

The Real Story The True Victory

Supporting Community Living
for People with Disabilities



This booklet was inspired by the individuals whose stories are told here. It was developed by The Coordinating Center and made possible with funding by New Editions Consulting, Inc., through a contract with the U.S. Centers for Medicare and Medicaid Services.



The Coordinating Center is a non profit organization that coordinates all services that individuals with complex medical needs and disabilities must have to be fully included at home and in their communities. The Center does this by partnering with individuals and families, housing providers, health care and other community service providers, as well as funders, in a dynamic program of comprehensive, person-driven care coordination.



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The Real Story



The people who have agreed to be interviewed for this project are individuals who are currently living in, or who have recently lived in, nursing facilities due to extraordinary health events or trauma. Some are now living in their own homes, or preparing to leave the nursing home.

They have all experienced the grueling – but exciting – process necessary to obtain the homes and services they must have to thrive in the community.

Each of these individuals has benefitted from the collaboration of the U.S Department of Housing and Urban Development (HUD) funded programs such as the Housing Choice Voucher, Project-Based Section 8 housing and now the Non-Elderly-Disabled (NED) Category II (transitioning from nursing homes or certain other institutions) Housing Choice Vouchers as well as Home and Community Based Services (HCBS) Waivers through the Centers for Medicare and Medicaid Services (CMS).

They have agreed to share their stories so that others will know the value of their struggles and the triumphs they have experienced through the opportunities that they have embraced. These are people who have chosen to take on the challenges of the hard work of rehabilitation and the even harder work of rebuilding lives that were completely transformed – some in an instant. They joined with peers, providers, and professionals to tackle the intricacies of programs that are essential to realizing their aspirations.

There are common themes that flow through these stories. Searing loss and loneliness. Corrosive disappointment and even desperation. But never defeat, as people begin to dream again. In some ways, while the details of their lives are theirs alone, there is one overarching theme. That is the rediscovery of oneself as a unique individual with undisputed value in the world. That is the real victory and the true story.

The True Victory



PERNEITA

What did I want most of all? I wanted to be me again. My goal was to be reunited with my son and to make a home for the two of us because we had been apart since 2005.

What would I say to people? Don't be discouraged and keep at it. Become a pest! And after everything else, just stand up.

Getting her master's degree, setting a date for her wedding, shopping for The Dress. This could be any young woman beginning her new life. But this is not any young woman. This is a woman who struggled to be free from a series of crushing medical crises and the overwhelming burdens of debt and loss that resulted from them. She remembers the date – April 5, 2005 – when she experienced a significant medical event arising from lupus.

Following was abdominal surgery, then a cascade of issues including debilitating spinal cord inflammation and the specter of organ shut down. After 884 days in the hospital, she was moved to a nursing home where she hoped to be able to receive crucial rehabilitation and to heal.

But healing was agonizingly slow and the professionals believed she would never leave the nursing home. There was no one in the nursing home who could help her with the “intricacies” of rebuilding her life in the community.

The financial and red tape barriers were daunting. The losses of her home, car, career, and most difficult, the loss of her relationship as mother to her son shattered her. As a certified education specialist, Perneita had had plans to continue in graduate school and earn a degree. But her sudden abandonment of the program meant that she could not be readmitted. She spent many months, and endured a series of hearings and appeals trying to be readmitted while she was still in the nursing home. Mobility was an essential service for her to travel to county offices and keep up her momentum. “I spent my last \$18 to overnight an appeal letter.” Then there were the unpaid debts, and the threat of losing much of her Social Security benefit to pay for a car she no longer owned or would even be able to drive. The humiliation of having to explain her story in detail over and over again to strangers who really held her future in their hands led to a feeling of deep desperation.

Living in the nursing home eventually took its toll. “My cries were not being heard within these walls.” Without assistance, Perneita “felt like David and Goliath.” But like the story in the Bible, she prevailed.

