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## FROM THE INSIDE OUT: PERSONAL PERSPECTIVES OF SIX GEORGIANS ON THEIR INSTITUTIONAL EXPERIENCES

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The landmark Supreme Court decision *Olmstead v. L.C.* established that it is a violation of the civil rights of Americans with disabilities to be segregated in institutions if the support and services they require can be appropriately provided in the community.<sup>1</sup> For many individuals, *Olmstead* has been the catalyst for obtaining the support needed to leave institutions and move into the community. Yet a decade later, over two million people who could be served in community settings continue to reside in institutions and nursing facilities in the United States.<sup>2</sup> For them, *Olmstead* is a promise yet to be fulfilled.<sup>3</sup>

This article presents the narratives of six people with developmental or intellectual disabilities who lived part of their lives in institutions, but have since transitioned into the community. Their stories reveal common themes and experiences of life in an institution, including the abuses they suffered at the hands of “care providers,” selected experiences from their new lives, and sage advice to those still awaiting the transition. The narratives offer

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1. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597, 607 (1999).

2. NAT'L DISABILITY RIGHTS NETWORK, A DECADE OF “LITTLE PROGRESS” IMPLEMENTING *OLMSTEAD*: EVALUATING FEDERAL AGENCY IMPACT AFTER 10 YEARS, at 4 (2009), available at <http://www.ndrn.org/issues/comment/Decade%20of%20Little%20Progress%20Implementing%20Olmstead%2012%201%20final.pdf>.

3. BAZELON CTR. FOR MENTAL HEALTH LAW, STILL WAITING . . . THE UNFULFILLED PROMISE OF *OLMSTEAD*, at 1 (2009), available at [http://www.bazelon.org/pdf/Olmstead\\_Call-to-Action.pdf](http://www.bazelon.org/pdf/Olmstead_Call-to-Action.pdf).

insight and motivation to those who seek to further the impact of *Olmstead* in their states.

## I. BACKGROUND FOR THE INTERVIEWS

The six key informants reflect a convenience sample of people who identified themselves when several Georgia self-advocacy and disability support organizations were approached. All participants stated that they wanted to share their stories to help others “get out and stay out.” The objective for this research was to collect individual narratives as part of the ten-year anniversary of the *Olmstead* decision. Because the case originated in Georgia, it was particularly relevant to honor the voices of Georgia citizens affected by the *Olmstead* decision.

As a convenience sample, these individuals should not be taken as reflective of the entire population of people who have transitioned into the community or of those still remaining in institutions. Each narrative is, however, compelling on its own, and among them are many common elements that are likely to be applicable to the broader experience of individuals living in institutions. Five of the six interviews were conducted in the participants’ homes. The individuals, who differed in their abilities and disabilities, ranged in age from twenty-four to sixty years. Their length of time in institutional settings ranged from three to thirty-five years. Participants provided informed consent for the interviews and the use of their stories in this paper. Several also gave explicit consent for the use of their real names.

## II. KEY INFORMANTS

**Lena** is a fifty-three year-old African American woman with a warm, hospitable nature. For the interview, she wore a purple shirt, white pants, and new, purple boots. Purple being her favorite color, she was proud of the rare find of her new boots. Lena was born in Newnan, Georgia where she lived with her family in her grandmother’s house. She is the youngest of seven children and

remains in close contact with two of her sisters. She has mental health issues and a mobility impairment necessitating the use of a scooter.

One of Lena's earliest childhood memories is the pain of leaving her grandmother's home with her two sisters to live with her mother's boyfriend in Alabama. As she reminisced, she painted a picture of a sobbing young child looking out the back window of the car. The image of her grandmother waving goodbye from the front porch slowly faded into the distance.

Lena has been in and out institutions for thirty-five years between the ages of fifteen and fifty. She recalled a story from age fifteen, when she was excited to be travelling "home" with her family to visit her grandmother. Upon the family's arrival, Lena was told the trip was for her grandmother's funeral. Not being able to say goodbye to the one person who loved her caused Lena tremendous grief. Lena explained that this grief and loss drove her to an intentional overdose on drugs. Following this suicide attempt, she was placed in a psychiatric institution, then a series of group homes. Soon after the overdose, she vowed to find purpose in her life and not attempt suicide again.

