My Life Now
RUTGERS
School of Public Health

Community Living Education Project
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“Educating families and staff about the possibilities in community living.”
Information about the Community Living Education Project

The Rutgers School of Public Health Community Living Education Project (CLEP) is supported by the NJ Division of Developmental Disabilities (DDD), as a part of the NJ Olmstead Plan, to orient people with developmental/intellectual disabilities and their families to the potentials of community living.

CLEP Learning Events: 1. My Life Now Alumni Stories Events, which are held at developmental centers. The purpose of the event is to celebrate and share the life story of a former Developmental Center (DC) resident to acknowledge DC staff who assisted in the transition of a former resident. The individual, family and agency staff talk about the challenges, successes and how supports are provided in the community today! 2. CLEP coordinates and facilitates Self-Advocacy Community Living Events (SACLEs) at developmental centers in collaboration with Community Access Unlimited (CAU). Self-Advocates from CAU provide peer-to-peer support and mentoring for individuals who are ready to move.

The New Beginnings in Community Living bi-annual newsletter features a “Spotlight Story” about current events in developmental disabilities, news and information about CLEP learning events, and a feature column called, Living in the Moment.

Guides: 1. Community Living: Explore the Possibilities guide provides information for family members who are considering moving their loved one to the community from a developmental center. The guide includes information about housing options, support staff, aging in place, emergencies, medical information, activities for individuals, and quality assurance measures. 2. Apartment, Townhome, Condominium Living guide provides information on non-traditional living settings and the support services that individuals who live in the community utilize. The guide explains the staffing, daily activities, and medical supports, provided for those living in apartment type settings.

My Life Now magazine features stories about individuals who have transitioned from a developmental center to the community. Also, included are stories of people living in community settings under the Self-Direction initiative.

Community Living: Envision the Possibilities DVD provides stories about individuals who are living in the community. The participants provide candid information regarding their daily activities and what their life is like in the community. The DVD can be viewed at the following website address: http://www.youtube.com/watch?v=HAd2Oa-9ORU

Our Life Now video shares the transition stories of individuals with developmental disabilities. It highlights the experience of their families in participating in the transition process and presents how people with developmental disabilities can successfully live in community settings.

Mini-Updates eNewsletter provides a snippet of a previous CLEP story and events taking place throughout the country.

Webinar — CLEP conducted a webinar entitled: "An Overview of Community Living for People with Developmental Disabilities in NJ". It can be viewed at the following website address: http://web.sph.rutgers.edu/linkweb/resources/links.html

Family to Family Advisory Group are family members who have successfully transitioned their loved one from a DC or from the family home to a home in the community. They assist CLEP with developing methods to increase informed decision-making for family members, and they help support and mentor family members regarding community living.

The CLEP website, http://sph.rutgers.edu/service/CLEP, provides access to all project publications and links to community information and resources related to Olmstead. The CLEP Toll-Free Number is 800-500-0448. CLEP’s email address is: CLEP@sph.rutgers.edu. CLEP is on Facebook! To view our page you can go to www.facebook.com/SPHCLEP.
November 2017

Greetings,

I would like to welcome you to the ninth edition of My Life Now. This publication is dedicated to presenting the stories of how people with developmental disabilities are successfully living and being supported in communities throughout New Jersey. As you read, you will notice how people and resources are pulled together along the way to developing quality outcomes for those featured in this edition.

The Community Living Education Project (CLEP) is committed to presenting the journey of individuals and their families in the transition process. The support of families, guardians, staff and stakeholders is vital to a person’s success. Along with the stories of those who have transitioned into new homes, this edition will include the stories of Myrta, Adelaide, and Gary. They are self-advocates from Community Access Unlimited (CAU) who have partnered with CLEP to do the important work of providing community learning for residents at developmental centers. Myrta, Adelaide, and Gary each share their own transition experiences and the many activities that they are currently involved in.

As always, CLEP is grateful to all the participants who contributed their time and efforts in order to present the stories in this issue. Your assistance has made this a very special edition.

Please enjoy My Life Now.

Sincerely,

David Wright
Letter from the Acting Assistant Commissioner of the New Jersey Department of Human Services

Dear Friends and Colleagues,

My Life Now provides us with a glimpse into the lives of some women and men with developmental disabilities who share their personal stories about community living and provide us with some insight into how they feel about their homes, their lives and their accomplishments.

Living in a home in the community has made a positive difference for the many people who have moved from Developmental Centers or from family homes into community living programs. Working, volunteering, attending events, meeting new people and having the new experiences that community living provides, results in greater self-expression and personal fulfillment.

Successful community living programs are built on a foundation of: the work of self-advocates; the support of family and friends; the commitment of New Jersey’s dedicated service providers, and; the Community Living Education Project at Rutgers University School of Public Health, which teaches individuals and families about community living opportunities.

We are grateful to the women and men featured in My Life Now for showing us how they have become an integral part of their communities; and, a special thanks to self-advocates and the disability community, their advocacy and dedication enables individuals to live and thrive in homes in communities throughout New Jersey.

Sincerely,

Jonathan S. Seifried
Acting Assistant Commissioner

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Love, Perseverance, and Strength…Michael’s Story

By Natalie Trump

It was a lovely warm, sunny morning as we arrived at Michael’s home. Antoinette Johnson and Natalie Trump from Rutgers, Community Living Education Project (CLEP) and Pauline Bailo, project director at Penn Reach were greeted on the front porch by Linda Kerr, Michael’s mother. She invited us into her home and we met Michael. He welcomed us with his big, beautiful bright eyes – a great way to start our day. We also met Jerry, Linda’s boyfriend, who has known Michael for 3½ years. “I love Michael. It brought me to tears when I first met him,” said Jerry.

We began our conversation with Linda sharing it was 10 years ago when she placed Michael’s name on the Division of Developmental Disabilities (DDD) Waiting List for residential placement. She put his name on the list in case she got ill, or if she could no longer care for her son. She wanted some assurance, as many families do, that Michael would be taken care of when the inevitable happens and she is no longer here.

The Early Years: When Michael was three months old, he couldn't hold his head up. Linda took him to the Institute for Basic Research, Newark, NJ, where he underwent brain scans, and was diagnosed with Immature Brain Myelination, the outer part of the brain did not develop. Doctors told her children like that don’t live long and Michael wouldn’t live longer than three to five years old. Linda stated, “I wasn’t having that,” and she worked that much harder to care for and support her son. Michael will be 30 in October of 2017 thanks to the love, perseverance, strength, and care of his loving and unstoppable mother.

Michael attended Project Child, a Pre-School program in Trenton, NJ, and then attended Mercer County Day Training Center on Stuyvesant Ave. in Trenton until he was 21. They provided him with many community and sensory (touch and scent) experiences.

