The Real Story
The True Victory
One Year Later
Supporting Community Living for People with Disabilities

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Real Victories/True Stories
One Year Later

One year ago, Sonia, Mary, James, Laura and Perneita invited us to witness an important chapter in their lives as they transitioned from nursing facilities to homes in the community. We followed them as they embarked on an intense and multi-faceted journey from an institution to independence. Each individual worked with a service coordinator to apply for Maryland Medicaid’s Living at Home Waiver program, which provides the supports they need to reside at home, and to locate affordable, accessible and appropriate housing in their preferred environment. Sonia, James and Mary wanted to live in the city, close to neighbors, services, shops and churches. Perneita and Laura were more comfortable in suburban and rural locations, close to family and familiar surroundings.

After many months and through a combination of project based housing vouchers, creative financing and traditional housing choice vouchers, housing was secured and the transitions were made. These included resources from the Non Elderly Disabled Category II voucher program, HOME funds, landlord incentives, and Low Income Housing Tax Credits. While the road to transition was long and fraught with challenges, the time and effort paled in comparison to the satisfaction of rebuilding their lives in homes of their own.

Now, a year later, we are visiting with Sonia, Mary, James, Laura and Perneita for a second time. This booklet will reintroduce you to these determined individuals and you will have the privilege of knowing them as they share the joys, fears, challenges and triumphs that marked their lives during the past year. Since last we saw them, James has decided to travel; Sonia is enjoying giving her children memorable birthday parties; Mary overcame her fears about an unfamiliar environment; Perneita started a new marriage; and Laura is struggling with a very difficult decision.

Through their experiences, you will see bravery in embracing independence and even greater courage in deciding to stay in the community. These five individuals do not know each other, but their stories share the same themes of independence - pleasure in making new friends, realizing long held individual goals like starting a job or learning new skills, and planning and making the small choices that make each day new. They also share some of the same challenges, including recurring depression, worries about the unknown, difficulty in finding attendant care, problems in reconnecting with family and friends, and everyday concerns with their housing. The decisions they have made and the directions they have taken are deeply personal, and their stories are gifts to us all.
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Sonia enjoys talking about the birthday parties she plans for her children, five year old Essence, who loves to wear pink, and two year old Ezekial who is devoted to Sponge Bob and the “Happy Feet” movie. For many parents, that’s a simple statement, and a one stop trip to a party store. But for Sonia, the parties are a real effort. They are important touchstones in her relationship with her children, one of the perks of being a mom. It’s one of the perks she did not enjoy for nearly three years. To have full custody of the kids, to build a life with them, to be their mother in every way — that was Sonia’s overriding purpose for her life as she left the nursing home for her own home in the community. “I love my house.” Sonia says with a wide smile. “Not just because it’s my house and it’s the way I want it, but because I couldn’t get my kids back without having a house.” The house is the way she wants it because prior to transition from the nursing home, she herself met with the landlord and explained her situation. In only the way Sonia can, she made him an ally in getting a home adapted for her special needs. Adaptations include an accessible entrance and ramp at the rear of her Baltimore row house, to ensure safety on the city street, and a roll out shower stall. Sonia is particularly pleased with the shower, the centerpiece in her “Hello Kitty” themed bathroom. About the theme, Sonia says, “You know, I still like girly stuff.”

As she awoke from the coma following an automobile accident that took the life of her older daughter, the first thing that came to Sonia’s mind were her children. At the time
of the accident, Ezekiel was only six days old and Essence had just turned three. While she was still in a coma, the children’s father made decisions about their care, ultimately separating them and placing them with extended family members, one of whom Sonia did not feel was “right for her Ezekial.”

Sonia was not a part of their lives for close to three years. At first, the children were shy and uncomfortable; Ezekial was particularly withdrawn. And it has taken many months for little Ezekiel to start to talk and to show affection. She says that it has “been so hard. At first I couldn’t even get him to laugh.” Essence, too, has been dealing with the stress of adapting to a new home and getting used to living with her mom, not just visiting someone called “Mommy,” whom she barely knows.

