

Appendix O: Case Studies

Transition of Elder Population

Mrs. Jones is an 83 year old woman who has been living in a skilled nursing facility since February 2005. Until Mrs. Jones moved to the nursing facility, she lived independently in her home where she and her husband had raised their three children. She and her husband had promised each other that they would stay in their home and take care of each other as they got older. Nursing homes would not be an option for them.

Circumstances changed for Mrs. Jones when her husband died suddenly in 2001. Mrs. Jones was left with all of the work involved in maintaining the family home that she and her husband had worked so hard to build. Only one of Mrs. Jones' children lived in the same town, her daughter Susan. Susan and her family helped Mrs. Jones with the lawn in the summer and the snow in the winter. Despite the extra responsibilities at home, Mrs. Jones continued to actively participate in her church. Every Sunday morning, a member of the congregation would stop by Mrs. Jones' home and take her to worship.

Mrs. Jones had fallen twice during the fall of 2004. One of the falls just led to some bruises. The other resulted in broken ribs. Each time Mrs. Jones returned home after brief visits to the emergency room. After the last fall, Susan had taken time off of work to help Mrs. Jones with personal care for a few days. Susan was concerned about Mrs. Jones living alone and discussed these concerns with her mother. Despite her daughter's concerns, Mrs. Jones had no plans to leave the family home.

On Sunday morning, December 12, 2004, Mrs. Jones was getting ready for church as she did every Sunday morning. She watched for her ride from the window in the living room of her home. When she saw the car arrive, she hurried down the driveway so that the driver would not have to wait. She never made it to the car. She slipped and fell on black ice leaving her with a broken hip.

She was hospitalized for a week following the fall. The plan for discharge included six weeks of rehabilitation at the local nursing home. Mrs. Jones was agreeable to the nursing home as a short term solution.

Complications increased at the nursing home. Mrs. Jones experienced a number of infections which increased the time anticipated for rehabilitation. At the end of three months, Mrs. Jones was still not permitted to walk without assistance from staff. She spent most of her day in a wheelchair. At the end of four months, the nursing home discontinued physical therapy. Mrs. Jones still wanted to go home.

Mrs. Jones' daughter reasoned that her mother could not return home without 24-hour assistance. While the nursing facility staff agreed, Mrs. Jones did not. The bills from the family home continued to mount. The likelihood of Mrs. Jones returning home to live continued to diminish. An important decision had to be made. It was Susan who took the lead and counseled her mother to accept the reality that going home was not an option. With her relationship to Susan in the balance and the bills escalating, Mrs. Jones agreed to sell the family home. It was agreed that she would spend down so that Medicaid would pay for the care that she could no longer afford.

Mrs. Jones struggled with the loss of independence. She felt she would never have the choice to live in the community again.

Susan read about Money Follows the Person Rebalancing Demonstration in the newspapers. The newspaper made it clear that 24-hour care at home would be an option for people who were living in nursing homes. Based on the availability of 24-hour care, Susan called the MFP Demonstration office number in the newspaper to request additional information. Later that day, Susan went to visit her mother. She took the newspaper article with her and showed it to her mom. Mrs. Jones mentioned that she had recently received a letter from the DSS announcing an upcoming meeting at the facility. The meeting would provide an opportunity to learn about the demonstration and ask questions. Mrs. Jones and Susan decided to attend the meeting.

On March 30 at the on-site meeting, Mrs. Jones, her daughter and several other residents of the nursing home met Rick, the transition coordinator for the first time. Rick told them about the demonstration and some of the new services available for people who wanted to live in the community. There were many questions about 24-hour assistance. Rick made it clear that 24-hour assistance was based on the individual care needs of the person. Rick also told them about a new service delivery model called self-direction. In addition, he mentioned that the demonstration provided assistance for finding and/or affording a home and talked about participants' rights and responsibilities under the program.

Rick had information packets about the demonstration available for residents who were interested in applying. He briefly reviewed the contents which included the application and a brief program overview. He described the application process which included a lottery system. He told them he would be available to go over the information in more detail or assist with the application process if they felt it would be helpful.

Mrs. Jones and Susan returned to Mrs. Jones' room that day very excited. They completed the application within the hour. The application was in the mail by 5:00 PM.