Even though Michael has significant needs, he grew up going everywhere with his mother, mother’s boyfriend Jerry and older brother Christopher. Jerry and Linda took Michael places he would enjoy. He loves going to the boardwalk in Atlantic City, NJ, and Seaside, NJ, where there are lots of bright lights, people, music and arcade game noises. He loves multi-color lights, Christmas lights, and country music. Linda has Christmas lights set up for him to enjoy in his bedroom. “I love Michael’s beautiful spirit, he’s my beautiful little boy, and
he gives smiles that light up the room, never cries or complains,” said Linda. She has driven to West Virginia with Michael for a weekend get-a-way, to Florida to visit family and Linda's two grandchildren. While in Florida, Linda stated, “I do it all myself, I set up a Tiki umbrella, and take Michael to the beach.” Linda has provided all of Michael's selfcare and medical care needs for 30 years.

Eight years ago, Michael's medical support needs increased. He required a feeding tube to receive nutrition and a trach to breathe. Michael is also someone with severe asthma and requires breathing treatments throughout the day and night. Michael uses a wheelchair for mobility and needs others to propel him in getting around. Assistance is needed in lifting and transferring him from his wheelchair to his bed or into his lounge chair. Linda has never had a day off or a break from caregiving. All she ever wanted was a few hours off – some respite time. Linda received a phone call from Adam Warman, supervisor, Waiting List Unit, at the DDD, that Michael's number had come up on the waiting list. Linda wasn’t sure what to think, she didn't want to place him residentially, as she thought the only place for Michael's care needs, would be in a nursing home. DDD offered Michael in home supports via the Supports Program or residential placement via the Community Care Waiver (CCW).

Michael was referred to Caregivers of New Jersey support coordination agency by DDD through the CCW program. Caregivers of New Jersey support coordination agency was assigned and Barry McManaman, support coordinator, met with Linda and Michael to discuss supports and services he could receive through the CCW. Barry stated, “I fulfill several duties as Michael's support coordinator by assisting him and his family to find services through qualified DDD providers for his care. I also follow up with a monthly phone call and visit every three months to ensure that the services are being delivered and that he is happy, healthy, and safe. If we need to speak more frequently, we can talk on any day, or multiple times in a
day. My first visit with Michael and his mother was on 11/28/2016. Upon meeting Michael and his mom, there was definitely a sense that mom needed some help. She was having difficulty with getting medical supplies for Michael’s feeding and breathing treatments. I knew at the first visit that a second visit with DDD present would be necessary to coordinate help with Medicaid and medical supply companies. Michael is a very loving young man, who requires total care. I was overwhelmed with the sense of love that I saw from mom toward her son. Linda had some assistance from We Care who provided a home health aide, but other than that she is the sole caretaker."

The Planning Process – According to Barry, “The planning process always starts with the person. Not what a diagnosis is or what they cannot do, but who they are. What they like and dislike, what they are trying to obtain for themselves in this world. From there, a discussion about how to help attain those things and what sort of supports they would need to chase those goals happens. Finally, but not less importantly, what sort of medical or health and safety precautions must be identified to ensure the person is healthy and safe.”

Barry felt Linda would benefit from learning about how supports and services are delivered in the community and contacted the Community Living Education Project, (CLEP) for assistance. Natalie, a CLEP team member, called Linda to discuss the different community living options available. She also set up two provider agency appointments where Linda could see, learn, and experience group home and/or apartment living with 24-hour supports. Until Linda visited a group home with nursing supports and services being provided to people with similar medical challenges as her son, she believed Michael’s only option would be to live in a nursing home. She was amazed at what she learned and experienced during our visit. Linda wanted to visit another provider to see and learn more.

Linda and Natalie then met with Krystal O’Dell, CEO of Penn Reach. Linda began telling Krystal about never receiving any respite in almost 30 years and her hope is to one day move Michael to an apartment, like an apartment at Project Freedom. (For more information on Project Freedom, go to www.projectfreedom.org.) Linda had considered moving Michael to Project Freedom years ago, but it didn’t work out.
Linda lives very close to one of Project Freedom’s locations and felt she could always visit if Michael could live and be supported there. Linda began tearing up as she shared she was not quite ready to let go of supporting Michael at home. Krystal said she could help her with respite to give her a break for a few hours during the week or on a weekend. Linda never had a weekend to herself, where she could go away for two days, get some rest, have some fun, and have a break away from caregiving. Linda began imagining what that would be like, she began smiling and chuckling saying “I could go away for the weekend by myself, I could even get some sleep, and I could actually go on a vacation to Florida or maybe Hawaii one day.”

Krystal said she could provide in home supports and respite to get the ball rolling. She would make sure Michael and Linda liked and approved of the staff. Krystal also suggested looking for a home for Michael over the next six to 12 months and that if Linda agreed, the staff Penn Reach hired would also move with him to make the transition easier. Linda liked this idea of getting to know staff, making sure it was a good fit for Michael and was working well before Michael moved out of the family home. Linda was very encouraged by the discussion and agreed.

Linda told Krystal about Karen, a person who provides self-care to Michael through We Care. Krystal then hired Karen to begin providing additional support and respite services through Penn Reach. Linda stated, “Karen is like a second mother to Michael, she loves him and takes great care of him.” Linda felt Michael was in great hands and would be well cared for if she went away for a weekend. This past summer Linda was comfortable and traveled to West Virginia without Michael for the first time.

Pauline Bailo, project director at Penn Reach, meets with families to explain the many options the agency offers. She interfaces with individuals and families, hires direct support professional (DSP) staff, prepares vouchers, DSP time cards, submits time cards for approval to the individual and/or family, and monitors the budget to make sure Penn Reach stays within the allotted hours. She also works with the support coordinator, in the event the individual’s needs change, and/or if the person wants to participate in outings or other programs that Penn Reach offers. Pauline stated, “Michael is very loved and handsome.” Pauline’s advice to families: “Plan for the future, it can mean many different things. Put a plan in place. In case anything happens, you have a plan, especially if you’re the only family. There are many options and choices. Check them out.”

Penn Reach is working diligently to assist Linda and Michael with their future plan to locate a home, whether it is at Project Freedom or an apartment close to Linda, where Michael can be supported and cared for. “I love what I do because it creates hope,” said Pauline. Barry has observed how Michael communicates and “shows happiness, sadness, and discomfort all in his face and eyes. His strength and perseverance are an amazing thing to witness.” Barry shared that “success comes in small doses, getting additional support hours, getting some of the medical equipment he needs, and getting some time for mom to live her life are all small successes we have had.”

Barry offered his advice to families on the waiting list. “Be patient and really think about the types of supports your loved one might need. The more planning and thinking that is done before they are referred for services, the easier it is to really picture the life of the person once they have the budget for services. I would finish by saying that Michael is an extremely strong willed young man, and he is fortunate to have a mother like Linda who is able to care for him the way she does. It is a testament to her love for him, and his inner strength that have carried him through life!”

According to Barry, planning for an individual’s future can be a difficult subject to discuss. “This can often be a touchy subject, particularly when the parents of loved ones are older. It is important to have discussions with families about what is going to happen 1, 5, 10 or more years down the road. We also talk about where a person might live in the future if they are living with their parents. Special Needs Trusts also come up as a part of future planning.”