The service coordinator built a close relationship with Sonia prior to the discharge. Seeing the struggles in rebuilding the family’s life, she felt that her role during this time had to be intensified. In this situation, she realized that transition didn’t refer only to Sonia’s discharge, but it also referred to the children’s ability to get used to things as they are now… to be ok with sitting on Mommy’s lap and swinging from the wheelchair. Knowing that she would be the mediator for the entire family, the first questions that the coordinator had to ask were hard ones, “Who will get up and take care of the kids at night? Who will be able to care for the children when they are hurt or sick?” “Will you be able to take Essence to school?” These questions led to family meetings and making detailed plans. The meetings included Sonia’s parents who ultimately became committed to taking on some of the children’s caregiving. Soon cousins, friends, and neighbors volunteered to help with things like food shopping and laundry when Sonia was too tired to take on household tasks. But Sonia noticed that the willingness of family had a flip side when several family members had different ideas about Sonia’s progress and expressed opinions about the children’s care and discipline. So the coordinator stepped in again, carefully.
Her skill at coalescing everyone’s ideas, while putting Sonia’s wishes front and center, succeeded in keeping everyone involved.

The Department of Social Services Family and Children’s Services Division was involved with the plan to return the children to Sonia as part of the custody agreement. Staff from the department oversaw visitations, and implemented a gradual return to minimize the children’s qualms – and Sonia’s concerns. Social workers from the department are still involved. At first, Sonia was nervous about them coming to her home, and perhaps judging her. But her service coordinator was able to shape this as an opportunity for learning, something positive, not as interference or something to be afraid of.

Today, Sonia’s little girl is very proud. She likes her mother’s new blond hair color and plays with the mom’s hoop earrings like the ones she hopes one day to wear. She is proud of the way she can help her mom, and pleased with her work in school. A neighbor walks her to school every day but she does homework with Mom. And Ezekiel is very proud that “I got a lot of toys and this baseball bat.” His grandfather gave him the bat during one of his morning visits. Sonia’s father has become a stable presence in the lives of this young family. And just as she hoped, Sonia now opens her door to family and friends nearly everyday. She is never alone. And of the program that made her new life possible, she says that “the waiver is the best thing that has ever happened to me.”

Now one of the things that Sonia wants to do most of all is to learn to walk again so that she can be a more active parent. Climbing the stairs, and walking into the bathroom have required the extremely hard work of retraining her brain and muscles in the fundamentals of movement. This is happening slowly with the help of dedicated attendants who follow up with the outpatient therapist’s recommendations. Initially, a cousin and aunt acted as attendants. It seemed like the ideal situation. But as Sonia observes, “It’s better not to mix family and business.” Eventually the service coordinator would help Sonia to find appropriate attendant care through an agency, even though it took many months of recruiting to find the right people—people who liked children, who had access to
transportation, and who had experience with working with a younger person with significant disabilities. It was imperative that the day time attendants be prepared to follow through with the basic home exercises and range of motion that Sonia believes will help her to walk again.

The coordinator’s regular contact is designed to keep Sonia on track with the spectrum of her concerns. For example, Sonia talks with her coordinator about the fact that she doesn’t want her children to think they have the obligation to help take care of their mother. But she needs their help from time to time and they enjoy the closeness that helping Mom brings. Sonia still falls prey to depression and when she does, the coordinator is able to remind Sonia of her achievements, such as the time she held participants in a national conference transfixed as she told her story, and the time she was interviewed by the Washington Post. Sonia is also planning for training to work as a secretary once the children are in school full time. But first, she is planning to sign up for a foreign language course, something she has always wanted to do.

But her greatest achievement is providing the gifts of mothering -- giving generous attention and praise and sharing the children’s interests, like “watching Happy Feet over and over and over again.” She is happy with the progress she has made, as she says “you have to live your life the way it is….things happen for a reason.” To those who are still in nursing homes, Sonia would say, “Don’t let anything or anyone stand in your way. Just get out!”
Mary

When Mary talks about “going back” she is talking not only about living in the nursing home, but also about going back to a place in her life, a place in her memory shadowed by loss and sorrow. In that painful place, she was not doing what she knew she was capable of doing. She was struggling with the debilitating depression that kept her from sustaining close relationships and from making her dreams for a fulfilling life a reality. For a long sixteen years, after an attempt at suicide that left her blind and disabled, Mary knew no other home than institutions and nursing facilities. While the nursing facility offered the safety of structure and the attention of staff, her life in the nursing home was not the life she had hoped for. “I felt claustrophobic and always ‘out of sorts’, You know?” Then she learned about the Medicaid waiver program and thought that this might be the way to start over, to be free of the struggles of the past.