About a month later, on April 2, 2008, Mrs. Jones received a letter and package of materials from the DSS MFP program office confirming her eligibility for the MFP demonstration and assigning her a transition number. The package of materials included a guide to the transition process, a self assessment tool, a guide to rights and responsibilities under MFP. The letter also indicated that she had been assigned a transition number '12' which meant that she should expect a call from the transition coordinator assigned to her case within the next three days. The very next day, Rick called Mrs. Jones to set up a time to meet with her so that they could get started. Mrs. Jones knew that Susan would want to be there for the first meeting so they set up the meeting for April 12, a Saturday morning. Rick encouraged Mrs. Jones to review all of the materials and complete the self-assessment. Mrs. Jones and Susan enjoyed completing the self-assessment.

At the first meeting, Rick learned many of the details which led to Mrs. Jones moving to the nursing home. He learned about her former involvement in the church and community and he learned about the close relationship she shares with her daughter. Together they reviewed her

completed self-assessment. Rick asked questions to better understand why she felt she did or did not need certain services.

Mrs. Jones was very concerned about the fact that she had no money. 'Where would she live?' Rick explained how Medicaid works a little differently in the community and suggested that together they would work on a budget. After taking the time to address Mrs. Jones' concerns, Rick reviewed the informed consent paperwork and releases that Mrs. Jones was required to sign for participation. Mrs. Jones felt comfortable and signed all required documentation. Rick left that day explaining to Mrs. Jones that he would be back the next week. He told her it was most important for her to gather personal documents such as her birth certificate and her Social Security card.

Rick returned the next week and Mrs. Jones already had all of her documents together. Rick continued the meeting by discussing housing options. He told Mrs. Jones that she could move to an assisted living unit or to an apartment. Mrs. Jones noted that she would prefer a home as close as possible to her church with a kitchen. Rick told Mrs. Jones that he would forward her request to the housing coordinators. He also asked if she had any friends at the church who may like to help plan her move back to the community. Mrs. Jones said she would invite some friends to the next meeting. In the interim, Rick told Mrs. Jones that a social worker from Connecticut Community Care Incorporated (CCCI) would be scheduling an appointment within the next three days to assess Mrs. Jones' level of need for community services. Before leaving that day, Rick had Mrs. Jones complete the paperwork for rental assistance.

Mrs. Jones' assessment was completed the following week on April 24 and Mrs. Jones was found to be eligible for the Home Care Program for Elders waiver. Mrs. Jones' individual budget for services was set. She was offered the choice of having CCCI assist with selecting services and providing case management for her or of selecting a fiscal intermediary who would counsel her on budget development so that she or her representative such as her daughter, Susan, could self direct. Mrs. Jones decided along with her daughter that they would select the self-direction model. CCCI assured them that if at any time they no longer wanted to self-direct, the option for an agency directed model would remain open. Susan expressed concerns that her mother was not offered 24-hour care. CCCI reviewed Mrs. Jones risk profile and discussed with both Mrs. Jones and Susan how there were some risks but that they were minimal given the range of services. 24-hour care was designed for people who need 'hands on care' 24-hours a day. Mrs. Jones did not need 24 hours of hands on care. Susan admitted that her mother did not need 24 hours of hands on care, but that her concern was about what would happen if her mother fell. They were reminded that it is impossible to remove all risk from life. People fall even with 24-hour care and people fall in nursing homes. Susan and Mrs. Jones agreed and decided to move ahead with developing the care plan within the budget allowance. Once it was completed, they would submit it to CCCI.

The next meeting on May 20 involved not only CCCI staff but also Rick, the transition coordinator, Mrs. Jones' friend, and Susan. The housing coordinator had identified apartments meeting Mrs. Jones criteria and forwarded this information to Rick. Locating an apartment was much quicker than in the past since Connecticut now has a housing registry to keep an inventory, housing coordinators to continually locate new housing, and housing subsidies that make

apartments other than subsidized housing possible. They scheduled the next meeting on May 27 to go see the apartments.

Mrs. Jones loved one of the apartments and a discharge date was set for July 1. The next month was busy as Susan and Mrs. Jones with assistance from Rick, identified personal care support and back up. Rick had Mrs. Jones begin to think about furniture needs. Based on the fact that Mrs. Jones had minimal personal belongings, Rick established a budget of \$400 to cover apartment set up costs such as furniture.