When a young man, who also uses a wheelchair, came to let her know that living outside the nursing home was possible, she was still too immersed in her struggles to believe it. She applied to Maryland’s

Home and Community Based Waiver program but at the time the cost of her care in the community exceeded the program’s financial criteria. She would apply three times before being successful. “My coordinator was with me every step of the way” – overcoming her financial history, locating an accessible home, finding dental care, eyeglasses and obtaining transition funding that made it possible for Perneita and her son to be reunited.

Another help was a computer. Perneita began tapping into blogs and communicating with people who were experiencing some of her struggles. Her computer searches eventually put her in touch with the Reeve Foundation and Project Walk. This intense physical therapy program gave her new energy as well as her motto, “After everything, just stand up!”

Perneita is still proud to show a guest to her home the creative adaptations like grab bars that she uses for physical therapy, a specialized bath chair that helps her transfer to the tub, and lowered sinks and cabinets. She shows off the extra bath room space for lotions and cosmetics, noting “I am still a girl, after all.” The adaptations allow her to cook, keep house with supports, and to be an active mother to her now grown son who is about to make her a grandmother. A new car with hand controls is parked in the blue lined space in front of her door. Self-sufficiency is a watchword for this effervescent young woman.

Back to the wedding. The young man who encouraged Perneita while she was in the nursing home will be waiting at the end of the aisle to put a ring on her finger. Perneita smiles a radiant smile when she talks about a surprise she hopes to have for him – a walk down that aisle.





MARY

What do I want to do most of all? I want to be an advocate. I want to give something back to the programs that have helped me, like the waiver program. I have so many plans and there are at least three books inside me that I want to write—and poetry. I want to help.

What do I want to tell people? I want to say that you should not lose faith in yourself. Don't let yourself be labeled. You will never get out of the nursing home if you don't make sure that people see you as a whole person.

Mary has goals for life after the nursing home. She has big plans for making the world a better place for people with special needs, especially people who have experienced mental health problems. She has been through tragedy to rediscover who she really is and she is not about to let go and not about to forget what she sees as her blessings. “I was blind, but now I see.” She refers to the words of the old Christian hymn to describe how an attempt to take her life resulted in blindness, loss of a limb, and significant functional impairment due to a stroke. “I’ll never do that again,” she remarks about her near suicide following the death of her mother. Then she smiles a radiant smile and begins a litany of plans for the future.

A visitor will notice that much of Mary’s conversation is focused on the needs of other people. It is clear that the setbacks in her life have only served to encourage her to commit to working on behalf of other people in need, including her 99 year old aunt, who is a very important part of Mary’s life. At one time, Mary was a member of the Little Sisters of the Poor; the fact that she did not take final vows and continue with the order didn’t stand in her way as she continued to strive to make a difference. As a health care worker in many different settings, she also volunteered to help at a school serving children with developmental and cognitive disabilities. Her other interests include working with the families of returning veterans as well as the Federation for the Blind. These are among the things Mary wants to accomplish as soon as she moves to her home in the community.

Being in a residential treatment program and subsequently transferring to the nursing home has not kept Mary from earning accolades for her advocacy and volunteer work. She smiles broadly as she

remembers receiving an Associate of the Year Award from the mental health treatment program she attended. Mary is hopeful that once she has left the nursing home she will be able to go to the state capital in Annapolis and testify on behalf of people in need. One goal is to have input into the various legislative and executive committees that address the funding for community programs such as the Home and Community Based Waiver program. Now it’s one of her dreams to become more involved in energizing other people like herself to leave facilities for home.

With her mother gone, Mary has little family support, so she has come to rely on friends and neighbors as well as professionals for social supports. Yet her experience with professionals and programs has run the gamut. She talks about nursing home staff not listening, pigeonholing people, even ignoring the potential that people have for personal growth. Getting ready to go to her own home has been a process fraught with frustrations such as lost paperwork, waiting for approvals that didn’t come in time, having to begin again. Getting approval for her housing voucher program seemed “like an elevator moving up and down and the doors never really opening.” Still, she is confident with her decision, especially as people who have left the nursing home come back to visit, all smiles and optimism.

All smiles and optimism define Mary as well. She is a poet, a bringer of positive messages for young and old, a dynamo who won’t allow others to lose faith.