Today, Lena lives alone in an apartment. Although she has lived in her home for two years, she has yet to completely unpack; this was apparent from her reaching into a box to get plates for dinner with the interviewer. In Lena's kitchen, she has a large refrigerator and freezer so she can store the food she buys in bulk. She said she does not like to go shopping and had not been to the grocery store for four months.

A drawing of Martin Luther King, Jr. by Lois Curtis, one of the plaintiffs in the *Olmstead* case, is framed and proudly displayed on top of the freezer. Also displayed is one of her most prized possessions—a clock with the ADAPT logo, which features a wheelchair user freeing herself from shackles.<sup>4</sup> Lena enjoyed telling the story of how she acquired the clock from Mark Johnson—a local

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4. ADAPT is "a national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom." ADAPT, <http://www.adapt.org/index.php> (last visited Jan. 28, 2010).

and national leader in ADAPT—at a conference. He offered to pay for the clock, but she refused the charity. He bought the clock anyway, giving it to her with the condition that she should sell four more. She boasted that she went on to sell six!

**Glen** has kind brown eyes and a warm, welcoming smile. He was born and raised in a tight-knit Jewish family in Atlanta. He is the middle child with two sisters. He has an intellectual disability and a mobility impairment from a surgery that fused his right knee. He now lives in an assisted living facility called Azalea House. At sixty years old, he is the youngest resident in this facility with the majority of the occupants having Alzheimer's disease. For this reason, Glen shared that when he is there he spends most of his time in his bedroom watching TV with the door closed as he feels he has nothing in common with the other residents. Despite having lived there for several years, his bedroom remains rather barren. There are no pictures hanging because he is not sure if he is allowed to hang anything on the wall. His bed is nicely made with an attractive bedspread. On top of his dresser is a small TV located beside the window with closed blinds and no curtains. The only seating in the room is the scooter he uses for mobility and his bed. Azalea House is a congregate living facility with password-coded locks on the front doors. Glen, however, has the codes, which allows him to come and go as he wishes.

Glen has an active life, rich with community service activities. He is a member of the Georgia Council on Developmental Disabilities and on the Board of Directors of People First of Georgia.<sup>5</sup> He volunteers at Disability Link, People First of Atlanta, and a self-advocacy program called Voices that Count. Glen was also appointed by the Governor as a member of the Georgia Olmstead Planning Committee. When he is not working as a volunteer, he is often out with friends.

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5. See Georgia Council on Developmental Disabilities, <http://web.me.com/gcdd/GCDD/Home.html> (last visited Feb. 8, 2010); IHDD, Institute on Human Development Disability, <http://www.ihdd.uga.edu/DisabilityRightsAdvocacy/People%20First.html> (last visited Feb. 8, 2010).

Glen has spent most of his life in residential schools and institutions. His whole appearance and energy level changed as he began to tell about his life in these settings. He went from being happy, friendly, and open to solemn and slumped in his chair. When asked about childhood friends, he stated he had none. When asked about fond childhood memories, he echoed the statement—he had none. He said that there was not one thing that he could recall from that time as being remotely good, much less a fond memory.

**Eugene** is a quiet and intensely focused, fifty-year-old African American man who was born and raised in Atlanta. He proudly recalled that he grew up in Grady Homes, a somewhat infamous housing project in the city. Eugene has an intellectual disability and is a double-amputee. Eugene was interviewed in a nursing facility in Macon, Georgia on the eve of his move to the community. He was in his bed wearing a T-shirt with his name written in permanent marker on the shoulder area.

Eugene had been in a nursing facility for eight years, originally entering after his legs were amputated due to frost bite while he was homeless. He lived for one year in an Atlanta nursing facility, but moved to a Macon facility when a tree fell on the building. It was during this move that he lost all contact with his family. Despite the fact that he was less than ninety miles away, it took seven years before he was reunited with his family again.

The hallways of the nursing facility were brightly painted and reminiscent of a young child's bedroom. The décor included cartoon characters, cars, Harley Davidson motorcycles, and purple walls painted with flowers and princess wallpaper. His room had three beds, one of which constituted much of his "home." In a space measured at approximately three by six feet, he had all of his possessions piled beside him; these included a small TV with a coat hanger as an antenna. Eugene's interview was cut short by the arrival of his family in preparation for taking him home. Echoing sentiments of the other interviewees, when asked what he would like to share with others who want to transition from an institution, he said, "Got to be strong, can't lay down . . . . [G]ot to have a strong mind and can't let anything get you down."