The week before the move was busy. Utilities were turned on, the phone was hooked up, and furniture arrived. Arrangements for medication were carefully tended to so that Mrs. Jones would have enough medication until her first doctor appointment in the community. Rick assisted Mrs. Jones in identifying a doctor in the community and in setting up the first appointment before leaving the nursing home. Rick also carefully explained the triage back up support system for the demonstration. Mrs. Jones noted that she had an emergency back up plan in her care plan. Rick explained that the demonstration 24-hour triage back up system was put in place as a last resort in the event that personal care plan back up systems did not work for any reason. He explained that someone would be available 24/7 to help her.

The day of the move arrived and Rick accompanied Mrs. Jones and Susan to the apartment to make sure that all of the details were in place. Rick left feeling that everything had gone well, explaining that he would be back to visit in a week. Mrs. Jones settled into her new home.

The first three weeks everything went very well. Then, on July 25, Susan's father-in-law had emergency surgery and her family flew to San Diego to help out. At the same time, Mrs. Jones' best friend was diagnosed with the flu. These people represented Mrs. Jones' back up plan so when her staff called in sick one morning, Mrs. Jones was left in bed with no assistance. Mrs. Jones used the 24-hour emergency back up number that she had been given for the demonstration. The nice woman on the phone had the back up coordinator call Mrs. Jones within five minutes. The back-up coordinator determined that this situation warranted support from demonstration emergency back up staff. Back up staff was at Mrs. Jones' apartment within two hours.

When Mrs. Jones completed her consumer satisfaction survey at the three month interval, she indicated that she was much happier than in the nursing home, had about the right amount of company, got out to church once a week, and felt that she had a great deal of choice and control over her services and home. Things appeared to be going well. Over the next few months there was no need to use the emergency triage system and Mrs. Jones was enjoying her own home again.

On December 4, Rick stopped in to see Mrs. Jones. This was scheduled as Rick's last visit. Mrs. Jones was confused when Rick arrived. She did not seem to recognize him and was confused in general about where she was. Rick suggested that she call 911. Mrs. Jones did not feel that was necessary. But, Rick noticed that Mrs. Jones was slurring her speech. Rick's concerns for the situation, translated into a 911 call. Mrs. Jones had many of the warning signs of a stroke.

The hospital confirmed the stroke. Mrs. Jones was admitted and cared for in the hospital for ten days. The stroke resulted in some paralysis to her left side and some difficulty with speech. It was recommended that she return to the nursing facility for rehabilitation.

On December 15, Mrs. Jones was admitted to the nursing facility. She was expected to be there for at least three weeks. Concerns regarding her apartment and personal assistants were increasing. Susan had paid for the personal assistants during her hospital stay. Mrs. Jones loved her staff. Susan wanted to assure that they would not take other jobs during her mother's rehabilitation. Mrs. Jones income was diverted to help pay for the rent and the state continued to pay the rental assistance portion during the next few weeks. When January 4 arrived, Mrs. Jones was disenrolled from MFP HCBS services. Rick comforted Mrs. Jones by telling her that he would help her return to the apartment as soon as she was strong enough. On January 18, Susan called Rick and told him that she felt her mother was strong enough to return home. Rick asked CCCI to visit Mrs. Jones and reassess her level of care to assure that the care plan originally developed was still adequate. A new care plan was developed with additional hours for hands-on-care.

Mrs. Jones could not wait to return to her apartment. Fortunately, that day arrived on January 23. Mrs. Jones returned to her apartment with MFP services. At the end of the first year in the community, CCCI revisited Mrs. Jones as they had several times during the year for her annual assessment. During the annual assessment, Mrs. Jones was reminded that she was no longer in the demonstration but that she was now formally enrolled in the Home Care Program for Elders waiver. The only difference to Mrs. Jones was in the paperwork. Her services were not affected.

Transition of Intellectually Disabled Population

Sam was moved to the nursing facility on June 3, 2001. He was 36 at the time. They said it would just be for a few days. He did not want to go. He wanted to go back home with his Dad. Actually, he wanted to go to his own place. He had always planned on having his own place. But, it had never happened. Mom had always said he needed to have a job first. But Mom died just before he graduated from high school 15 years ago. And, when he got his first job, he still did not get his own place. It had not happened the way she always said it would.