After her transition from the nursing facility, Mary experienced the euphoria of freedom. But that euphoria quickly melted away as she experienced a new kind of claustrophobia. In the nursing facility, Mary lived by the schedule and recognized the voices of other residents and staff. It all felt familiar and the familiarity resulted in a comfortable routine. Whereas, in this more spacious apartment, she no longer knew the difference between day and night, which in itself was frightening. Without the nursing home bustle her perceptions of the environment were skewed. She felt hemmed in by her senses. She felt lost. She felt alone.

“I can’t go back. I don’t want to go back. I’m here and I’m doing what I am supposed to be doing.”
In many ways it was terrifying, those first months of change. Mary wasn’t prepared for the new palette of feelings and didn’t really know what to expect from day to day. When Mary says that those months were “pretty rough”, the listener knows that they were more than just pretty rough. As she experienced bouts of anxiety and fear, she often lost confidence in her abilities to live on her own. So much so that it was not long before she asked her coordinator for help to move back to the nursing home. The coordinator, a licensed social worker, struggled alongside Mary. She felt an immediate partnership with this special woman. She talked through Mary’s fears and reiterated her initial reasons for wanting to strive to help others around her, her reasons for wanting to live away from the nursing facility.

It didn’t help Mary’s decision to live in the community that it was exceptionally difficult to locate attendants who were not put off by the vision impairment and the concern that Mary’s care would be more complicated than most. After many months of trying agency after agency, attendant after attendant, Mary finally found a young woman, a student nurse, who would be her primary caregiver. The two have formed a close bond, so that a visitor can immediately see the results of the respect and affection they have for each other. The attendant’s strength and commitment helps keep Mary on track, particularly with her physical therapy regimen.

Once Mary was able to discern night and day again and she could make consistent schedules for herself, things began to look up. Her coordinator helped with this effort by locating “talking” appliances like an alarm clock and oven.
timer. There was even a “talking” thermometer and wrist watch. An accomplished poet and writer, Mary now has a computer from a recycling program that she is using to write a long planned book. She uses a tape recorder to save ideas for the book, and is getting training through the Department of Rehabilitative Services to learn how to use a talking computer program (JAWS) designed for people with vision impairments.

Yet even so, Mary episodically asked her coordinator for help to return to the nursing home. It seemed as though when Mary reached a new level of confidence and achievement, the fear of taking the next step in her life’s journey rattled her. The service coordinator sustained their conversations about Mary’s apprehension, and continued to help Mary work through her anxieties. She reminded Mary of her reasons for leaving the nursing home in the first place — lack of privacy and autonomy, little opportunity to meet new people. There was no opportunity to make good on her plans to help others in nursing homes, especially the youngest and oldest residents who, like her, were afraid to embrace independence. The coordinator recounted for Mary the many personal accomplishments that she had made over a very short period …making new friends in the apartment complex, attending concerts there and taking part in the singing, even baking desserts in her small kitchen. This was something she had enjoyed years ago, and she found delight in doing it again, the smells of chocolate chip cookies making everyone smile. The coordinator would also remind Mary of some of the most impressive things she has done in the wider community — her well received presentation at a federally sponsored conference focusing on community living and housing options; and commenting on a local National Public Radio program about jobs for people with disabilities. She is already becoming known as someone who can put a face on disabilities, a person who can speak cogently from her own knowledge and experience.