**Mary** is a fun and fiery fifty-six-year-old Caucasian woman. She was born in Atlanta, but her family moved to Macon when she was seven so that she could attend the Georgia Academy for the Blind. She has a visual impairment called retrolateral fibroplasia, which stemmed from damage to the retina caused by over-utilization of oxygen at birth. She also uses a wheelchair due to cerebral palsy. Mary lived in a nursing facility for twenty-seven years, sharing a room with her mother for twenty of those years until her mother passed away. They entered the facility together after her mother fell and broke her hip.

Mary has long, sandy blond hair that was pulled up in a pony tail on top of her head. She was wearing a floral house dress while sitting in her wheelchair in front of a sliding glass door. She now lives in a beautiful apartment within an assisted living center with furniture that she picked out with the assistance of her support staff. To select her furniture she used her hands to feel the textures of the upholstery and heard it described. She was quite proud to talk about choosing her favorite colors, mauve and red, to fill her home.

Mary's interview began with her description of a visit to the Capitol to address the Georgia Governor and legislators about implementing the *Olmstead* decision. She advocated for herself and others to transition out of institutions and into their communities. Mary recalled, "We're at the podium at the capitol. Adreana put her hand out and touched my shoulder. I asked her where is the person I'm addressing—Roy Barnes, Zell Miller, and, most importantly, Tommy Olmstead." [Tommy Olmstead was the former state Director of the Department of Human Resources and the named defendant in *Olmstead*.] Adreana oriented her and Mary directly asked Mr. Olmstead, "Why are we better off in nursing homes?" When he walked off without answering, she said, "I wish he could be in a nursing home for a year."

**Jeremy** is a handsome and articulate twenty-two-year-old Caucasian man who was born and raised in Auburn, New York. He has cerebral palsy and uses a wheelchair. Jeremy requires assistance with positioning and transfers, such as getting in and out of bed and in the restroom. He spoke of a love for learning, helping others with

advocacy, and conducting training on self-advocacy. He is currently working toward a Bachelor's degree in human service at Mercer University and plans to pursue a graduate degree.

Jeremy lived in an institution for three years. After an accident at Disney World and a subsequent surgery, he was placed in a nursing facility in Florida. His girlfriend, who had made the trip with him, left for home after his surgery. While in the Florida institution, Jeremy was labeled "non-compliant" because he demanded to be fed, bathed, changed, and positioned regularly to avoid bed sores. After being left in his own waste for hours, he would scream and demand help. This "deviant" behavior precipitated a transfer to a psychiatric nursing facility in Georgia. He was rescued from the Georgia facility when a disability advocate heard his screaming and offered to help. It took three long, grueling years for his dream of leaving the nursing facility and living in the community to become a reality.

He now lives in Macon, Georgia and resides in an assisted living apartment. His sparsely decorated apartment is cluttered with papers and books from his university course work. He has a couch, covered with papers, and a dinette table with two chairs. The wall above his TV features ribbons for academic excellence and a National Honor Society plaque. Most notable in the apartment, however, are the many locks on the door, which offer Jeremy feelings of safety and protection against past abuses he endured in his own home and in the nursing facility. As he describes his initial life outside the institution, "I had to be hospitalized for depression a couple of times. When you looked at me, I would cry. But I had to make the change for myself and I'd be damned if I went back into the institution."

**Sarah** is an energetic twenty-four-year-old Caucasian woman with soft, dark eyes. She has a buzz cut hair style that accents her personality and features. She had cut her own hair with shears several days before the interview. Sarah grew up in various institutions, group homes, and foster homes across Georgia. She has an intellectual disability and mental health issues. She was in and out of institutions since the age of five.

When asked about her childhood, she echoed the sentiment of others who had been institutionalized at childhood. "As a child, don't

know what I liked to do, I bounced around too much to know what I liked. I never had the opportunities. I would be there one day and gone the next. I wouldn't know what to expect. I have no special childhood memories, no special childhood friends. My mom never came to see me. I went in at five, left at seven, back at twelve, and then spent ages sixteen to twenty-two at Central State Hospital. I did not have a childhood."

