Why Transitions Matter

1-855-761-9030

http://dma.ncdhhs.gov/providers/services/long-term-care/money-follows-the-person
It’s difficult to believe that Alyssa, a smiling 10-year-old with a loving family, could have a personal history that caused deep stress and ultimately led to a crisis placement in a state facility.

But thanks to Money Follows the Person (MFP), the story has a happy ending.

As a toddler, Alyssa was diagnosed with autism. Her parents became very involved with the TEACCH Autism Program at UNC Chapel Hill. But Alyssa wasn’t progressing as hoped. Before she was 4-years-old, Alyssa started to have seizures and her behavioral challenges were exacerbated.

It was difficult for Alyssa’s older sister to see her struggling. Alyssa’s father was often deployed with the military, leaving her mother alone with the girls. It became clear the family needed another option; so they reluctantly enrolled Alyssa in The Murdoch Developmental Center (The Murdoch Center) in Butner.

Alyssa was at The Murdoch Center for four months when the family learned about the Money Follows the Person (MFP) program through Dena Cannon, MFP Transitional Coordinator/Olmstead Liaison from Alliance Behavioral Healthcare, who was on Alyssa’s interdisciplinary team. She convinced the family that, through MFP and the Innovations Waiver, Alyssa could come home with the support she needed.

“Dena was very present and an amazing advocate. She did everything possible to push the process forward and make it all happen,” Alyssa’s mother said.

A month later Alyssa did come home, but this time the family had specially trained staff support for 31 hours a week – divided up between before-school, after-school and weekend assistance.

The family now has a dedicated caregiver who accompanies Alyssa wherever she goes. In addition, MFP-funded technology helps Alyssa communicate and is used in conjunction with her school-based speech and occupational therapy.

“We want her to continue to grow and become as independent as realistically possible, and the staff member she has works on those goals every day,” Alyssa’s mother said. “Alyssa surprises us every week with what she can do. The staff person never underestimates what’s possible and rejoices with us when Alyssa accomplishes new things.”

In the summer of 2014, the family was able to spend a relaxing vacation in Disney World together.

“MFP and the Innovations waiver has given us help in the home that we didn’t have,” Alyssa’s mother said. “Alyssa’s happiness, a routine with staff every day; it has made the whole family happier. All we want is for her to be happy and know she is loved. That is more important than anything else in the world.”
Sam’s Story

Sam, is a quiet, 69-year-old man with FragileX, a genetic intellectual disability. Sam lived with his parents in Wilkes County until he was 50. Because he is very mechanical, Sam often helped his father with the chicken coops and other chores at home.

Sam’s father became sick; his mother was overwhelmed. With help from the Smoky Mountain Center, Sam moved into an Intermediate Care Facility (ICF) associated with Community Alternatives, which provides a continuum of community-based services for people with physical and mental disabilities.

While at the ICF, Sam had a part-time job working in a grocery store and took odd jobs fixing mechanical items, such as lawn mowers. While at the ICF, Sam became very close to a support person named Megan.

As Sam aged, he developed Parkinson’s disease and was not able to do as many physical tasks. During that time, Sam became more and more withdrawn. Most of his family interaction had dissipated.

Sam then moved into a group home, where he lived for 16 years. A doctor believed Sam was headed for a nursing home. But Sam, Megan and Community Alternatives created a better option. Megan became authorized to provide services to Sam as an Alternative Family Living provider* and invited Sam to live with her and her family.

MFP was a crucial part of making the transition happen.

Since Sam moved in 2011, he has become a regular at the Ruby Pardue Blackburn Adult Day Health Center in Wilkesboro and has developed a friendship with a staff member who takes Sam to dinner and other places.

Sam has become part of Megan’s family, showing a playful side he often keeps hidden from strangers. Three of Megan’s sons work in group homes and the youngest volunteers at the Ruby Pardue Blackburn Adult Day Health Center. Megan’s family is embarking on a major home project in pursuit of a second AFL, and Sam is in charge of painting.