Mary is currently participating in a program at the local Center for Independent Living, preparing to become a mentor for individuals wishing to leave nursing homes. “I want to be able to open people’s eyes. Not just the people in the home, but the social workers and the nurses. When I was in the nursing home, hardly anyone knew about the waiver, or if they did know, they didn’t share the information.” Mary is looking forward to attending a nearby university to complete a degree in Health Management.
Looking back, Mary says that she chose her apartment primarily “because it was available right away” and she was desperate to be on her own. Furnishing the rooms, using essential transition funds, was an exciting project even though it was largely a matter of the coordinator describing new overstuffed chairs, a dining table set, and bedding that she could order from an online catalog. Though she couldn’t see how well they matched, Mary ultimately approved of the wood grain of the new tables and the soft cushions on the chairs. She believed that the rooms were “cozy”, that they fit her taste. A real home, at last.

“I had help through this transition and I won’t go back”, she says with a touch of defiance, punctuated by a broad smile. Mary notes that she will always deal with depression, but she handles it best when she is doing good things for other people who she believes are having problems much greater than her own. She worries about the elderly people she knows who don’t have enough help, about youngsters who may be a little bit different and who are bullied at school. She worries about fractured families, and people who have disabilities and those who are homeless, cold, and hungry. It’s a tall order for one person. But one that she is eager to accept, using the powers of prayer, poetry and community work. “Yes, I struggled for a good while. But I am where God wants me to be. And I know I can help.”
James

And it hasn’t held James back. Rather, he has used the chair, his computer, and an array of equipment and essential services to rebuild his life. After a long hospital stay, and many months in a nursing home that turned into years, James is doing what he dreamed of doing. As a former big rig driver, clocking thousands of miles up and down the Eastern seaboard, James has the curiosity and nature of a traveler. And the fact that most of his family members live in North Carolina gives further impetus to his desire to get away and visit. With the help of his computer, and his service coordinator, he is able to make his own plans and to go by bus to see his children and grandchildren in the South. A few short years ago, that would not have been possible. Recovering from a stroke that left him with a speech impairment and issues with balance and ambulation, he was too fragile to attempt such a journey. But since he has moved from the nursing home to his own home in Baltimore, he has achieved not only better health, strength and stamina, but he has also developed the confidence in himself that he had lost. “They told me I couldn’t do it,” he says of the nursing home staff. “Even the (nursing home) owner came in and said that I wouldn’t be able to make it in here in my apartment, on my own, that it would be too hard on me. They said I wouldn’t be safe.”

“I won’t let a wheelchair hold me back.”
And in some ways, living in the community has been hard for him. For example, while his speech impairment seems worse to him than it does to a visitor, he still perceives it as a barrier to getting his wishes across to others. This is particularly so with attendants in his home. In fact, issues with attendants have been problematic since his move from the nursing facility. James says that he “lost count” of the number of attendants he tried before he found the staff that is committed to him now. “So many of them really didn’t want to be here,” he says. “They just wanted to do what they wanted to do.” He describes attendants who would watch television instead of helping with range of motion, for example, or who would be resentful when he asked them to assist him, particularly with bathing. James believes that there was even one attendant who was trying to steal from him. When he caught her, he immediately used his personal safety alert pendant to call for help. At first, he scoffed at using a safety pendant. Now, he has made sure that his 83 year old mother wears one too.

James and his service coordinator spent many hours together, searching for the right people that he could count on. Finally, when they arranged for a core staff, the agency that was providing the attendants closed its doors, with virtually no notice to any of their clients. It was a shock to James and it meant a few hours of real anxiety for him. However, the service coordinator located a new agency that was willing to take on the providers,
and James recounts that “I didn’t even lose one person. Not one. And there was not even one day that I didn’t have help.” And speaking of his service coordinator, he says “He’s real good at his job.”

One of the reasons that “he’s real good at his job” is that he respects the choices that James makes and helps him to think things through. For example, while James was planning his trips, the service coordinator reminded James that his attendant would not be available to him either on the bus or in North Carolina. He then asked a series of questions to get James planning realistically about what he – and his children—would have to do to support their father and to get him back home for a visit. The result was that James’ daughter would ride the bus with him, and James’ son would be the primary caregiver in his home. The coordinator always acts as a facilitator and as someone with a store of ideas and resources that can help James make good things happen in his life, including learning how to manage at home.