Sarah now lives in a lovely suburban neighborhood in a two-story home with the host family who had previously offered her respite care. In the background, a grandfather clock chimed as the time passed during the interview. The interview was conducted in the dining room at a formal table with floral placemats, a matching table runner, and a matching china cabinet with a set of beautiful patterned dinnerware. Although Sarah had lived with the host family for three months, she still had not yet unpacked. She has a private bathroom and her own bedroom, which is filled with "Winnie the Pooh" memorabilia, including stickers, statues, and an entertainment center decorated in the theme. The character is significant to Sarah because her father, the one person who did come to see her and send a card every now and then during her childhood in the institution, gave her a "Winnie the Pooh" toy several years ago.

### III. FROM THE INSIDE

Our informants identified several problems present in institutional settings in which they had spent many years—ranging from the benign to the insidious and criminal. One issue brought up by several people was that the *food* was awful. Sarah described the food as "nasty." Mary stated,

The food is terrible and they give certain excuses that people can't eat certain things or the budget won't allow it. Well, if they don't have the money to run the facility then why in the knick knock paddy-whack are they running it? What are they doing with all the money—from Medicaid or whatever—what do they do with it?

A number of informants noted that one of the newfound freedoms in community living involved deciding what and when they wanted to eat.

Both Jeremy and Mary noted that there was a *discrepancy in age* among people who were housed together in nursing homes. Jeremy stated, “Most of the people in the nursing home were older. There weren’t any younger people there. I’d like to see where [the state] couldn’t institutionalize younger folks because there’s some place to put them. Nursing homes are for people who cannot take care of themselves.” Mary echoed Jeremy’s sentiments: “I know one thing is if you are older and sickly, [a nursing home] might be a good thing for ya, but if you are a young person, you don’t have a life.”

Our informants almost universally commented on the *extensive rules* that they were required to follow governing their behavior and possessions. Mary took issue with the fact that regardless of her abilities or age, she was faced with the same rules as all of the other residents. She said,

the (same) rules shouldn’t apply to everybody . . . . They shouldn’t mix everyone all together . . . . I don’t think my mother should have had to endure all of that because the state made rules. I think it hastened her death because they took her pride by taking away her ability to do things she could do.

Glen said, “I had to have a bath by eight o’clock, because everybody had to have a bath by then. I had to be in bed with lights out at 9:30 and then we were all up at 5:30.”

The mandated schedule comprises only one aspect of the rules in institutional settings. As Glen explained,

If you did something wrong they would take away your privileges and make you go to bed right after dinner. [The privileges included] things like watching a movie at night or going to the gym. I don’t know what they considered bad, but some of the things I did [that were wrong] are things I don’t want to talk about.

Sarah described a system of rules and privileges using colored cards that had to be earned for specific tasks and behaviors; the cards then represented different levels of freedom to move about the campus or participate in off-site activities (such as football games or visiting Six Flags Over Georgia). Glen, Sarah, and Mary took issue with these rule systems because they forced them into situations that they had not consented to and were unfairly applied to all residents regardless of need.

Mary stated that one of her problems with the nursing home was the complete *lack of privacy or personal space*. She explained,

[I] didn't want wanderers in my room because they would tear up my belongings. I'd yell, 'get out.' Oh, it made me so mad. The wandering patients would pull out my stuff two or three times a day. Because I complained, I was labeled 'difficult' [by the nursing home staff] but would they want someone coming into their room tearing things up?

Mary explained that the problem of privacy extended to watching television; she said that there is a big television for everyone to watch, but she would have preferred her privacy and freedom to choose what she watched.

Severe *boredom* was a pronounced issue for several of the informants. Glen stated, "I didn't do much in the institution—no cards, no bingo, no nothing. I'd sit around watching TV or be outside." Lena said,

There was nothing to do; you just sit around. [Sometimes] there were little projects that some organization would pay you if you made the quota, but I never did that . . . There were dances, but I never danced. I just didn't feel like doing anything—I just didn't feel loved there.