JAMES

What did I want most of all? I wanted the freedom. You don't think about it, but the nursing home takes away everything. Nobody saw me laugh in the nursing home. I was just staring into a wall.

What would I tell people? I'm living now! When people tell you that you can't move out like I did, say "Watch me!" There are some good people out there, good people who will help you. Listen carefully and ask a lot of questions.

A native Baltimorean, James' work as a trucker took him to Charlotte, North Carolina where three of his four children and five grandchildren were born, and where most of them continue to live today. One daughter now lives nearby in Baltimore and is a faithful help to him.

When James's wife passed away a few years ago, his life took a dramatic and frightening turn. Having struggled with diabetes for most of his adult life, he began experiencing complications and fell into a diabetic coma. This was followed by a stroke and significant brain injury that resulted in a speech impairment and inability to walk, as well as some cognitive loss. When James gradually awoke from the coma, he did not know where he was, nor was he sure of his own identity. Unable to make himself understood, and unable to form words or completely understand what was said to him, he would sometimes ask if he were truly in the United States and if people were really speaking English. He was in constant frustration – and fear- trying to transmit the words that were bursting from his mind. Then he began to believe that his mind was slipping away and himself with it.

Initially, doctors told James that he would be “bedridden” and would not leave the nursing home. In fact, he would be in the nursing home for nearly five years. Therapists did not have high expectations for him, thus therapeutic goals were not vigorous or very realistic. Eventually, a local clergyman began to visit, and interceded, obtaining a computer for James that suddenly opened the world for him. He was able to research his situation, and learn more about what was happening to him and even found a physician who was able to manage his demanding medical regimen. Using the computer, he learned more about his own family and background. At last he had a context for himself, an idea of who he was and where he belonged in the world. “I felt for a time like I wanted to kill myself. But when I got going on that computer, it all changed and I stopped thinking about killing myself.” As he relates this transformation, he smiles broadly, his eyes bright with remembering that crucial victory.

The computer led him to the Home and Community Based Waiver program that would possibly help him to leave the nursing home. James contacted the local HCBS care coordination organization and was stunned to find a service coordinator standing in his room the very next day. When he was told

that he might be getting out into the community and that the coordinator would work with him until that happened, his response was “Yeah, right.” James had been working through obstacles for such a long time – from aides who abused him physically, to nursing home staff members who ignored his requests for help with personal hygiene – that he really expected to be disappointed again. Nursing home administrators discouraged him from even thinking about moving into the community with stories of people who had been robbed and attacked once they left.

James gradually saw his dreams realized from embracing the moment of his baptism through finding a home in a Project-Based Section 8 development, found by his coordinator. After a long and tedious search and several discouraging stops along the way, the coordinator was able to find a studio apartment that he could afford with his modest Social Security income. And during his baptism, the pastor saw the scars that proved the abuse and was able to advocate even more strenuously for this man.

The first few weeks in his new home were rocky as the diabetes interfered once again. He collapsed in his wheelchair while out in his neighborhood only to learn as he was awakening, that he had been hospitalized and discharged to a shelter. It seemed that people who told him that living on his own wasn't safe might be right after all. But it was only a matter of hours before neighbors and family found him and brought him home again. James' eyes twinkle when he notes that he “likes doing things my way.” And he has found solace and assistance from neighbors who have become friends.

Circumstances seem now to be converging in his favor. Even the very arrangement of James' small apartment has made a positive change in his life. While stunned visitors watch, James arises from his chair, slowly takes his hands from the arm rests, and then thrusts his arms out with a joyful shout of “Look at me! No one thought I could do this. I couldn't if I was still in the nursing home. It's being here that made this happen.” Then he assures those around him that he will walk one day, and no one doubts that he will.



LAURA

What did I want most of all? I wanted to go home; I wanted to be with my son. I wanted my own freedom. I wanted to be me.

What would I say to people? I love it here. It's wonderful to be in your own home. It's wonderful to have freedom and decide things for yourself.