James’ efficiency apartment is located in an adults only complex situated in the city’s core. He is able to afford it as he obtained a project based subsidy. He selected this place he calls home because it was recommended by his church’s bishop, even though it was unavailable at the time. One of the primary reasons the bishop thought it would suit James is the fact that the common areas would help him to socialize again, have the opportunity to play cards, share meals, and make new friends.
At the time of transition, James’ two goals were to talk more clearly and to walk again. The environment he chose supports at least one of those goals. After a few months in the efficiency he could stand and was pleased to show that new skill to anyone who visited. He could move around the room, holding onto furniture as he was learning to walk. With physical therapy continuing, now he is taking small steps independently. So now James is thinking about moving to a more spacious apartment, convinced that he will be able to manage. This will mean taking on a process for James to either find another project based subsidized unit or to apply for his own voucher that may result in more housing options.

As to the second goal, with ongoing speech therapy he is practicing exercises that are having a noticeable effect on his ability to make his comments clear. And when he tells jokes and be understood, then he knows he’s really getting better, in spite of himself.

The traffic noise and hectic activity on the street outside his window don’t bother James. Rather, he kind of likes it and he has made some acquaintances in the neighborhood as he runs his errands to the bank, the cleaners, the convenience store. He is becoming well known in the neighborhood, just as he is inside the apartment building. The value these connections became very clear to James one day when a stranger – with questionable intentions -- approached him just as he was leaving the bank. Another younger man who James often sees in the on the street, came to his side and offered to help. An dangerous situation was averted. “I was surprised. This has never happened to me before. I didn’t really know this young guy, but he was right there and now we’re friends.”

James says that his computer is still one of his more important pieces of equipment. He used it to help plan for his trips to North Carolina. Now he is spending some time planning far into the future toward possibly visiting old family friends in Jamaica. This is more of a dream right now, but the more independent he becomes the more this trip to the Caribbean is becoming a reality for him. And the vision of the days in the nursing home are beginning to stay in the mists of his memory. When he is asked if his decision to move out and into the community was what he ultimately hoped it would be, he replies, “Yes! 100%!"
Laura

The effects of Laura’s worsening Multiple Sclerosis, with an associated loss of function, made Laura’s stay in a nursing home completely appropriate. However, it was not the loss of function that drew Laura to the facility, it was the fact that she was being evicted from her home and had no other option for shelter. The eviction from her apartment was due to neighbors’ complaints about her son’s activities around the complex. As a high school senior, living with his single divorced mom, he did not have the supervision that he needed because of her frequent hospitalizations. After the divorce, it was still Laura’s intention to make a stable and loving home for him. But her health problems made that purpose nearly impossible to achieve. It was a heartbreaking situation that seemed to have no solution.

Now, it is a year after Laura’s transition back to the community, from the nursing home to a new apartment in a quiet area of rural Carroll County. It is a year after a transition that took many long hours of searching for an accessible home, negotiating with an accommodating landlord, obtaining the appropriate voucher and building a service complex plan designed to keep Laura safe and healthy at home. The plan rested on the willingness of family members – including her son – to help.

It is a year after… and Laura is once again in the same position. She is facing the possibility of eviction, again because of her now young adult son’s actions. A broken window. His refusal to contribute to the rent. His girlfriend and her two little ones living in the home. His friends’ loud laughter and music spilling out onto the parking lot.

Upon her transition, Laura was elated. She had that sense of exhilaration that freedom brings, that she could do what she wanted, when she wanted. The most simple tasks were tinted with the joy of being free to choose. “I can use my own shampoo again, I can make up my own mind about what I’m going to wear. I get to decide what to watch on television. “It was

“I really like my freedom. I just do what I want to do and when I want to do it. Freedom is good.”
Laura did not have lofty plans as yet. Her MS episodes had taken their toll and she was still too ill to spend many hours out of her hospital bed. But gradually, with her attendant being careful to follow the service plan, the care coordination team staying in regular contact, and family members taking on the tasks they had promised to do, Laura was finally getting better. She was able to do without a gastrostomy tube. Then she had even more choices – what to eat, and when. Eventually she looked forward to sitting in her comfortable overstuffed chair in the living room. She would have long talks in the evenings with her son, she had hoped. “I’d like that, but he is so busy with his job and all.”