Sam's move to the nursing home was not planned at all. After his Mom died, Sam continued to live with his Dad in West Hartford. Things were going fairly well. Sam's Dad helped Sam regulate his diabetes even though Sam did not think he needed the help and Sam helped his Dad with the household chores. Everyday, Sam took the bus to work at the local grocery store where he worked 20 hours a week. Sam loved his job and everyone loved Sam. Sam and his Dad never talked about Sam getting an apartment the way his Mom had. They actually never talked about anything other than dinner, chores and the Yankees. Sam's Dad liked having Sam at home.

The situation changed suddenly on May 25, 2001. It was on that day that Sam's father became ill and was hospitalized. Sam was at work when the ambulance arrived at the house. When Sam arrived home, a neighbor stopped by to tell him that his Dad was in the hospital. Sam went with

the neighbor later that night to visit his Dad. That was when Sam learned for the first time that his Dad may not be coming home for a while. Sam was on his own for the first time.

Sam liked being alone and everything went fairly well for the first week. He got to eat whatever he wanted in his bedroom, not at the dinner table. When he ran out of clean dishes, he just used the dirty ones over again. He did not have to brush his teeth and he did not have to take a shower. He did not even have to take his insulin. When he ran out of groceries, he bought more at the store where he worked. No one there said anything about what he bought: soda, pretzels, milk, cheese and bread.

On June 3, the trouble started. Sam woke up not feeling well but still knowing that he had to go to work. Going to work was the rule. As he walked across the yard to the bus waiting at the end of the street his decision to no longer take his insulin caught up with him. He never made it to the bus. A neighbor found him on the ground and called 911. Sam woke up hours later in the emergency room surrounded by strangers. They explained that he had become hypoglycemic and asked questions about his diabetes and about who was taking care of him. Sam explained about his diabetes and about how he could take care of himself. But, no one could understand his speech. While Sam wanted them to see the independent man that he was, all they saw was a 36 year old male with Down Syndrome who had a severe intellectual disability, diabetes and severe apraxia. Sam did not really have a severe intellectual disability but people always thought that at first since he had such trouble communicating. With significant concerns regarding judgment and maintenance of chronic illness, a call was made to the Department of Developmental Services (DDS). After some difficulty finding Sam's Dad, they finally located him in XYZ nursing home where he had been transferred after his hospitalization. Given the options, Sam's Dad wanted Sam to come live at the nursing home with him.

Some six years had passed since that day. Sam's Dad has since passed away. Sam's brother in San Diego agreed to be Sam's limited guardian for residence and medical issues. Sam spent most of his days at the nursing home in front of a television. The staff had become his only friends and he missed his job in West Hartford. While Sam struggled to be understood when he first arrived, most of the staff now could understand a few words. If nothing else, they knew he loved the Yankees.

Sam's social worker at the nursing home was named Anne. In January of 2007, Anne saw a press release about the state's Money Follows the Person Demonstration. She then attended a workshop about MFP at the Connecticut's National Association of Social Workers Annual Conference. She called the DSS Central Office asking for additional information and mentioned that she knew someone whom she felt would be appropriate for the demonstration.

It was early in the month of March when Anne learned about the informational meeting scheduled at the nursing facility where she worked. She went to Sam and told him about the meeting. They agreed to go together.

Sam decided that he liked Claudia, the transition coordinator who was running the informational meeting on March 20. Claudia explained what the demonstration involved and the responsibilities of participants. She told him about the rules for getting accepted into the

demonstration and asked if his name was on the DDS “Olmstead list”. Sam replied that his name was on the list and Anne confirmed that it was true. What Sam understood from the meeting is that he could probably have a job and his own place, just like his Mom had said he could. Sam took the packet of information Claudia gave to him and asked Anne to help him with it.