A visitor may wonder about the idea of freedom when the person must, for most of the day, remain in a hospital bed and be dependent upon the skill and kindness of an attendant care provider as well as faithful family members. On the face of it, at least in the visitor's mind, there seem to be many limitations to her freedom.

But Laura is clear about that. She reminds us that in the nursing home there were rules for eating, rules for washing, for sleeping, for visitors – the list goes on. Yet when she tried to make rules about herself for walking and receiving therapy, she was not successful. The rules conquered her so that she was left to sit in a wheelchair for most of the day and for most of the three years she spent in the nursing home. This exacerbated her multiple sclerosis to the point that her muscles could not support her efforts to walk on her own. And now rehabilitation at home is excruciatingly slow, and progress is measured in painful inches.

Laura's journey began when her husband brought her, complaining of abdominal pain, to the hospital for what would become a simple gall bladder operation that led to complications, including a stroke resulting in a nursing home stay. She was diagnosed with MS as a very young woman, and each of her three pregnancies – one of which resulted in a still birth -- increased the effects of her disability. As so often happens, friends drifted away, family members lost faith and her marriage was destroyed. With her mother and stepfather losing their own battles with cancer, she had nowhere to go. She knew she did not belong in the nursing home where there was no one even close to her age, no one with whom she could hold a conversation. But she believed she belonged nowhere else either. She faced a stark choice. Swallow hard and learn to survive in the nursing home or refuse to survive at all.

But Laura found another way when she realized “I don't belong here but I do belong in my own home. I do belong with my son and with the people who still love me.” She would no longer allow her voice to be ignored. A fastidious person, with a dazzling smile and striking blond hair, Laura would

begin to demand that her most basic needs for cleanliness, good nutrition, and care be met. Then she heard from others in the nursing home about a program that might help her as she began traveling the road that would bring her home.

Home for Laura also meant returning to the town she had always known. This was the place where she grew up, laughed with her friends, visited her grandparents, was married and gave birth to her son. It was important for her to return to that special place. But because of conflicting housing voucher rules of the city and county housing authorities, that was not to be. There would be many other disheartening detours. There would be a dearth of affordable and accessible housing in the county and a lack of resources for attendant care. Her eyes rim with tears as she tells of friends who offered to help but who disappeared and disappointed, in-home staff that failed to come or walked away with her funds and supplies.

But her own tenacity and the commitment of her dedicated care coordinator, attendant care provider, visiting nurse and therapy providers as well as family members like her son and ex-husband have resulted in what Laura calls a “good life”. While she is not in her home town, she's learned to love her new town. “I make my own rules now. I watch my stories and then sit in the living room with my cat Midnight. I had to give up my cat when I went to the nursing home. When it's time for bed, I rest and then I wake up and start a new day all over again. It's wonderful here.”





SONIA

What do I want most of all? I want to get back to being me. I am still a girly girl when I wake up in the morning. Most of all? I want my children to get used to me the way I am. I want them to know me.

What do I want to tell people? You still have to be yourself no matter what. You still have to ask the questions when there are things you don't know and you need to know. Remember, this is not the end of your life!

But it could have been the end of Sonia's life as she gradually awoke from a coma of five months' duration to find that her little girl, seven years old, had died after the two of them were hit by a car on a Baltimore street. That accident changed Sonia's life forever.

She also learned that baby Ezekiel –born days before the crash--was now five months old, and little Essence was just two. Her surviving children were being cared for by two different foster mothers and living apart from each other.

Family members shied away from telling Sonia the truth about her older daughter’s death, fearing that the news would be too much for her fragile spirit to bear. After all, she had been a vital, outgoing young mother; in her early twenties, supporting herself and her children as a certified nursing assistant. The accident left her with the effects of significant injuries that impaired her mobility and physical functioning and her ability to care for her basic needs. A brain injury during her convalescence exacerbated her situation.

When the full story of the aftermath of the accident became clear, Sonia experienced a deep depression in spite of the best efforts of her “most tremendous support,” her mother. Upon leaving the acute care hospital for the nursing home, where she would spend the next 29 months, she believed that everything had been taken from her. As she asked, “Why?” she experienced a deep despair that prompted her to consider ending her life. But then she looked to her faith, believing that “God – He never leaves us.”