Linda’s advice to families is to “Think about the future, what is best for both of you. I am his mother. Letting go is difficult, and I have to think about the future.” Love, perseverance, strength and care the main theme supporting a mother and son throughout life!
Frank sat on the porch of his home, blowing bubbles and enjoying the summer day, as he waited for his interview to begin. He has lived in his home since April of 2015 and is supported by REM, The Mentor Network. Frank grew up in Passaic County with his family before moving to Greystone Psychiatric Hospital and then North Jersey Developmental Center. When North Jersey DC closed he moved to Woodbine Developmental Center with his friend Michael Muldowney (also featured in this issue). Frank began attending CLEP Self-Advocacy Community Living Events, or SACLE’s, when we first began at Woodbine in October of 2014. He was an active participant and shared much about his hopes and dreams about moving to the community. Frank and Michael transitioned to the group home together and met their other housemates. Frank had...
one visit to the home and then easily transitioned. Frank shared that he likes living in the community because it is quiet. Frank tried attending a day program when he first moved into his new home but did not like it...so he decided he is retired since he is 67 years old.

He now chooses how to spend his day either listening to his CD’s or watching one of his movies (he has a collection of 300). Some of his favorites include: “The Little Rascals”, “Abbott and Costello”, “Happy Days” and “Laverne and Shirley.” Frank also enjoys going fishing. He recently bought a new fishing pole and staff will take him to the lake at Giampietro Park in Vineland to enjoy the outdoors. Frank rides with staff in the afternoon as they drive to pick up his friends at their day program. He gets a chance to say “hi” to other friends who attend the program, too. Frank grew up with two sisters and two brothers. When Frank was younger he dreamed of forming a singing group with his four siblings. He thought “The K5”, short for “The Keryger 5,” would be a great name. “Why not?” said Frank, “There’s the Jackson Five so why can’t there be the K5?” Frank used to play the drums, and he still enjoys singing. Frank likes all genres of music including disco, rock and roll, and country.

Frank has a remarkable memory. He maintains extensive records in his notebooks. He has listed all the movies he owns, an inventory of his 77 tee shirts (including what is written on each one of them) and the 33 hats/caps he owns. He also has lists of all his friends from North Jersey Developmental Center and the cottages they lived in. Frank likes the New York Jets and Philadelphia
Eagles football teams and he has inventories of all sports teams by state. Another notebook lists the names of every President of the United States and restaurants he has visited. Some of his favorites are Red Lobster, Golden Corral, Applebee’s, IHOP, and Moe’s Grill. His birthday is in October and Frank shared that he wants to go out to have dinner at Red Lobster to celebrate. Frank’s notebooks are very important to him so he keeps them with him at all times.

The four housemates enjoy going to Six Flags Great Adventure, Dave and Buster’s, and Clementon Park. They have also visited the Cape May Zoo and the Camden Aquarium a few times. Frank loves Halloween and Fright Fest at Six Flags Great Adventure. Last year he dressed up as Spiderman and is thinking about being Captain America or Thor this year. Frank likes both Marvel Comics and DC Comics. Frank also bowls at Legacy Lanes in Vineland or King Pin in Pleasantville. In addition, the men like going to the movies, to a local park to feed the ducks, and taking walks. They do these activities during the week after 4 p.m. and on weekends.

Crystal Durham, program coordinator at REM, was asked what she likes and admires about Frank. She shared, “Frank is very helpful, and I like and admire his humor! He is polite and loves to go out to eat.” Crystal began working with Frank about six months after he moved to his new home. Currently, she is assisting him as he learns about his medications. He writes them down and they review them together. She shared that Frank “…loves to sit and write all day, it makes him happy.” He
also does his own laundry and does not want to be interrupted since he wants to complete his chores. Frank also has worked very hard to be more patient especially when they are all getting ready to go out. Crystal also spoke about Frank’s helpfulness; he regularly puts out the garbage and shovels the snow around the cars during the winter. When Frank first moved to his home, he hid his belongings because he was use to them being taken at the developmental center. He would forget where he hid his things and staff would help him look for them. Staff found a better solution; they bought Frank a lock and key so he could secure his bedroom. Frank is happier now that he knows where everything is including the pet Beta fish, Curly (named after one of the Three Stooges!) that he keeps in his room. Frank shared that he likes his house especially the cans with the easy open tops. He jokes with Crystal when she is preparing his lunch by asking her “What is this restaurant called?” Crystal responds “Crystal’s Kitchen” and Frank will then ask “How much does the lunch cost? I don’t have any money to pay.” Crystal will answer “You’ll have to wash the dishes if you don’t have money to pay.” Barbecues and holiday parties organized by REM are also a favorite activity for Frank. Frank does miss the food truck vendors at the parks in North Jersey. He told us he would like to visit them soon and get “hot dogs and other things to eat.” As we finished up our interview, we asked Frank what his advice would be to people who may be interested in community living. Frank responded, “Do what you’re supposed to do. It’s a good idea. Do what staff tell you to do. Follow the rules because they help keep you safe.” That’s good advice for us all.
SACLE stands for Self-Advocacy Community Living Event. Michael was a member of this group when he was a resident at the Woodbine Developmental Center. He learned skills while attending SACLEs which helped him in his transition to the community.

Prior to moving to his community home, he lived with his grandmother until he was 21 then moved to the North Jersey Developmental Center. When North Jersey DC closed, he moved to Woodbine DC. While living at Woodbine DC, Michael received a visit from REM/The Mentor Network. After the visit, the agency wanted to support Michael and the process began.

Michael lives in a beautiful two-story home, which is spacious, has wood floors throughout and has a grand fireplace. His backyard is exquisite along with the front porch which is very inviting. He has lived in his new home for two years, and he loves it! The transition happened fast and literally overnight. He shares his home with three additional housemates. One of which is Frank Keryger, who is featured in this issue of My Life Now. To keep himself busy one day a week, he cleans at an REM-run day program located in Vineland on Thursdays. He will also be volunteering for the Salvation Army in the near future.
He shared one day he would like to work for the Williamstown Fire Department.

**SACLEs HELPED HIM TRANSITION**

Michael credits the SACLEs at Woodbine with piquing his interest in moving to a community home. His participation in the SACLEs gave him the insight regarding what the community would potentially be like for him. A staff member at Woodbine DC named Tyrone helped Michael manage his behavior so that he could move. When he moved, he was a bit nervous because he didn’t know the staff or the area he was moving to. When he moved in, he met his housemates. Once he got familiar with everyone, he felt more comfortable with the move.

Since his transition, he has had an active life. He recently went to the Clementon Park Amusement Park. He recalled a staff member who went with him to the amusement park and the staff member who went on a big rollercoaster got scared. Michael had us laughing during the interview as he recalled the details regarding the fear that the staff member displayed on his face while on the rollercoaster.