Despite the over-crowded nature of many institutional settings, participants described a prevailing sense of *social isolation*. This issue derives directly from several factors: first, the disconnection

from family and community; and second, the somewhat random assignment to living in a place with people with extremely different backgrounds and needs. As Sarah explained, “I had no friends there. I basically stayed to myself in my room.” Sarah described that she did not want to play bingo because the other players would get angry if they did not win and she wanted to avoid the chaos. Despite this, she was forced to do so, as it was an activity in which everyone was expected to participate.

On a very serious note, a number of informants described incidents that must be regarded as *abuse and neglect*. Note that informants responded to a number of open ended questions seeking descriptions of their experiences, but were not specifically asked for details, nor was there an attempt to corroborate the allegations or determine how they had been resolved. There was no reason to believe that any of the informants was currently in a setting in which abuse or neglect was occurring.

Several of the incidents included the actions of staff members that reflected an absence of simple caring and respect. As Jeremy stated,

Nobody would check on me. One day I was really sick in the nursing home and I was telling the CNA [Certified Nursing Assistant] that I needed to go to the hospital. The CNA laughed at me and told me, ‘We’re not paid to care—if you do get out of bed, they won’t lay you back down until eleven o’clock tonight.’ I was left in saturated diapers and had sores all over my body.

Mary concurred with these ideas, saying,

Sometimes I’d lay in bed for nine or ten hours a day. I’d be soiled because no one would help me get up. People would walk by me and say they couldn’t do anything for me. And I’d say, ‘Even a two year old could help me, I just need a little balance.’ But they didn’t care.

Several people felt that they had no protection from indifferent or abusive staff members. Sarah said, “The staff didn’t treat you right

. . . [and] if you talked to the shift supervisor about it, they'd slap you around. If you ain't had no hot water, they'd make you take a cold shower and they wouldn't figure out why there was no hot water." Jeremy said, "I was afraid because I had a female CNA come in and rape me. It takes your pride away because you can't get away, and they know you can't get away."

Several of the informants directly compared institutional living to being in *hell*, saying that they would do anything to avoid going back. Sarah stated, "It was pure hell, and the people, if they didn't slap you around, they would talk junk to you. Then they'd try to be nice the next day . . . . Would I go back? Heck, no!" Mary's version of this theme was, "A nursing home is hell on earth. Tommy Olmstead is the devil's brother and God let me know that so I'll tell it." Sarah said if she were forced to go back, "I'd just say let me go six feet under." Similarly, Mary stated that during her time in the nursing home, she prayed to die because the whole experience was terrible. Jeremy compared his time in the facility to being in *prison*. "You can't go anywhere," he said. "You aren't given the freedom to get out of bed or to take a bath when you want to. I told somebody the day I left the institution that 'they're releasing the bars' because that's what I felt."

A number of informants identified themes related to social control and how they struggled to assert the right to make decisions about even minor things. Mary noted her trouble with making phone calls by stating, "In the beginning I was afraid of decisions because it was always done for me and things like phone-calling were hard because I was afraid I'd do it wrong . . . . [Then] I was afraid to dial the phone because it felt like someone was watching me." Mary noted that she had difficulty in making decisions after leaving: "Adreana would ask me what I wanted to eat and I'd go, 'uhhh.' I just didn't know because I was always just fed something. It was like starting all over." Negative comments about the institutions were met with derision, as Mary noted: "[They] brainwash you. Like I'd say 'I sure do want to get out of here and have a decent meal' and they'd say, 'Well no, just think you got it all here and you don't have to pay for it.'" Jeremy explained that the control exerted over a person in a facility takes away the person's pride and makes him question his

abilities. “It’s like when they say, ‘You’ve got it all here; you’ve got it made.’ And you hear it so much, you come to believe it. So you want out, but you’re very scared of it.”

#### IV. ON THE OUTSIDE

It is apparent from the interviews that community living dramatically improved the quality of life of each of the informants. Despite experiencing social isolation and boredom at times, all of the informants contended that they are happier and healthier outside the institutional setting. This shift in quality of life hinges primarily on the ability to exert a sense of agency—*choice in matters of life*. Glen shared that he was happy and is able to get out and go to volunteer jobs anytime he wants:

When I have a meeting, I give the information to Jackie (the social worker here) so she can give that to the cook and they make me breakfast or lunch when I need it. I can invite friends over and do what I want. I have TV in my room and I can keep to myself if I want.