Digging deep within herself, Sonia decided that she did not want to be in the nursing home and that she needed to do all that she could to make changes for herself. She remembered that she “is not an old lady yet” and she still “likes doing things my way.” She started to work faithfully in therapy and the rehabilitation program that included job training.

While in the nursing home, she endured a custody hearing that ended with Sonia now looking forward to reuniting her family, bringing her children home. That makes her eyes dance. Sonia has been on

the journey down the path toward a discharge and home for many months. Working with her coordinator, and her housing specialist, she has just become eligible for the Home and Community Based Waiver program. And, at last, she has become eligible for a special purpose housing program designed for non elderly people with disabilities who are transitioning from nursing homes and institutions. This voucher program is clearing the way for her. Now, an electric company hook up and furniture delivery are all that are left before she opens that nursing home door for the last time. Her lease has been signed and her new landlord, after hearing her story, was moved to help with home modifications that she will need for independence in her new home. That milestone is now just days away. As she recounts the stops and starts in the process, she laughs and shakes her head in wonderment, gold hoop earrings catching the light.

Sonia has become accustomed to the intricate planning that she now must do just to dress, to move from room to room, to prepare to go down the hall for lunch. And after all the tragedy in her life, she’s found that it’s the little things that begin to have more meaning for her as she looks forward to a time when she decides what to eat and when, what to wear, how to arrange her cosmetics, and what to read to her children.

And it’s the little things that make the nursing home most frustrating to an individual like Sonia who appreciates order, cleanliness and choices. A visitor will notice a bucket of grimy water with a wet mop leaning against the doorway, crumpled socks waiting to be retrieved from the floor. But the visitor will also notice the bright smiles and eager hands of the people who are there to help and are proud that Sonia is readying to be on her own. It really is the little things.



The Real Story



As we listen to the voices of the people featured in this booklet, themes for policy makers, service coordinators, housing specialists, and other professionals emerge. These watchwords are:

- **Individualized** approach to planning, understanding that each person has specific goals as well as needs for living at home that is right for him/her.
- **Creative resource development**, realizing that as planning begins with the person, not the limits of a particular program; the innovative use of community resources and the creation of community linkages and relationships is essential.
- **Flexible systems navigation**, meaning that as the plan for transition evolves, expectations for time, process, and program will be fluid.

Community living and transition from nursing homes require innovative approaches to realizing the core elements of the process including:

- **Person driven care coordination**
- **Affordable, accessible housing**
- **Transition services and requisite transition funding**

These same principles apply as care coordination continues after the person achieves his/ her initial goal for community living. The plan, proposed funding sources, the need for daily personal support, as well as the goals of the person are likely to change as the reality of community living unfolds. The interrelationships of the diverse HUD housing programs, Home and Community Based Waivers and such essential initiatives as Money Follows the Person are key to the ability of service coordinators, nursing home professionals, community providers, and the individuals themselves to craft realistic and cost efficient strategies for community living.

The True Victory



Postscript

As this publication was being printed, both Sonia and Mary overcame the last barriers to their independence in the community. At the beginning of June, 2011, they picked up their keys and unlocked the doors to their new homes. In Sonia's case, a reasonable accommodation for unit size had been requested and approved. Mary's new apartment is in a midrise building that is accessible for her. Their lives are now theirs alone to create, theirs

to direct. But they will still be able to count on their community care coordinators for help in navigating the systems and resources that will keep them eligible for the essential CMS/HCBS and HUD programs that will keep them independent and at home. Both Sonia and Mary overcame the last barriers to achieving their independence with HUD Non Elderly-Disabled (Category II) Housing Choice Vouchers.

Credits:

Photography: Michael Ciesielski Photography

Layout and Design: Chrystal Creative



8258 Veterans Highway, Suite 13
Millersville, MD 21108
410-987-1048
www.coordinatingcenter.org



6858 Old Dominion Drive, Suite 230
McLean, VA 22101
703-356-8035
www.neweditions.net
www.hhs-hud-housing-collaboration.net