Last summer the entire family (including Sam) went to a wedding in Missouri. This was the first time Sam has ever been on a plane and may have been his first real vacation.

“I know how much this has changed him to come home,” Megan said.

* Alternative Family Living (AFL) is a support option allowed under the Innovations waiver that enables an individual to live with a paid caregiver and the caregiver’s family.
Money Follows the Person supports both participants and the family members (caregivers) who love them.

In 2012 almost 30% of the U.S. population provided unpaid caregiving services to a loved one who was ill, disabled or aged.* Unpaid caregiving services were valued at $450 billion per year in 2009 – up from $375 billion in 2007.**

Etta, 86 and her daughter, Lulu, 70, are an example of such a family. Etta was living with Lulu when she became sick and unable to walk. After two weeks in the hospital, Etta spent nine months in Woodhaven Nursing Center in Lumberton, N.C.

Etta’s illness took its toll on both the mother and daughter. Both wanted Etta to return home, but Lulu was concerned that she and her husband could not meet all of her mother’s needs. Lulu was getting mixed messages from both friends and professionals, ranging from “this will be very, very hard for you” to “it’s possible to do this.”.

Then a social worker told Lulu about the Money Follows the Person (MFP) program. After some prayerful thinking, Lulu decided it was time for her mother to come home. MFP and New Hanover CAP/DA Waiver Program made that decision a reality.

The program provides Etta with a Certified Nursing Assistant (CNA) to help with bathing and other activities of daily living and she uses a specialized van to get to medical appointments.

“She’s been no trouble, not sick, just fine,” Lulu said. “Without MFP, I’d probably be sick and she’d probably be sick. Now she’s happy and I’m happy.”

* "Caregiving in the U.S.,” The National Alliance for Caregiving and AARP (2009) - Updated: November 2012


Without MFP, I’d probably be sick and she’d probably be sick. Now she’s happy and I’m happy.” - Etta’s daughter, Lulu
Jacqueline Lee (Jackie Lee) had diabetes for about 15 years, but at age 57 her life was going well. She was living in beautiful rural Franklin, NC, working in a job she loved. But then she lost her job, health insurance, and soon became unable to afford her essential medications. As a result Jackie Lee became very sick. She was falling often and had peripheral neuropathy (pain and numbness in her feet). Eventually it became difficult for her to even stand up.

Despite the support of her sisters, Jackie Lee could no longer live in her non-wheelchair accessible house. Jackie Lee moved into a nursing home for a month of post-acute rehab, but she had no safe place to return home. She applied for subsidized housing vouchers, but the waiting list was between two and three years long. Other potential housing options also fell through. A year later, Jackie Lee was still living in the nursing home.

Jackie Lee described her experience in the nursing home as akin to homelessness. “I had nowhere to go and no hope of having anyplace to go home to,” she said. “I felt forsaken and didn’t see anyway out. I was in tears 100 percent of the time, always waiting for the other shoe to drop.”

Then she found out about the CAP/DA and Money Follows the Person programs through the Local Contact Agency Options Counselor, Donna Case, and Independent Living Transitions Coordinator, Lori Massey. Through their help, she was able to obtain affordable housing at Life House, a 20-unit transitional housing complex for people living with disabilities.

“Life is fabulous here,” Jackie Lee said. “It is safe, quiet and very secure. The people who live here – it’s a community. We watch out for each other.”

The MFP program also helped her find home furnishings and affordable primary medical care. Her new primary care doctor “prescribed” a cat to help with anxiety and depression. That is how she got Tony, a gray-and-white tabby who – after living in a shelter for a year – was also seeking a “forever home.”

Looking ahead, Jackie Lee wants to volunteer at the nursing home where she once lived, and assist at the local Meals on Wheels program. She hopes one day to drive again and actually deliver meals to homebound residents.