Anne helped Sam complete the application. They both decided to use Anne’s phone number as a contact since Sam had trouble talking on the phone. By March 25, the application was in the mail. About a month later, Sam received a letter from the DSS confirming his eligibility in the MFP demonstration. The letter noted that his transition number was ‘5’ and that a transition coordinator should be contacting him within three days. The letter was accompanied by a transition guide, a self-assessment tool and a description of Sam’s rights and responsibilities as a MFP participant. Sam asked Anne to help him with the materials and with completing the forms so that he would be ready when his transition coordinator called. They did not have to wait long for a phone call. On April 28, Claudia called Anne asking if she could talk to Sam about a good time for a visit. Sam and Anne had already discussed that if Claudia ever called, Sam wanted to see her as soon as possible. Anne indicated this to Claudia and a meeting was set up for May 2.

Anne was in Sam’s room when Claudia arrived. Together they reviewed Sam’s self-assessment. Claudia was surprised that Sam did not feel he needed help with anything. She mentioned that everyone needs some help. They talked about how Sam came to live in the nursing home and Claudia learned about Sam’s mom and dad. She also learned about Sam’s love for the Yankees and Sam’s old job at the grocery store. Finally, Sam talked about the night that his former neighbor called 911. Claudia looked to Anne to understand Sam as he talked. She could not understand his speech at all.

Claudia told Sam that his brother in San Diego would have to agree for Sam to participate in MFP. Sam objected but Claudia explained the rules. Claudia also explained Sam’s rights and responsibilities under the demonstration once again. While Sam would have some help, it was really important for Claudia to know that Sam understood how to use the emergency back up number appropriately. While Sam said he understood the information, Claudia was sure they would have to review this again before Sam moved. Sam signed his letter of interest which Claudia copied and sent to his brother along with a letter explaining the MFP Demonstration Project.

On May 22, Claudia called Sam’s brother in San Diego to follow up on the letter. He confirmed that he had received the letter but unfortunately did not feel that the program was appropriate for Sam. Claudia mentioned how many people with more severe disabilities than Sam were living happily as part of the community. She went on to explain the quality assurance mechanism in the community and that she could tell Sam how much wanted to move. While Claudia was generally successful with guardians, she was not successful with Sam’s brother. He did not want Sam to move to the community.

The next meeting with Sam and Anne was scheduled for May 29. Claudia was concerned about sharing this news with Sam. She knew how disappointed he would be. She decided to talk to Anne first. Anne was notably upset by the news. She had known Sam from the day he had first moved to the nursing home and had grown quite fond of him. Despite how much she would

miss him, she wanted Sam to move to the community. She knew how much he wanted to live on his own in the community with a job. Anne discussed the possibility of becoming Sam's limited guardian rather than his brother. Claudia explained that there were two ways this could happen. 1) They could explain to Sam's brother that Anne was interested in assuming the responsibility and see if he agreed. 2) If he did not agree, they could request a status hearing and request to have him removed as guardian based on the fact that due to living in California he has not been able to attend any of Sam's meetings and he has been difficult to contact as his job requires frequent and lengthy travel. Clearly the second option would not be easy.

Anne and Claudia went together to explain the situation to Sam. Sam liked the idea of Anne being his guardian. He wanted them to call his brother. A phone call was made the following day to Sam's brother. Claudia, Sam and Anne were all on the phone. Anne talked to Sam's brother about how fond she was of Sam and how much he wanted to live in the community. She then mentioned that she would be willing to serve as guardian, assuming responsibility for Sam in the community if Sam's brother would allow it. Sam's brother agreed since he was unable to travel to Connecticut as often as he used to and felt that someone who lived closer could be more involved in developing Sam's support plan. He asked to be kept informed of important events in Sam's life and planned to visit Sam once he was settled in his new home. Paperwork was filed with the court on June 3 to change guardianship.

Transition plans continued on June 7 while they waited for the final paperwork appointing Anne guardian. It was explained that Anne would have to be appointed guardian and sign informed consent prior to Sam moving. Claudia mentioned that Sam would need to find his birth certificate and social security card. Sam did not know where they were. Claudia said she would help him get duplicates and that they had to start this process right away because sometimes it takes a long time.

The third meeting with Claudia was the most exciting one for Sam. They talked about where Sam would like to live and work. They also talked about friends that Sam used to have at the grocery store. Sam was sure they were all still there. Claudia was not so certain. Sam wanted to move back to West Hartford and work in his old job with his old friends. Claudia left that day telling Sam that she would try to find a place for him to live and that his next visit would be from a case manager at the DDS. DDS would determine his level of need for support in the community.