He gave additional examples of freedoms he had in the community that could not be realized in an institution: the ability to go out, make friends, have spending money, and to be able to go to a movie by himself or with family. He went on to explain that he felt respected in his new home and that he has “freedom, like if I’m in my room they won’t come in without knocking on the door.”

Jeremy emphatically stated, “I felt like I was starting a whole new life again; like I had been reborn.” The transition out of the nursing facility was a major adjustment. He is now on the Independent Care Waiver Program funded through Medicaid, and he gets to make his own decisions. He expressed a sense of *empowerment* because he hires and fires his staff as well as sets the rules. In Jeremy’s words, “That’s freedom to me.”

Another common theme with the interviewees was that their dreams in life centered on *inclusion* in the community and being

economically sustainable. Jeremy went into great detail in describing his dreams, saying, “[My] dream is to buy a house with lots of land. I want to have horses and someone who can take care of them because I just want to look at them. My dream is also to have a family. I don’t care how old I am, I don’t care if I have to adopt. I want to change the way people look at adoption by people with disabilities.” Jeremy talked about employment and the dream of being hired. He noted that he would like this job to be in advocacy, because advocating for another is one of his dreams yet to be realized. “I want to be an advocate,” he said. “I want them to call me at home and bother me. I want to fight for their rights because I know what I have been through.”

In contrast to Jeremy’s dream, Glen and Mary shared short-term goals. Glen’s dream is to lose weight. He said that he doesn’t want or need help with his dream; “I just gotta push back from the table more.” Mary’s dream was realized shortly after the interview. Being blind and deaf for a short time as a child due to illness, Mary wanted to know how children who are deaf and blind learn. An introduction was arranged with a consultant for the Georgia Sensory Assistance Project at Georgia State University who works directly with children who are deaf-blind. Mary and the consultant have met several times to share ideas and educational strategies.

The connection between Mary and the consultant highlighted another common thread in the interviews—*social support*. Social support is a critical need for all, and it is especially important for individuals transitioning from an institution to the community. Jeremy passionately described his support staff as his chosen family. He stated that many of his favorite people are those who work at Disability Connections, an advocacy agency, because “They taught me a lot when I transferred out.” He described being petrified when he transitioned out of the nursing facility, saying, “I was always pushing the emergency response because I was never used to being alone. You have to adjust and know that you’ll be OK. I don’t have contact with my family, so my staff is my family.” Similarly, Eugene’s family, specifically his brother, will serve as a paid support provider.

Sarah's story offers evidence of the negative effects of lacking social support. She repeated throughout her interview that all she really wanted was a family. She felt she did not know how to act around people because she never had familial interaction and support. Sarah said, "I'm still learning what a family is like. I have my ups and downs but hopefully I'll learn how to be a better person. I'd like to learn how to be respectful. I'd like to learn more about people to let them in." She explained, "Just knowing I had someone to support me would be enough."

#### V. ADVICE TO PEOPLE TRANSITIONING

During the interviews, informants were asked if they would like to offer advice to individuals transitioning from an institution to the community. Each of the informants was willing and forthcoming with advice. As mentioned earlier, Eugene's advice focused on the need to have a *strong will and a strong mind*. On a more pragmatic, day-to-day level, Glen explained the importance of fiscal management by stating, "Try to *watch your budget*—be sure you stick to your budget because once you spend more money than you plan, then you'll be broke."

Sarah shared, "*Listening and learning* really helped me. I had to learn about what the [transition] plan is and what I liked and what I didn't like. I think that's one thing that helped me get out." Sarah explained the critical importance for the individual who is transitioning is to be at the center of the transition plan. She talked about how important it was to stay focused on the plan, offer extensive input, and be present at every meeting. "If you don't go to the meetings, then you are going to end up somewhere that will make you scared. I think fully participating in your ISP [Individualized Service Plan] meetings is the best thing." Sarah also stressed the importance of getting to know those who will be providing the community support, whether it be a host home or a direct support professional at a group home. Her statement draws attention to the

importance of person-centered planning and philosophies in promoting quality of life.<sup>6</sup> Jeremy explained that a crucial step in the transition process is for the person to realize they will experience resistance from others, stating, “[You] got a lot of push; you got a lot of pull. Even if you have all the support in the world, it’s not going to help if you don’t want it for yourself.”