While the mission of each agency is a smooth transition, the REM Program Coordinator, Crystal Durham, stated that Michael’s “…attitude has improved, and he doesn’t throw temper tantrums anymore.” She also stated that he is very friendly. He’s is doing well with his behavior. He is being taught to be independent and to take care of himself such as his hygiene, i.e. showering, shaving, and personal care. Some of his current goals are to keep his room clean and do his laundry. He’s very helpful around the house and takes out the trash and brings the cans back up to the house. He’s reminded that this is his home and everything he does is important in keeping his home intact. Michael likes keeping his home clean. He currently knows how to use the microwave and a future goal is teaching him how to cook and to take his own medications.

Crystal stated that family members are welcome to come visit when they would like, however, it’s always best to call before coming to make sure they will be home as they are out in the community a lot participating in activities. REM staff will take Michael to his grandmother Jeannette’s house in Plainfield, NJ, approximately once a month to visit her, or they will take him to Atlantic City to meet her there to play the slot machines.
Also, he will be seeing her for Thanksgiving and Christmas. In addition, he travels up to Dunellen, NJ to visit with his uncle.

His grandmother mentioned that she and Michael are very close and they see each other often. She likes to cook and, after he visits with her, would often send Michael back to his home with a home cooked meal that he enjoys sharing with his housemates and staff members.

Crystal stated that they are looking for a suitable job for Michael. His case manager is working on pursuing a job coach for him. While he’s waiting for a job to come through, besides the volunteer activities and the day program work, he participates in track and field with the Special Olympics. The Special Olympics coach keeps in touch with him regularly.

Being healthy is very important to Michael. Although he likes eating at places like Wendy’s and Burger King because he likes fast food, during the interview, he mentioned that he can only eat food like that “in moderation.” He is very aware of what is important to maintaining a healthy life. He doesn’t get sick often and the REM staff make sure that he goes to his doctor’s appointments when needed.

During the summer months, the individuals and staff of group homes run by REM get together for BBQ’s and other fun events. They pick a home to host and everyone enjoys the events! Other activities include trips he takes with the day program. However, there are moments when some of their activities are impromptu. If the housemates don’t have anything planned during one weekend and they decide they want to go out, they are able to do that according to Crystal. They like going to
the movies on the spur-of-the-moment.

Michael loves gadgets like his computer, Walkie-Talkie, and his cell phone. In his private moments, he likes to go on his Facebook account, look up information on trains on the computer, play games on his PS4 and watch television shows like “Cops” or “E.R.” He’s also a fan of gospel music. As a future goal, Michael would like to go on vacation and wants his housemates to go with him. He would also like to take transportation by himself one day. I asked him if there is anything that he dislikes about his home, and he could not think of anything that he dislikes.

During the interview, Crystal was asked if she had any advice to offer family members who are interested in pursuing community living for their loved one. She said, “I don’t think some individuals are placed appropriately. Make sure you do your research before deciding on placement. Really do your research. Don’t just make one phone call.”

Michael’s grandmother feels he is happy in his home. “Since his friend is there, he’s happy so he wants to stay there,” said his grandmother. Michael had some advice to offer as well for any individuals at the developmental center who would be interested in moving to the community. He said, “Make sure you get up on time, don’t sleep in when you have to go to work.” He believes some of his friends at Woodbine DC would do well if they moved to the community.

Michael is very intelligent and enjoying success living in the community. He is well-liked and very aware of what is important to and for him to continue to live a successful life in the community. With each day, Michael is making positive strides and is a strong advocate for community living. It is his goal to live the life that he desires by making his own decisions with support and participating in activities which make him happy.
A Beautiful Soul Finds Peace in Her New Home
By Antoinette S. Johnson
JANICE IS A WOMAN OF GREAT CHARACTER, CONVICTION, AND A WARM-LOVING SPIRIT. She has overcome many obstacles and is living the life that she deserves to live. As eloquently stated by her Aunt Karen Dalton-Williams, “Janice absolutely deserves to be here [in her new home].” She is a woman to be admired because in spite of everything that she’s been through, she has never given up and her determination is both amazing and admirable.

It’s no wonder why everyone is so drawn to her. When you meet her, you see and feel her spirit and energy emanating throughout the room. When in her presence you say to yourself, “I have no reason to be down in spirit because the brightness of Janice’s spirit has lifted me right up.”

My co-worker, Natalie Trump, and I were taken by Janice during our interview. Not only were we drawn to her spirit; we were captivated by her kindness and pleasant personality. Because of her personality and wonderful spirit, you would never think went through anything difficult. However, she has not let anything get her down. She has risen to the top with grace and dignity. When you read her story, we are sure you will be as captivated by Janice as we were.

A TRAGIC SITUATION TURNED VICTORIOUS…

In the early years, Janice lived with her mother and stepfather. During this time, Janice gave birth to two sons. Her youngest son was adopted by a family in Millville, NJ and unfortunately, her mother passed away from a brain aneurysm. After her mother passed, she and her oldest son were left with the stepfather. This was a less than ideal situation for Janice and her oldest son as they suffered the horrors of abuse at the hands of her stepfather.

The stepfather decided to move to Baltimore, Maryland, and Janice and her oldest son went with him. As stated by Karen, “He moved to Baltimore because he thought one of Janice’s sisters or family members on her mother’s side would lay claim to her and her oldest son. The stepfather was unem-
employed and functionally illiterate and Janice and her son were his main source of income." Moving to Baltimore to live with the stepfather would prove to be difficult for Janice and her son because of the abuse they suffered – starvation and other forms of abuse. Janice's son's starvation would cause him to steal lunches every day from students at school and, subsequently, the Baltimore Child Protective Services was contacted. He was removed from the home and placed into foster care.

Because the starvation was so bad, Janice was driven to eat leftover food from public trash cans. Not to mention she also suffered abuse from her stepfather's brothers. Because of Janice's cognitive impairment, she did not report the abuse to anyone. "She had no social life, and she was not aware that she was being taken advantage of," said Karen. Karen continued, "On occasion, the stepfather's girlfriend stayed over his house. One day while he was asleep, she tied my niece up by the wrists, threw an accelerant on Janice, and set her on fire. Her upper torso, arms, neck, face, and ears were burned." Janice suffered third and fourth degree burns over the upper portion of her body. After she was burned, she was placed with the stepfather's sister by the Adult Protective Services of Baltimore. While hospitalized, she was interviewed by the police and was unable to articulate what happened to her. Therefore, charges were never pressed by the prosecutor against the stepfather's girlfriend who was suspected of setting Janice on fire.

After Janice was convalescing in the hospital, a person who knew Janice's family contacted her Sister Stacey. Stacey then contacted their Aunt Karen, and she stepped in to care for Janice. Karen "went to Baltimore to check on Janice's welfare to find that she had been treated horribly over the years." She petitioned the city of Baltimore and was granted custody of Janice. Adult Protective Services would not allow Karen to take custody of Janice until she found a hospital with a burn unit to treat Janice's horrible burns.