At first, family members were often in and out, checking on her and helping with groceries and household chores. Her former husband was committed to evening visits and helping to keep track of her many medicines. An aunt was especially eager to help, and was called on to manage Laura’s finances. Old friends from high school would stop in or call to check up on her. There was real support for Laura, at least initially.

Another aspect of community support that was essential for Laura was recruiting and selecting attendant care providers. It took many disappointing attempts before she found an attendant whom she could count on. The fact that Laura lives far from public transportation was the primary reason that attendants were so difficult to find. But Laura made an instant connection with her current provider, who now spends most of the daytime hours with her. And it is this attendant who is now having those late afternoon chats with Laura in the living room.

Now, as Laura’s health has measurably improved, she is beginning to have more energy and to take more interest in her surroundings. A visitor can see the healthy color in her face and the humor in her eyes. She spends more time out of bed, and looks forward to the change of scenery. But at the same time, those same family members and friends, even her favorite aunt from childhood, have drifted away. During a recent weather crisis, when there was the threat of power outages, no one called. Her former husband is the only one to continue their still fond attachment. Without her support network, Laura is finding it difficult and tries to explain this loss. “They say that there isn’t enough room for them to sit with me because of my son’s friends. They don’t really like them so they don’t come to see me anymore.” Because of her earlier experience with eviction, she knows that she...
may have to make a very hard decision to have her son and his girlfriend leave the home. But that option is almost too much for her to speak about. With a wave of her hand, and her face turned toward the wall, she comments softly, “I won’t talk about that [stuff]. I just won’t.”

When she is asked about initially leaving the nursing home, and whether she made the right move, she emphatically says, “Yes. Because I have my freedom.” An outsider might assume that for a person who spends most of the day in one room in her home, in a hospital bed, that “freedom” would not have much meaning. And whether she is at home or in a nursing home, how much could it matter? But for Laura it matters very much. With a diagnosis of Multiple Sclerosis there are the cycles of progress and regression that she has to deal with. There is physical therapy that she must continue and medicines she must take. Laura has no real control over the physical aspects of life. She can only react when her body betrays her. Thus the shadow of a nursing home setting is always behind her.

So now, while she is still in her home, she cherishes the chance to make those small choices that she talks about. Her coordinator understands this, and has helped her along with thinking about the ways in which she can control her future and stay in her home. She has worked diligently with Laura, knowing that the time will soon come when Laura will have to face the questions about her role and her bond with her only child. Then her choices, her decisions, her burdens will be weighty ones that she alone must carry.

NB: At this writing, Laura was preparing for a hearing relative to the eviction.
Perneita

Perneita likes to say that “Google is my secret weapon”. A woman with as full a life as Perneita’s, needs a secret weapon to manage the extraordinary demands on her time and energy. With a full time job teaching adult students, planning a wedding, welcoming twin grandsons, and finishing up masters degree requirements, this past year has been a whirlwind, even a merry go round for her.

Her life had been put on hold while she spent nearly four years in a hospital recovering from a cascading series of health crises related to lupus. During that time, she lost the close everyday connection with her son, lost her car and home, and had to abandon her master’s degree program. While in the nursing home, she decided that “It’s my life, and I am taking my life back.” So while she was working with her coordinator, preparing to transition to the community, she decided on two goals that would be her impetus for grabbing that brass ring once more – reviving her relationship with her son and learning to walk again. One walk would be particularly special for her – the walk down the aisle to meet her husband-to-be. This was a dream that she had nurtured ever since his proposal, one year ago.