Mary offered advice for those planning to live with others upon leaving a facility. In the interview, she discussed her challenges with her first roommate, whom Mary described as “an upside down staircase.” Mary identified her this way because the roommate would ask her to do certain things, such as turn down the radio, and immediately recant the statement; this was only the beginning of the discord between them. Because of her difficult experience with her roommate, Mary stated it is important to “show the person that you live with, if you live with anyone, that you can *be your own person* and don’t give into their controlling atmosphere. It took a little while to learn this [even with support from others] because I was in the nursing home for so long.” She wanted transitioning individuals to know that they have a lot out there waiting for them. She cheered, “Go on with it, I can do it, I will do it, keep going.” She strongly suggested the person set goals to accomplish. “When you wake up one morning, you’ll see them accomplished, you think ‘Gosh did I do all of this.’ And you say, ‘Yes, I did; I am doing this.’” Lastly, Mary shared how her strong Christian faith pulled her through the difficult times and disappointments. Her closing comment for advice was to “Trust in God. God has got you that far and he’ll get you the rest of the journey.”

Just as Mary drew on the strength in her *faith*, Lena explained, “Believing in God and Jesus Christ—that helped me put my life into focus. That’s what got me to realize I wouldn’t go back to an institution.” Her faith gives her the strength to fight for her rights “in every category and every situation—in work, going to school, living

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6. Rosalie A. Kane, *Long-Term Care and a Good Quality of Life: Bringing Them Closer Together*, 41 GERONTOLOGIST 293 (2001), available at <http://gerontologist.gerontologyjournals.org/cgi/reprint/41/3/293>.

in an apartment, having friends, discussing myself with people.” Lena wants those who want to transition to understand they have basic human rights that the institution cannot take away.

Related to this point, a final theme identified was the importance of *self-advocacy* in day-to-day activities. Jeremy used the example of going to a medical appointment: “When you go to the doctor and your aide is with you, he [the doctor] asks the aide, ‘So, what’s wrong?’ Excuse me, but I have a voice—ask me!” This point was underscored by Lena, who stated, “It just came to me, knowing that I had to stand up for myself and my rights.”

## VI. ADVICE AND CHALLENGES FOR ADVOCATES AND POLICYMAKERS

In addition to the encouragement offered to those still in institutions, the informants provided specific perspectives for consideration by advocates and policymakers. Some of these came in the form of criticism, others as challenges, some as advice, and several as reflections on the services or supports for successful community living. They are, however, consistent with an extensive body of literature related to the movement from institution to community.<sup>7</sup>

Jeremy spoke of the cost-effectiveness of living in the community and criticized the nursing facility industry for *profiting* from his time there. Jeremy stated, “They had to keep people in to keep their money. It’s cheaper to live on your own . . . . It’s frustrating because there’s not a lot of funding available to us. The government wants us to stay there because it’s easier, but it’s not about what’s easier, it’s about what’s right.” Jeremy’s point draws attention to the critique levied by the disability rights movement that institutions generate profits by maintaining people in facilities who could be supported in the community.<sup>8</sup>

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7. J.L. Howell, S. Ramirez & D. Crimmins, *The Olmstead Decision: A Promise Still Unrealized*, INT’L J. PUB. HEALTH (forthcoming).

8. M. Russell. BEYOND RAMPS. 1998.

Jeremy and Mary both suggested that policy-makers gain personal experience with the *realities of institutional living*. Jeremy stated,

For people to realize, we have to put them in our shoes[;] . . . they need to hear our stories. I wanted to tell my story because people don't know. It does happen. The only people who can make the change are the people at the state level. They need to actually go in there and see some of these places. Sometimes the state will go in there but they tell them they are coming so they are prepared. What happened to surprise visits? What happened to our lives? So many people die in there and I could have been one. . . . I don't want to offend people, but people can work in these fields and not know what we go through. If you haven't been institutionalized you have no clue. You can sit there and advocate, but until you've been there you won't understand.

There was a clear call for community supports for meaningful engagement during the day. Lena spoke both to the importance of *employment* and the frustration of low-wage work:

What I really want is to have a [living] wage from a real job. I want a career and family. I want to be comfortable and self-sufficient. When I was leaving all of those jobs, I knew I was a good worker but I want to have longevity and permanency for good pay. All I've ever had was minimum wage.