She found a burn hospital called Crozer-Chester Medical Center, in Chester, Pennsylvania, for Janice's convalescence. Janice was treated as an outpatient for almost a year. She wore a burn suit as a part of her treatment which covered the complete area of her burns all the way up to her head and face. Karen gives much respect and praise to Social Security and Medicare who approved her account on the same day that they applied for funding immediately after they saw Janice's condition. As a result of this atrocity, her stepfather became paranoid and died in Ancora Psychiatric Hospital. When Janice's Aunt Karen got involved, things began to change in her life. She was surrounded by love and no longer had to endure abuse in any capacity. Janice could finally have the life that she deserved to have. When Janice was able, she moved into Karen's house. Karen would take her to places like the dance club at the McGuire Air Force Base so that Janice could dance. Everyone who knows Janice knows she LOVES TO DANCE!!! Karen shared a wonderful memory. They were in a store shopping one day and the music was playing over the speaker system. As Karen was in one part of the store and Janice in another, Karen wondered what the commotion was on the other side of the store. There Janice was in her glory, stealing the show, and dancing to her heart's content. Many of the store's customers gathered around her and cheered her as she danced. "I like to dance and boogie. It's my number one thing. I can dance to any kind of music," said Janice. In fact after our interview, she turned on her music and danced for us.

WAITING LIST PROGRAM INVOLVEMENT...

Karen and Janice have a wonderful relationship. She lived with Karen for 17 years before moving into her own home. The reason why the decision was made to move was due to the Division of Developmental Disabilities Waiting List number system in which her number came up for residential placement. They decided to explore the options at that point. Kenya Welch, transitional case manager for the DDD Waiting List Unit, contacted Janice and Karen to discuss possibilities. Karen was pleased with Kenya's professionalism. She moved with expedience and Kenya had a lot to do with Karen feeling good about things.

Kenya reached out to Janice and Karen in October 2016 regarding Janice's number coming up on the Priority Waiting List. According to Kenya, "I discussed eligibility for services based on her New Jersey Comprehensive Assessment Tool (NJ-
CAT) results; in Janice's case, she was eligible to receive services under the Supports Program. It was at this time that I was informed by Mrs. Dalton-Williams, that Janice was in need of more services than the Supports Program could offer her. Mrs. Dalton-Williams indicated that Janice needed more supervision and assistance with self-care needs, money management, household activities, etc. Mrs. Dalton-Williams was also informed of the Community Care Waiver (CCW) and offered a Level of Care (LOC) review to insure the NJCAT completed depicted a true representation of Janice’s abilities and level of assistance needed. After completing the LOC review, Janice received the approval to move forward with the CCW process for residential placement.”

The process for residential placement doesn’t happen overnight. Each waiting list coordinator works tirelessly to make the process move as quickly as possible so that individuals can start their lives in the community. “…we as WL coordinators understand that many of our families have been on the Priority Waiting List for some years and many changes have occurred. We are dedicated to making this experience as pleasant as possible; however, there are processes that may take some time. There are several things that may make this process longer if encountered, loss of Medicaid being one of those things. It is important for families to pay attention to information mailed out to them and the lines of communication stay open. Families should always feel encouraged to advocate for their loved one and ask questions when they need help understanding something,” said Kenya.

One of the challenges that occurred in Janice’s process pertained to the NJCAT. When the NJCAT is completed, it is important to make sure that the information given is accurate so that there are no delays in the process. Any inconsistencies could impact the funding provided for the LOC needed for the individual being served. Once the LOC was approved, Janice was considered eligible to move forward with the process to find an agency interested in supporting her. In Janice’s case, REM/The Mentor Network decided they wanted to provide her with supports and services in her residential placement.
JANICE’S TRANSITION…

When the process began, REM invited Karen to see the accessible home in which they were renovating to support four women. The renovation would only take about eight weeks. When Karen saw the home after renovations were complete, she was in awe. She shared her thoughts. “There are angels at work. I wanted to cry. I was elated about the home. It was beautiful.” Janice was the first to move into the home on April 6, 2017. She was able to choose her room and decorate it to her delight. According to Kenya, “Janice was very excited throughout the entire process” about moving to her new home. Karen bought Janice a television and a radio. During the transition, Janice spent an evening with the staff. They took her to get her nails done and out to dinner so they could get to know each other. Her transition was easy.

Not only was the home beautiful, the staff are equally as beautiful. “I love the staff. They all seem to be quite sincere in taking care of Janice and the ladies [her housemates]. They keep in touch and I hear from them,” said Karen. Karen met all of the staff, the ladies who moved into the home, and some of their family members. Janice keeps her room clean. She is a very neat and clean person and makes sure her bed is made and enjoys sweeping around the house. Both Karen and Janice have built a great relationship with the staff at REM and Janice’s housemates. Karen trusts REM and Kenya and feels she is kept informed concerning anything related to Janice’s well-being. Because Karen is getting older, her main concern was making sure that Janice would be taken care of. Karen feels that the staff are full of love and sincerity concerning Janice. Karen feels that Janice is a “…very loving and friendly person who can adapt to any environment. She is very giving and has a lot of great attributes.”
LIFE IN THE COMMUNITY...

One of her great attributes is coloring and making gifts for people. Another great attribute is Janice’s work ethic. She is learning to be more independent by learning how to wash clothes, sort laundry, fold clothes and towels. Also, she keeps up with her hygiene and is learning how to choose appropriate seasonal clothing. In addition, Karen stated that she loves going to work and doesn’t like to miss a day. She works in two positions for the Burlington County Occupational Training Center. One job is cleaning up debris along the roadway, and she is proud to wear the orange vest and gloves for safety. The other job is janitorial work cleaning offices and bathrooms.

Janice lives in a beautiful ranch-style group home with three additional women who are like sisters to her. Two of the ladies, Diane and Lisa Marie, were present during Janice’s interview. Lisa Marie did a fine job entertaining us with her Elvis Presley impression. She is named after Elvis’ daughter Lisa Marie Presley. Diane happily joined in with Janice and Lisa Marie taking pictures for the magazine printing.

Tamar Thomas, Janice’s direct support professional, loves Janice and the other ladies who live with her. From the moment she met Janice, she loved her. “I fell in love with Janice. She’s very helpful – loves to help. She sweeps, takes her plate to the sink, and washes dishes. Also, the ladies like to eat dinner on their deck in the backyard. Janice will help propel the ladies in their wheelchairs outside.” Lisa Marie serenades the ladies by singing Elvis’ songs while they have dinner.

“Janice is learning independence and gets along well with everyone here,” said Tamar. Tamar continued, “She [Janice] has a heart of gold and is a sweetheart of a person. She helps when she sees the need and loves people.” Tamar also likes
that Janice is a hugger just like her!

The ladies are enjoying life by going out on weekends to the mall and going out to eat. They get to choose where they’d like to go. Their favorite place is Cracker Barrel. Some weekends, Janice goes out with Karen, her sister, Stacey and her niece, Natasha. During holiday time, Tasha picks Janice up for holiday events with the family.

In reference to the staff who support Janice, Karen likes them, she trusts them, and feels they are sincere. “You can tell when people are insincere. Everyone here is sincere,” said Karen. Jakeira Kelly, senior direct support professional for REM, considers Janice a family member. She’s been working with Janice since she moved to the home in April. She likes the fact that Janice is “…very determined, sweet, and easy going.”