“None of this could have been possible without the support system I have – case workers, nursing,” she said. “I’m totally in awe of the ongoing support system.”
Mandy’s Story

Mandy, is a gentle, soft-spoken 35-year-old woman with cerebral palsy. She resided in a group home in Wilkes County for 11 years prior to moving to an Intermediate Care Facility (ICF) for medical reasons in 2011.

Mandy’s greatest love is animals, and the ICF could not permit animals due to allergies among the other residents. Mandy liked the ICF but longed for a home where she could be around animals. Smoky Mountain Center, in collaboration with Community Alternatives, which provides a continuum of community-based services for people with physical and mental disabilities, informed her about Money Follows the Person (MFP).

Community Alternatives introduced Mandy to Clara, who was authorized to provide services as an Alternative Family Living provider.* Clara invited Mandy to live with her and her family.

MFP coordinated the transition to the AFL, including making several accessibility upgrades so Mandy could live there safely. Mandy moved into Clara’s home in 2013.

On a typical day, Mandy gets dressed and puts on her leg braces. Then she goes to Wilkes Vocational Workshop, where she works while socializing with the other employees. On Tuesdays, she looks forward to spending a half-day working with the animals in a veterinarian's office. When Mandy is not working, she likes to watch cooking shows on TV and experiment in the kitchen. She enjoys going to church on Sundays, taking walks around the neighborhood and catching up on the neighborhood “news.”

Last summer, Clara, Mandy and Clara’s niece took a trip together to Washington DC.

“This is a real home, compared to the other place,” Mandy said.

* Alternative Family Living (AFL) is a support option allowed under the Innovations waiver that enables an individual to live with a paid caregiver and the caregiver’s family.
Evelyn was in her late 50s/early 60s when she was brought to the hospital for severe leg pain. This was the beginning of a painful odyssey which resulted in her moving into a nursing facility in New York City and was told she would never again live on her own.

Eventually, she moved to a facility in Wilmington, N.C. to be closer to her children and grandchildren. But she never felt comfortable having them visit her at a skilled nursing facility. She loved the nursing home staff, but wanted her own home.

A social worker told her about the Money Follows the Person Program. By that time, she had been living in nursing homes for seven years. With the help of MFP and the New Hanover CAP/DA Waiver program, she was able to move into her own home.

“I was a little scared of the world now because I’m in a chair now and the world looks so big,” she said. “But I’m in a lovely place, a little house with a garden.

“It was a huge adjustment from going, going, going (before the illness) to sitting in a wheelchair. I thank God that I can make little things to eat and appreciate the sun, the garden, the people around me.”

Evelyn says her goals are modest – to see her grandchildren grow into teenagers, to sit in her garden, maybe to get a computer and learn to drive again.

“I want my children, my grandchildren, my great-grandchildren to never give up,” she said. “I want to leave that legacy behind.

Evelyn believes Money Follows the Person provided a special inheritance for her family.

“I want my children, my grandchildren, my great-grandchildren to never give up. I want to leave that legacy behind.”
Alex, 24, has Wilson’s disease, a condition similar to Lou Gehrig’s disease, which affects motor functioning but not mental abilities. Though non-verbal, Alex can answer yes/no questions with the help of a communication board.

Alex had lived in nursing facilities in Siler City and Durham for almost two years after being an inpatient in an acute rehab hospital in Raleigh.

“I always wanted him to come home,” said his mother, Marianne, “but as he deteriorated more, it was difficult to care for him. I felt daunted and depressed to have him at the skilled nursing facility and not be able to have him home.

“I wanted to give him better care than the nursing home was able to give him. And it was wearing the family out going back and forth.”

MFP and the Wake County CAP/DA Waiver program helped Alex get the care he needed to move back home. Alex now lives in Pittsboro with his family and a caregiver who helps him with activities of daily living from 8:30 a.m. to 5:30 p.m. Marianne said the difference in Alex since leaving the facility is like “night and day.”

