. The only thing William had to look forward to was the prospect of someday leaving the hospital, having his own place, and living a normal life again.

WHAT HELPED WILLIAM

After several months, a new doctor recommended that William be transferred to a different unit that was more focused on moving patients out of the hospital. But because his transfer depended on a bed in the second unit opening up, there was no way for William to know how long he would have to wait. He found the wait to be “agonizing.”

After about a month, William was finally able to move to the other unit. There, he could focus on the logistics of returning to the community. He met with social workers, peer support specialists, and caseworkers from community-based service providers, who helped him prepare the details of his upcoming move, such as applying for Social Security Disability Insurance and obtaining a new government ID. His caseworker was supposed to help him find an apartment in the community, but he did not make quick progress.

William eager to move out as soon as possible, began looking for an apartment as well. Even though it was difficult without Internet access and without knowing the area, he soon found a newspaper listing he liked. William's caseworker and social worker accompanied him to look at the apartment, and William thought it was perfect. His caseworker, worried that William was jumping at the first apartment that came along, persuaded him to view a second unit before making any decisions. William consented but found that he still preferred the first apartment. At that point, his caseworker started talking about moving William into a group home instead of an apartment.

William's caseworker and social worker accompanied him to look at the apartment, and William thought it was perfect.

Fortunately, William was also working with the state's Protection and Advocacy organization. They supported his desire to live independently, recognizing that a group home would continue to limit him and would function more as an extension of the institution than as a true community placement. They helped him apply for a state housing voucher program that covered his moving costs and his first few months of rent until he could access his Social Security benefits. Almost a year after he had entered the psychiatric hospital, William moved into his new apartment.

William now has a new caseworker who is more supportive of his independence. The caseworker has helped him arrange transportation to medical appointments, complete the paperwork for the local paratransit service, and connect with new doctors and therapists in the community. He has also facilitated William's exploration of his new neighborhood and helped him find nearby stores and other amenities. William has also been able to grow the support network he had previously lacked. He is a regular participant in group therapy, where he can play cards and talk with others who share similar experiences. He has built friendships with these and other individuals in his community.

William is a regular participant in group therapy, where he can play cards and talk with others who share similar experiences. He has built friendships with these and other individuals in his community.



WILLIAM'S LIFE TODAY

Now that he is back in his own place, with the ability to decide for himself when to eat, sleep, or watch television, William says he feels like a human again. His apartment is a home in a way that the hospitals never were. He enjoys the ability to host friends in his apartment and to serve homemade baked goods to his support workers. Even though it is only a small apartment, he says, having his own home has helped him recover his sense of self and identity that he had lost in the hospitals.