Regarding advice to families, Kenya suggests that they “…ask questions about how to complete the NJCAT assessment correctly so that the assessment will accurately reflect their loved one’s needs and abilities. This will make sure that the person is slated to receive the most adequate level of services and assistance. I would also inform them to get educated about the Supports Program and the Community Care Waiver programs through webinars, family meetings or through CLEP. They should assess their loved one’s needs and make sure that Medicaid is active and stays active. Getting familiar with Support Coordination agencies that service their county is very beneficial. Begin purposeful planning with their Support Coordinators or Case Managers. Seek education, seek education, and seek education! There are no irrelevant questions when it comes to making sure a loved one is receiving adequate services.”

Kenya admires, “…Janice’s positive attitude. She has faced so much adversity in her life, but that has definitely not stopped her smile and zest for life. She is such a resilient person and I was so happy to help her transition to her new home.” Kenya continued, “I would just like to add that at every turn, Janice was very pleasant and kept a positive outlook about her future. She has a very loving Aunt, who showed that she wants the best for Janice’s future. She was an absolute pleasure to work with throughout this process. It was my honor to be a part of her transition.”

Ultimately, Janice is living a great life in her new home. Her aunt wishes Janice be taken care of well, that she be protected and safe and that she finds her true happiness. Janice and Karen’s relationship has grown exponentially since Janice lived with Karen, and Janice understands that she can talk to her aunt about anything. Janice hopes she can remain in her home for the rest of her life.
Joe was sitting at the head of the kitchen table enjoying an Amish glazed donut. My colleague Sheilah and I were warmly greeted with hospitality and donuts from the Amish Market in Mullica Hill; Joe ate with gusto and his enjoyment of the doughnut was appreciated by everyone. His youngest sister, Angela Hiller Johnson and oldest brother, Frank Hiller (Joe’s co-guardians) were also sitting with him along with Cherelle Price, REM group home manager Monique Lusby and Nie’Je Green, REM direct support professionals. Joe is 53 years old, lives in a beautifully decorated sprawling ranch in Pilesgrove, NJ. The home is situated on a large property with a beautiful front and back yard.

Angela and Frank first met with REM at a meet and greet where they were offered the opportunity to visit the home where Joe would live. They were amazed and moved forward with choosing REM as Joe’s provider agency. They chose his bedroom since they were first family to select the home. Joe has the lovely master suite, with bathroom! Angela stated, “The REM staff are incredible, I love the people that work here!”

Hiller Family History: Joe grew up in Burlington County with his mother and father, Rosemary and Francis AKA Frank. He was one of seven children. Joe and his sister Rosemary were born with developmental disabilities. They attended school in Westampton. After leaving the school system, both attended Burlington Day Program, a state funded service. Angela stated, “I felt Joe and Rosemary were frustrated and wanted to be out and about.”

Angela, Joe, and Frank
When they came home, their behaviors were challenging. If Joe wasn’t having a good day, he would often throw clothes, blankets and things out the window where they would land hanging off trees, or around the property. Rosemary was like a tornado and would tear the house apart, usually after Dad just made repairs. Angela continued, “Their neighbors were very kind, understanding, and patient. They never complained; they understood.” Frank and Angela remembered one incident. When Joe was in his 20’s, he got out of the family home one night and went to the 7-Eleven a quarter mile away. Their dog stayed close to Joe protecting him and would not let anyone come near him. Someone recognized Joe and called his father to come and get him. The police department cordoned off the street to protect Joe until his father arrived.

Angela and Frank felt Joe wanted his independence. It had become very hard for the parents to manage and care for both Joe and Rosemary at home. Angela stated, “Mom didn’t want to let go of Joe and Rosemary. They were offered openings for residential placement, years prior, however, they opted not to take them.” Then, their father had a triple bypass and their mother had a stroke. At this point, with their parents’ approval, Angela and Frank became the guardians for Joe and Rosemary in the 1990’s. Angela shared another an incident when “Rosemary turned on the oven with pizza in it. She could have burned down the house.” She continued, “No one ever knew what we as a family went through. The police came, with Rosemary stripped down naked. It was embarrassing. She was hospitalized, and we made the choice to leave her at the hospital.”

It was her challenging behavior that caused an emergency placement in a group home by a hospital social worker. Her transition to the Group Home did not go well. After a week, Rosemary, who was in her mid-twenties was transferred to Vineland Developmental Center (DC), once again an emergency placement. Around this same time, an opening became available for Joe who was 30 years old and he went directly from home to Woodbine DC, as an emergency placement as well.

Advice to Families Regarding Emergency Placements: “it didn’t have to be this way for Rosemary and Joe. If you have the opportunity and want what is best for your loved one or sibling, do it when you are young enough to make the decision to get them situated and be involved in the process, you have to be involved,” said Frank. According to Frank and Angela, “It was difficult at first placing our siblings in the DC’s. They were being placed with strangers, and we felt we were abandoning them. However, it made sense to make the decision to place them while we were still able to.”

Every three months Angela and Frank would bring their parents down to Vineland DC to visit Rosemary and then drive over to Woodbine DC to visit with Joe. “The staff at each DC was good. Joe and Rosemary were always clean, happy and well fed,” said Angela and Frank. Over the years at the Individual Habilitation Plan (IHP)
meeting, community placement was discussed and many conversations were had. Angela said, “It was a scary thing to consider. What if something happens? I was concerned about safety in the community.” “We were against community placement until Frank attended a CLEP family event at Vineland DC called Pictures of Community Living,” said Angela. Frank felt, he “…was willing to listen and was able to talk and network with provider agencies that were at the CLEP event.” The more they learned, the more they felt community living would be a good option for Joe.

Frank also wanted to learn about community living because his daughter, Darlene has a developmental disability. Frank stated, “I didn’t want to go down the same path as my parents, I wanted something different for my daughter. I wanted Darlene to have a life of her own.” Frank used the information he heard at CLEP’s family event to help make the decision of community placement for Darlene. “My daughter lived at home until she was 26, and is currently living in a group home with Delta Community Supports. Darlene is 30 years old and doing well.” Rosemary took longer to place in the community due to her medical challenges. She successfully transitioned from Vineland DC to a group home in Atlantic County. Sadly, she succumbed to her medical challenges on January 27, 2015, at the age of 44.

The transitional case manager at Woodbine felt Joe would be easy to place in the community with two of his Cottage 8 friends. A fourth gentleman was also identified as a good housemate match, and they all moved into their beautiful home. “All four are like brothers,” said Angela. They each have their own bedroom, share a very spacious home and all four gentlemen attend REM’s Day Program. Angela and Frank were involved with Joe’s transition meetings leading up to his move in December of 2012.

Frank feels “It takes more than one person being involved. There is a lot going on and Angela and I worked together. It takes a village and input from a lot of people; don’t do things alone.” Frank shared that it takes a lot of talking and more than one person to prepare for a move of an individu-

Darlene, Frank’s daughter
Cherelle continued by saying, “In the winter months, they like to play with the Wii on the big TV and share and take turns. They also play games, puzzles, and blocks.”