“He never really ‘lived’ in the nursing home,” she said. “Home is where he belongs. He would cry when he had to go back. And I don’t have to worry about him like I did when he lived in the nursing home. The caregiver is just a phone call away.”

Alex recently got an accessible van so he can get out into the community more often, and is currently looking into taking college courses.

“I just knew that he could not stay in the nursing home forever and I needed to do anything I could to get him home,” Marianne said. “MFP was the ticket!”
Nettie’s Story

Nettie, an intelligent, communicative 69-year-old woman, from Caldwell County, reared three children in the small town of Hudson, N.C.

In her 30s, she had three small strokes and had arthritis. After breaking her leg and with her arthritis advancing, she began to use a wheelchair. She lived for 13 years in an accessible home before moving to a nursing home.

Nettie lived a nursing facility for 15 years. During that time, her children did their best to balance the demands of working, supporting their mother and raising their own small children.

Nettie learned about Money Follows the Person (MFP) through a social worker at her nursing home. She immediately began advocating for herself through the county’s Vocational Rehabilitation-Independent Living Program (VR-ILP).

“Nettie is all about making her own choices – down to food products and the clothes she wears,” says MFP Transitions Coordinator Tara Williams.

However, finding affordable and accessible housing proved to be a challenge and it took nearly two years before the transition took place. Working with other family members, Nettie found a doctor and her daughter, Nancy, agreed that “it was time” for Nettie to move in with her.

Nettie transitioned out of the nursing home on October, 14, 2015. She was packed and ready to go two months before the date.

Nettie now lives in a private home with her daughter and grand-daughter and is receiving home support through the N.C. Medicaid Community Alternatives Program (CAP).

“I love it here because of my daughter and my family and because I have more choices,” Nettie says.

Nettie can’t stop praising the MFP program and her two transitions coordinators, Williams and Keisha Mack with the state’s Community Alternatives Program for Disabled Adults (CAP-DA). “She thanked us a thousand times,” Williams said.
Dylan, 18, was removed from his mother’s home due to neglect and abuse when he was 4-years-old. Misunderstood behaviors associated with his childhood experiences, intellectual/developmental disabilities (I/DD) and mental health issues led to placement in more than 60 facilities over 14 years, including foster homes, group homes, hospitals, and even prison.

Dylan was living in a Psychiatric Residential Treatment Facility (PRTF) in a border county of South Carolina* when he met Jen Branham, MFP Transitions Coordinator at Smoky Mountain Center. Branham supported and encouraged Dylan to move back to North Carolina under the MFP program.

Thanks to the Money Follows the Person (MFP) program, Dylan now has a stable and loving family home.

Branham was able to coordinate both Dylan’s mental health and I/DD care – allowing his service providers to better understand his needs and desires.

As a result, Dylan has been living at an Alternative Family Living (AFL)** home in Asheville for the past three months.

“I got to choose where to go this time. In the past, they didn’t even let me choose,” he said enthusiastically.

“Life is fun now. I get to go outside, go to football games, get to do things I’ve never gotten to do.”

Dylan has a full schedule of volunteering with local service providers (such as Meals on Wheels) and playing in the adult football league. He will soon begin supportive employment to gain job skills. He also has become good friends with another young man with developmental disabilities living in the same AFL.

“I’m the one that helps him,” Dylan said, “I just try to make him laugh.”

Dylan’s goals for the future include getting a driver’s license, a job, a girlfriend and a place of his own.

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* N.C. Medicaid sometimes uses PRTFs within 80 miles of the N.C. border.

** AFL is a support option allowed under the Innovations waiver that enables an individual to live with a paid caregiver and the caregiver’s family.
Teresa is a 59-year-old person with quadriplegia resulting from a car accident 33 years ago. She lived in a nursing home for two years “and 23 long days” before she successfully transitioned to living in a one-bedroom apartment in Greensboro.