Setting goals is something that comes naturally to someone like Perneita who says of daily living, “You have to show up. You have to be accountable for yourself.” Her primary aim, to become closer to her son and to become more involved in his life was realized when she found her new home. She was there for those critical high school years, and could offer him the guidance that he needed to reach adulthood and to be out

“My surprise wedding gift to him was to walk down the aisle. And I did it!”
on his own, just like his mother. During this past year, her life took a surprising turn when he announced that he was going to be a father. Her boundless energy and pride in her son would now lead her in yet a new direction, as she is now the beaming grandmother of twin boys. Eager to show off their photos, she sees the three of them often. And all of a sudden, the person who once seemed to be so alone in the world of hospitals and nursing facilities, whose life was not her own, is happily at the center of a growing family.

It was several years ago that Perneita obtained an apartment in a completely new development in suburban Howard County, Maryland. It is a planned community, that accepts low income housing vouchers. And it was designed with some of the amenities that people with disabilities appreciate. With assistance from the transition coordinator, Perneita became a pioneer of sorts, the first person with a disability to live in the complex. The property owner agreed to install wider doors, lowered sinks and counters, and other adapted items to accommodate her specific disability related needs. The kitchen and bathroom were already basically accessible. And there was even a reserved parking space for her, with a curb cut, directly in front of her door. Perneita would still need to have additional specific adaptations – such as lowered locks on the exterior doors – and assistive technology, such as additional grab bars to use for physical therapy. Therapy continues to be critical for Perneita if she is to walk again; she continues to receive this service through a rehab center in Baltimore.

When Perneita and her fiancée were planning their wedding, the rehab center contributed by contacting a cable television show and sharing Perneita’s inspiring story with the production staff. Her therapist was persistent until Say Yes to the Dress paid for Perneita and her sister to travel to New York. There they spent several days in the city, seeing the sights, while she selected a dress at a famed wedding studio. Once her decision was made, the seamstresses got to work. They adapted the dress so that it would gently drape over the wheelchair, but would still hang perfectly when she stood and walked. On the June wedding day, a man she had known for 20 years, waited for her at the altar. But this would not be the end of the wedding story. Perneita’s and James’ celebration will be the December centerpiece in Essence magazine.
Perneita laughs, eyes dancing, as she recalls her first meeting with James at his cousin’s wedding. They had only sporadic contact with each other until her illness and the aftermath that saw her in the nursing home, devastated not only from the effects of the illness, but also from an incapacitating depression. Now she too used a wheelchair, but she didn’t believe that fact could be the basis for a genuine friendship. Yet they became closer while she was in the nursing home, as he helped her overcome the desperate feeling that her life was over. He offered her a lifeline to the world outside the nursing facility. He helped her to re-energize her sense of purpose and get moving toward independence again.

Perneita is surely the embodiment of one of her mottos, “A body in motion stays in motion.” After she negotiated with the car dealer regarding her credit worthiness – negatively affected by the long stays in the hospital and the nursing home – she was able to get a new car. The next step, with the help of her coordinator, was to have the car adapted with hand controls. Then she was able to drive to school, to work – wherever she wished. This past May, she participated in the graduation ceremony at the University of Maryland. And no sooner did she receive her M.Ed. in Instructional Technology than she took on more responsibility as an instructor with Anne Arundel Community College at its prison outreach campus. There, she teaches computer literacy to incarcerated students. For the most part, these are young people, and each one, she says “has a story to tell.” She enjoys the job and the student’s energy. She appreciates the need for flexibility and creativity in teaching there, as she says “I am not a 9 to 5 kind of person.”

When she first started at the facility, she also taught prison authorities about accessibility, insisting that she needed automatic doors to get into the institution. Prison staff told her that she “opened our eyes to how easy it is to make things accessible.” She is hopeful that this lesson won’t be lost as people with disabilities are incarcerated as well.

Perneita sees a reflection of her time spent in the nursing home in the time that her students spend in prison. After all, she says, “the two most important things are freedom and independence and you don’t have either one in prison or in a nursing home.” She also notes the metaphor she saw in the prison doors. They were too heavy for her to open by herself; she needed help. Just as she needed help to get free of the nursing home and to become Perneita again. “Without the waiver,” she says, “I just wouldn’t be here.”

This brief was prepared by Barbara McCord and Karen-Ann Lichtenstein of The Coordinating Center. For additional information and related resources, visit http://www.coordinatingcenter.org/.