Angela is in constant contact with Cherelle. She visits Joe approximately once a month or more and calls at least once a week. Angela’s son goes with her to visit often. Angela stated, “My son knows so much about his Uncle Joe, and always asks for him. People must be involved!” She continued by saying, “Joe has been successful in becoming more independent. He enjoys his new home, his own bedroom, his new brothers, he has privacy, and is a lot happier.” Frank stated, “It’s happy here, look at the accommodations, it’s beautiful, new furniture big deck and yard.” Angela shared, “The most helpful to us was Joe’s transition; it went very smoothly. He made a day visit, an overnight visit and then moved in. This was the easiest thing and I thought it would be the hardest.” Joe enjoys and loves the warmth of the sun, fresh air and often spends time sitting out on the backyard deck in his Adirondack chair.

Cherelle has been with REM for four years, and has been the group home manager for over a year. REM staff provide all supports 24/7 for all the men including supervision, guidance, medication administration, cooking, cleaning, laundry, outings, recreation, transportation, shopping, scheduling, and going on doctor visits. The men help whenever they are able to assist. Cherelle stated, “Joe loves being outside, listening to the birds, watching the butterflies, hearing and enjoying the sounds of nature.” Angela shared, “Joe likes to chill and relax, and is not confrontational and tends to walk away from problems. He is safe and happy here; the neighbors are nice and he is not hidden away somewhere. Joe gets out and about, is content and is meeting new people!” She continued by saying, “The community accepts him and he has a good life!”

Advice when considering community placement of moving a loved one to the community… Frank and Angela’s advice: “My sister and I were both involved as guardians of Joe and Rosemary. Remember that the situation is about your loved
one. The emphasis should be on their life, not yours. Don’t let your own personal judgments overcome any possible opportunities for your loved one’s future happiness and independence. It’s also possible your loved one may get moved when you’re not around. You should move your loved one when you feel it will be to their benefit.” Angela reiterated, “It’s their life, not yours,”

They continued, “We made a lot of decisions together based on how we would want our lives to be. Once we saw how well they were supported in the community, it made community placement an easier choice for my daughter Darlene. While this decision is difficult and heart-wrenching, I would encourage any parent or guardian to explore community placement options. Your loved one will be placed somewhere, eventually. Wouldn’t it be better for YOU to be involved in the process? It has been very rewarding to us to see our loved ones being supported by their communities and living amongst their peers in a home-like environment.”

Cherelle’s advice to families about community living, “It’s a great way for your loved one to learn and experience new things. Our staff have the same love and care for your loved one. It’s a family here, not just a home.” Frank stated, “My hope and dream for Joe is to continue to stay healthy and happy and safe!” “Joe is calm, cool and likes to explore. Living in the community is a great way for him to experience new things. His housemates are his family, and they all get along. His favorite food is pasta! He enjoys a snack when he comes in from day program and likes being out and about on weekends,” said Cherelle.

Angela and Frank shared their top three advantages of community living: Freedom, Independence, and Location. Having a LIFE. When asked what they like and admire about Joe, Angela stated, “Joe’s smile, he lights up the room, and his chill attitude. If he doesn’t like something, he just gets up and leaves. When he gets upset, he will just hum and walks away.” Frank agreed, “I admire Joe’s chill attitude. Wherever he is, he is relaxed. NieJe shared “I admire that Joe is calm all the time.” Cherelle continued by saying, ”Joe is calm and easy going. I love Joe, he likes to explore things, go for walks, enjoys playing with water toys and balls. The guys all get along very well and are all good brothers!” Our interview was complete, with Angela saying, “We are the voice, their voice, to make sure things are right! The community has worked for three people in our family with success – Joe, Rosemary and Darlene.”
The Community Living Education Project (CLEP) began Self-Advocacy Community Learning Events (SACLEs) at North Jersey Developmental Center after its closure was announced. As we planned our approach to sharing information about community living with NJDC’s residents we knew who our partners needed to be: Adelaide Daskam and Myrta Rosa. We knew they would connect with the residents and provide hands-on experience around their transition from a developmental center to a community setting. Both women are supported by Community Access Unlimited (CAU) and live in Elizabeth, NJ. They traveled to NJDC with Gene Tavera, information and referral director at CAU and William Busch, assistant executive director of membership services at CAU. A brief PowerPoint presentation, large laminated photos and auditory cues were all used to interact with the residents and their staff. The success we had during the year before its closure was summed up by Charles Westbrook, the Quality Assurance Coordinator at NJDC: “During such a difficult time, I think it was great to have you here.” We knew the success was because of Adelaide and Myrta.

In October of 2014 we brought our meetings to Woodbine DC and in October of 2015 to New Lisbon DC (NLDC). Gary Rubin joined us as health issues sidelined Adelaide. Some of the residents at WDC had been transferred from NJDC and were happy to see us again. Michael Muldowney, who attended our SACLE’s at NJDC and Woodbine, and Frank Keryger, who attended at Woodbine, are also featured in this edition of My Life Now. Gary has also reconnected with an old friend at NLDC that he has not seen since they were Boy Scouts. Gary has also met someone at Woodbine who used to live at Johnstone while he was there. While Adelaide, Myrta, and Gary are extraordinary self-advocates, their work goes far beyond their partnership with CLEP.
Myrta’s expertise was evident as she shared her self-advocacy career with us. She lived at home with family until 1998 when her parents passed away and she moved to Woodbridge DC. She recalled her advocacy skills began while still in school. According to Myrta, she was the only Spanish speaking student in her school (Myrta was born in Puerto Rico) so she “…could be the interpreter for the staff. Advocating for other people taught me about self-advocacy.” While she was living at Woodbridge DC, she began attending Helping Hands meetings (CAU self-advocacy group).

Currently, Myrta is the second vice president of Helping Hands in addition to being on CAU’s Board of Trustees. She also attended and graduated in 2007 from Partners in Policymaking (PIP), an annual DD Council advocacy training while living at Woodbridge DC. It consists of eight weekend-long sessions (http://rwjms.rutgers.edu/departments_institutes/boggyscenter/projects/NJPartnersinPolicymaking.html). She was also appointed to the Olmstead Advisory Council for the Division of Developmental Disabilities in 2007 while living at Woodbridge DC.

Myrta was an active member of Monday Morning, a self-advocacy group through the DD Council that met at the East Brunswick library. Myrta worked with Monday Morning to determine where curb cuts and widened doorways were needed in NJ and if they were compliant with the Americans with Disabilities Act (ADA). She is now an active member of the New American Movement for People with Developmental Disabilities at CAU.