She contacted her advisor and then Greensboro Social Services, who referred her to Mark Steele in the Division of Vocational Rehabilitation Services’ (DVRS) Independent Living program. Mark referred her to the MFP program and recommended a Sure Hands ceiling lift to assist her in getting in and out of bed. Each day she receives five hours of personal assistance services to help her perform various activities of daily living.

“Being on my own has just been incredible,” says Teresa. She has more money now than she had in the nursing home, allowing her to purchase newspapers to do Sudoku puzzles and clip coupons. She enjoys shopping for her sister and niece’s families and passing her savings on to them. Teresa also has Internet access, something she did not have in the nursing home, and enjoys growing her own tomatoes.

When asked about the impact MFP had on her life, she commented that, without MFP, “I would have been stuck in the nursing home – could not have done anything in a manual wheelchair in a nursing home.” She now feels “wonderfully blessed” and stated, “This program is a life changer.”

“I would have been stuck in the nursing home – could not have done anything in a manual wheelchair in a nursing home… This program is a life changer.”
Growing up in Benson, N.C., Sherwood made a living doing farming, landscaping, bricklaying and carpentry in Raleigh. At age 33, he started a family and now has a 14 year old daughter - a straight-A student who is a source of pride for her dad.

His active lifestyle changed abruptly when he had a stroke at age 48. He lived in Warsaw Rehabilitation Center for more than a year while working hard to regain his previous strength and abilities. He can now speak clearly, use both hands, manage stairs and ambulate with a walker for 250 feet.

As his abilities returned, Sherwood wanted to return to an apartment of his own. He learned about the Money Follows the Person (MFP) Program from a social worker at the rehabilitation facility.

On April 6, 2016, he was able to move into his own apartment with personal care services – such as meal preparation, help around the house and running errands – five days a week. The move was supported through a collaboration of MFP, Eastern Carolina Council (ECC) Area Agency on Aging, N.C. Office of Housing and Homelessness Regional Housing Targeting Program, N.C. Division of Vocational Rehabilitation Independent Living Program and N.C. Medicaid’s Community Alternatives Program for Disabled Adults (CAP/DA) waiver.

“I have more privacy,” he says. “I come and go as I please. I get to cook what I like to cook – like potatoes, fried chicken, vegetables and spaghetti.” He loves being part of the community and enjoys watching TV, sitting outside his building and talking with people, going out with friends – and buying hats.

He also has a supportive girlfriend who comes over several times a week and whose family feels like family to Sherwood. “Having her in my life has been wonderful. She has really stuck her neck out for me.”

His future goals include walking longer distances, going to the gym and being able to drive again. “If there’s a will, there’s a way,” he says. “You’ve got to try. It is not good to sit around and watch TV.”

When asked what he would tell others living in a facility who want to move home, he said, “If you ever get in a situation like this, don’t let other people tell you that you can’t make it. You can do it if you put your mind to it.”

Andi Reese, Transition Coordinator with ECC, said Sherwood’s perseverance inspired others in the facility to make positive changes in their own lives. Sherwood’s thinks equally highly of Andi.

“Andi has been a great help and encouragement to me,” he said. “I mean that from the heart. Since I’ve been at this place, I really feel like I’m home. It’s a blessing!”
All Oshin really wanted for Christmas 2013 was to go back home to Asheville. She received her gift shortly before Thanksgiving Day.

Born in Jamaica in 1994, Oshin had medical issues from birth. These were complicated by a Traumatic Brain Injury (TBI) caused by brain surgery at the age of 5. Eventually Oshin was placed in an institution in Swannanoa.

Oshin was lonely, as there were not many people at the group home her age. She was placed in a sheltered workplace and given menial tasks. Oshin was very unhappy at the institution and wanted to go back home to live with her mother. She stopped eating, lost weight and was given nutritional supplements.