Many informants were encouraged to pursue *volunteer* activities, in part to ensure eligibility for Medicaid. Glen, for example, cited his work with several organizations and committees. Sarah is also an active volunteer with Atlanta ADAPT, the Long Road Home, and People First of Atlanta.

Jeremy spoke to the broader issue of *flexibility in financial supports*:

What I want to change is to look at the world to know there's more freedom out there and that we have more money available.

Right now I am having trouble with the waiver; they claim I can't have more time because my school schedule is not medical. What about people trying to go out there and make a life so that some day they may not need the waiver? They don't want to give any more money because it's not medical.

Sarah's host home support is concerned with the lack of *mental health supports* for individuals who have transitioned into the community. Sarah is contending with significant anger management issues at her home; her anger has escalated four times in the previous three months to a point where the police were called and she was taken into custody. Sarah's host mother was asked if she believed that social isolation experienced in institutions was the cause of Sarah's outbursts. She responded, "To tell you the truth, I don't know. I don't know what went on in the institution. From five years old, she was in the institution seeing people with all different behaviors. She got a temper. I think the institution had a part to play in this." It also speaks deeply to the need for follow-along behavioral supports, particularly those that can be provided to prevent crises.

*Safety* was also identified as a concern for several informants. Jeremy described his transition concerns:

To me it was difficult at first. I didn't know if I was safe in my apartment. I didn't know if I was safe anywhere because of what I had been through. I wouldn't even open my door for the staff people when I first moved out. They had to say exactly who they were. A lot of the homecare agencies care only about money; they don't think about us as people with a lot of fear because of what they've gone through. I know what I've been through and I'll never do it again. I have to be real careful about letting my guard down because . . . it's hard to trust people these days. I have to watch myself because nobody is going to protect me but me.

Mary spoke of her *public advocacy for change*:

You have to be in there to realize what's going on—and a lot of people don't want to hear this! This is what Tommy Olmstead did and when I asked him why we'd be better off in here, he just walked off. I said, 'You didn't answer me.' But he said nothin' because he probably didn't want the truth. One day he's gonna find himself flat on his back and he's going to say, 'I wish I could get out of this nursing home.' But he'll be there one day. And I told every one of 'em [in the state legislative meeting] that everyone opposed to getting out of nursing homes could be disabled and stay in a nursing home for a year. Then they couldn't say, 'You've got it good there.' I said, 'I wish to God that every one of you could be in a nursing home.' And I beat on that podium [while I said that]. They said to calm down—and I said, 'Calm down about what? And what's wrong with telling the truth?' They said it'd get better, but I said it would get better if they exercised the power Georgia has because people trust you to do the right thing. And you earned that trust before God and man and you should do what you professed to do.

Lena's advocacy identity took hold after she visited Disability Link:

[They] invited me to attend Disability Day at the Capitol in 2006. I had never in my life had anything happen like that. It was so great to see people fighting for their lives. The first organization I joined was ADAPT and I was shy and so scared. When I went in there, I met these great people. It overwhelmed me. These people had such an impact because of what they talked about and what they were fighting for. I started opening up and talking. I joined People First of Atlanta and Long Road Home and I just didn't have time to get depressed and boo-hoo. These strong personalities and convictions about what they were doing made me change. I just blossomed. I found this courage and it helps me stand up for others.

## CONCLUSION

We wish to thank Lena, Glen, Eugene, Mary, Jeremy, and Sarah for taking the time to tell us their stories. We and they understood that we were likely to encounter painful or unpleasant memories, and we did. During the interviews we reminded our participants several times that they were free to choose to *not* talk about topics. With only a few exceptions, this was not elected. We appreciate their willingness and courage in sharing.

We also understood that our interviewees were motivated to help others. Their narratives have the immediate intent of shedding light on the lived experiences of those who have survived institutionalization. In many ways, the audience for this information is the advocates to encourage them to continue their work and the policymakers to understand better the human cost of not enforcing *Olmstead*. The narratives also spoke to the successful transition to community living. And, while the audience for this information clearly includes the advocates and policymakers, there was an overwhelming sense across our informants of a message of hope being extended to those still in institutions, “Hold on, your time is coming.” Our collective hope is that this time needs to come quickly; our fear is that it will not.