Myrta has been supported by CAU since 2010 when she transitioned from Woodbridge DC. She currently lives in her own apartment with some support. She was appointed to the NJ Council on Developmental Disabilities (https://njcdd.org/) in 2003 and was recently elected vice chair. She is also acting chair until a new appointment is made and confirmation by the NJ Legislature is completed. Myrta worked tirelessly on the Council’s “R” word campaign.
to raise awareness of the word “Retarded” and the impact it has on people with intellectual and developmental disabilities. Myrta’s passionate work helped remove the word from New Jersey legislation. Myrta also regularly visits NJ legislators throughout the state and local Elizabeth, NJ representatives including the mayor and city council members to advocate for the needs of people living with intellectual and developmental disabilities. Myrta has worked at the polls during local and national elections for the past few years. She also conducts weekly interviews for potential support staff at CAU. Every year Myrta attends the Council’s DD Awareness Day at Six Flags to educate the community about people living with developmental disabilities. In 2016, Myrta graduated from CAU’s Mentorship Program and is currently mentoring new members of the CAU family.

In addition, Myrta is a statewide and nationally known disability rights speaker. Myrta has spoken at the American Association on Intellectual and Developmental Disabilities (AAIDD), American Network of Community Options and Resources (ANCOR) and TASH (formerly known as the Association for Persons with Severe Handicaps; the name was eliminated in 1995, but the acronym kept due to recognition), national conferences in recent years. She has also spoken at the statewide Alliance for the Betterment of Persons with Disabilities (ABCD) conference.

Myrta has received many awards and accolades including the Jane Miller Leadership Advocacy Award from the NJ Self-Advocacy Project, an arm of the Arc of NJ, in 2012. Myrta was given the Colleen Fraser Award from the DD Council in 2014. According to their website, “The Colleen Fraser Self-Advocate Award honors a self-advocate who has shown outstanding efforts in advocating on behalf of themselves and other individuals.”

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Myrta is currently employed at CAU in their accounting department. When Myrta is not busy working or advocating for others she enjoys bowling, attending church services, going out to dinner (Cheesecake Factory is her favorite) and working on her computer. For the past three years, she has been a cast member in CAU Players, partnering with a community theater group, in their annual theater productions.

When asked what she enjoys most about self-advocacy Myrta replied “Speaking to people…just because we have a disability it doesn’t
stop us.” She enjoys the monthly SACLE’s because “they’re good, we teach people, help people to come out [of the DC’s] and maybe someday they can teach others.” Myrta would like the people she meets at Woodbine and New Lisbon DC to “look at yourself as a human being, feel as if you were in my shoes… get involved with advocacy, picture yourself like one of us. Maybe someday you can achieve what we have.”

The most important piece of advice I have heard Myrta give repeatedly as she speaks to the residents of the developmental centers is this: “Don’t leave until you are ready because you won’t be successful if you’re not ready.” It is advice we can all use in our lives as we transition to new circumstances but Myrta speaks from experience. She did not leave a developmental center until she was ready to move ahead. As we finished our interview, Myrta was asked, “What would you like people to know about you?” She shared, “I’m a fighter and I’m a believer and I get it done.” That sums up the Myrta I have known for more than ten years; my colleague and my friend.

Gary Rubin was dressed for business when we arrived for his interview. His crisp white shirt and tie demonstrated his professionalism as he shared his many years of advocacy work. He is also known as a “NJ self-advocacy historian” and can tell you all you need to know about the work our state’s self-advocates have accomplished. Gary lived at home with family before moving to Woods Services School in Pennsylvania. From Woods, he moved to Edward R. Johnstone Training and Research Center in New Jersey. When Johnstone closed in 1992, Gary transitioned to CAU in Elizabeth where he has been supported for 25 years. He currently lives in his own apartment.

Gary shared that he began attending self-advocacy meetings with the Association for the Advancement of the Mentally Handicapped (AAMH) in 1974 (http://www.aamh.org/about-us/aamh-history/). It is now known as All Access Mental Health.

Gary was encouraged to join Helping Hands by Sid Katz, founding member, when he
began receiving supports through CAU. Currently, Gary is President of Helping Hands. Like Myrta, Gary joined and worked with the Monday Morning project through NJCDD and was appointed to the DD Council in 2008 where he remains an active member participating in activities such as the “R” Word Campaign and DD Awareness Day at Six Flags. In addition, Gary is a founding member of CAU’s Jump Start program which educates social services professionals through presentations and trainings on how to best serve people living with intellectual and developmental disabilities.

Gary is also involved with Self Advocates Becoming Empowered (SABE), a national self-advocacy organization founded in 2000. According to their website, SABE’s mission is “to ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves, opportunities to make new friends, and to learn from their mistakes.” Gary’s advocacy is a shining example of this mission and throughout the state and local Union County representatives to discuss and advocate for all people with intellectual and developmental disabilities. Gary also attended and graduated from the PIP program in 2002. He received the Jane Miller Leadership Advocacy Award from the NJ Self-Advocacy Project in 2012 and the Colleen Fraser Award from the Council in 2013. When asked what he most enjoys about self-advocacy Gary replied, “Helping others who are afraid to speak up especially those whose mom and dad didn’t help them speak up.” Gary credits his mom for teaching and encouraging him to speak up. He also enjoys our monthly SACLE’s because they give him an opportunity to “see people I knew growing up.” Gary would like the people he meets at New Lisbon and Woodbine DC’s to “keep fighting to be treated as you want to be treated, don’t give up. People with different abilities aren’t looked at the same. We are people just like everyone he was appointed a SABE Region Seven board member. He has attended and participated in board meetings in Silver Springs, Maryland, and Chicago, Illinois, and Denver, Colorado. This fall, he will attend a SABE board meeting in Little Rock, Arkansas.

Like Myrta, Gary is a mentor supporting people who have just begun to receive support from CAU and interviews potential new staff for CAU on a weekly basis. In addition, Gary also visits New Jersey legislators
In his spare time, Gary enjoys going to the movies, spending time with friends, and meeting new people. Gary’s final words to us were “I’m a fighter, I don’t give up and I’ll tell you like it truly is. Gary does tell it like it truly is every time he speaks and when he does, people listen.

Adelaide’s staff helped us interview her for this article as she recuperates from ongoing health issues. She began to think of herself as a self-advocate in 1992 because she “cares for other people.” Adelaide became involved with organized self-advocacy by meeting and working with other people. She most enjoys “seeing and speaking up with my friends” and hopes to be able to attend our self-advocacy meetings at New Lisbon and Woodbine DC’s soon.

Adelaide graduated from Partners in Policymaking in 2006 and she, too, is well known throughout New Jersey and the country for her tireless efforts in advocacy. For people who may not know what self-advocacy is, Adelaide shared that “it’s a great movement to be a part of…” She also stated that “I’m a good, strong advocate and leader.” Adelaide’s sense of humor makes an impression on all who meet her and CLEP hopes that she will able to return to her self-advocacy work in the near future.

In 1991, CLEP began as a family support project based in the Rutgers University School of Social Work. It was created in collaboration with the NJ Council on Developmental Disabilities to assist family members of people living in developmental centers to become more active in decision-making during the individual habilitation planning (IHP) process.

CLEP provides information and education to individuals, families, provider staff and the community, but it is the self-advocate who does it best. We would not be as successful without their wisdom and expertise. Thank you, Myrta, Gary, and Adelaide.