The institution contacted Oshin’s mother about the Money Follows the Person (MFP) program. The goal was set to have her home by Thanksgiving. Thanks for MFP and the support of Smoky Mountains MCO, Oshin was able to access the Innovations slot and was home with three days to spare!

Once home, Oshin has become healthier and now sells her art!

Oshin’s long-term goals include returning to an earlier hobby of making baby clothes for dolls – and perhaps one day owning her own boutique and/or hair salon.

According to her Care Coordinator, Robin Shaw, Oshin is smiling much more and is very animated. “Her facial expression alone tells you it is a success,” she said.

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“Her facial expression alone tells you it is a success.”

“Christina’s Story

“She is so much happier now,” said Patti, the mother of 33-year-old Christina, who is unable to speak, roll over, or raise her arms much above table level.

Patti says she could not get a smile from her daughter when she would visit her in the institutional group home, but now “she smiles, she laughs and she sings.

“She’s home and she can decide what she wants to do.”

“She’s so much happier now.”
CeCe, 53, has an eating disorder which caused various medical problems, including problems with walking, bathing and other personal care issues. Following weight reduction surgery, she lived in a rehabilitation center in Ohio for four years, followed by seven months in a rehabilitation center near Morganton, North Carolina.

Though Cece enjoyed the staff in both centers, it was hard for her family to visit and she missed them terribly. Thanks to the Money Follows the Person and Catawba County CAP/DA Waiver program, she now lives in her own home near Hickory – reunited with her husband of 15 years, as well as other friends and family.

“It is awesome here at home,” she said.” I can go outside and get sunburned. I love the animals. My neighbors have dogs, my mama has dogs. I would love to have a dog, but it would be hard here.”

Her personal care assistant says CeCe is much happier at home with her own possessions, including an extensive collection of NASCAR collectibles, especially Jeff Gordon, memorabilia.

Henry, 69, had lived in an institutional group home in Charlotte after his family had become unable to provide him with the care that was needed. He was able to move to his own home with the help of MFP and the Innovations waiver program. He now lives with one of his favorite people, Anthony – his support provider.

Since he moved, the county social worker reports she has seen tremendous change; that his demeanor and attitude have become more free and relaxed. Henry now attends classes and takes part in a day program.

Anthony reports that Henry is comfortable in the new setting and helps with laundry and other household tasks, but really enjoys going out to community events and “getting out” on long trips.”

The MFP Demonstration Project is founded on the principle of individuals having the right to choose where they receive their long-term support services. As the social worker notes, “people have a great desire to have control over their day-to-day activities, to lead self-determined lives and to be included in their local communities.”
Jabreel, 21, has autism and lived at home until two years ago when he moved to a group home. His mother soon saw that he was becoming depressed and that his communication and social skills were declining. Because of MFP and the Guilford County CAP/DA Waiver program, Jabreel moved out of an institutional group home to an apartment in Greensboro where he lives with Kevin, his support provider. The experience has been liberating. Now Jabreel has an opportunity to share his interest in sports with friends and enjoys singing and dancing.

Jabreel and Kevin travel to New York often, typically to attend sports events, and also are actively involved in the Greensboro community. “My son now has a warm, broad network of people in his life, and there are more opportunities for normalcy for my son,” his mother, Shelia, said.

Ronald lived at home until he was 14 and then moved to a group home. He lived the next 20 years in an institutional setting. Ronald is deaf, has autism, a seizure disorder, and does not use words to communicate.

A year and a half ago, with the help of the MFP and Catawba County CAP/DA Waiver program, he moved to the Hickory area, where he lives with his mother, Ruth. Formerly frustrated and uncommunicative, Ronald now interacts with his mother and sisters and goes out in the community, with regular visits to a nearby Starbucks.

Ronald’s sister once worked at the institution where he lived for 20 years and understood the limitations of institutional life. She advocated continuously for him to come out of the institution. Tears well up in her eyes as she recounts the changes that have happened because of MFP, and observes: “We are a family again, and you can see how much this new freedom means to him.”