The case manager arrived on June 15 and asked Sam lots of questions. Sam did not know the answer to some of the questions. Anne stepped by and helped answer some of the more difficult questions. When the interview was over, the case manager talked to Anne and Sam about self-directing and individual budgets. She explained that Sam had a choice of hiring his own staff, hiring an agency that would help him hire staff, or just having one of the DDS approved agencies arrange his supports in the community. Sam wanted to do everything himself. The case manager told Sam that was called self-directing. She went on to explain that Sam's 'level of need' would be determined based on his answers to the questions she had just asked. The level of need would then be translated into a personal budget. Then, Sam and Anne could work together to develop an individual plan. They could get help from a support broker. The support broker could be someone who works for DDS or someone else they wanted to choose as long as

the person met the qualifications. The qualifications were all written on a piece of paper that the case manager had given Sam. Sam decided that he wanted to choose his own support broker. He was told that he could use money from his support budget to pay for the broker services.

Sam received a call from DDS letting him know that his budget for community supports had been established at \$36,000. He called the independent broker with Anne's help and set up a time for the broker to visit Sam in the nursing home. The broker's name was Molly. Sam liked her. She took the time to try to understand what he was saying. Molly explained that she would help Sam decide what services he needed and even help with finding staff if he wanted her to. Molly also explained that there was something called assistive technology that was like a computer Sam could use to help him communicate with other people. That way, the next time he went to McDonalds, he could order his food himself. Sam liked that idea. By the end of the meeting, they had drafted a budget for Sam that included among other things, staff support, transportation and assistive technology. They sent the plan to the DDS case manager for approval.

On August 3, the Probate Court hearing was held to change guardianship for Sam. Claudia coordinated a meeting immediately following the hearing with all of the people helping Sam. Anne was now permitted to sign the informed consent for Sam to move to the community. The paperwork was signed. Everyone offered status updates on Sam's transition plan. Molly reported that she had already found a few people for Sam to interview that could help him at home. Sam showed Claudia the Social Security card and birth certificate that had arrived. Claudia also mentioned that the housing coordinator had found an apartment that they thought Sam could afford and may like close to a bus line in West Hartford. The paperwork for rental assistance was completed. A visit was scheduled following the meeting so that Sam and Anne could go look at the apartment. Claudia mentioned that they could also stop and visit the grocery store where Sam once worked.

On August 10, Sam went to see the new apartment. From there he went to the grocery store, where he hoped to see his old friends. When he walked through the door of the grocery store, he was immediately recognized by Mr. Radzins, the store manager. By the end of the brief conversation, Mr. Radzins was asking when Sam was coming back to work. Sam left very happy and eager to move to his own apartment.

The next team meeting was held on August 17. The team members were all present and all documents and paperwork had been received and approved. Claudia explained that the landlord was anxious to rent the apartment beginning September 1. Claudia asked Sam if he had found staff to help him and he reported that he had. He showed her the names of the people and told her that they all liked the Yankees. Claudia asked Sam and Molly if the home health agency had been contacted to support Sam with his diabetes management. Molly reported that the nursing was all set up. Claudia asked Sam what he thought he needed in order to move on September 1. Sam responded that he needed food and a bed. Claudia asked if he thought he would need a place to put his clothes and a place for people to sit when they visit. Together, they created a list. Claudia told Sam that based on the list he would have a budget of \$1,000 from MFP to purchase what he needed.

The following week Anne took Sam shopping. They found furniture and a few other things for the apartment and made arrangements for delivery on September 1. While they were out, they stopped at the New England Assistive Technology (NEAT) marketplace in Hartford. Claudia had set up a meeting for them there so that they could see some of the computers that are available to help people communicate. Sam tried lots of different computers then he chose the one he liked best. The people at NEAT said that he could borrow it for a month to make sure that it would work for him. Sam and Anne left that day with the computer. To help Sam learn how to use the computer, Claudia coordinated the rental with the State's Assistive Technology Peer Assistance program which offers training support from persons who have had success using similar computers.

The discharge date approached quickly. Claudia helped Sam set up appointments with his old family doctor and with Mr. Radzins at the grocery store. They checked to make sure that he had enough medicine to last until he visited his doctor and they started to pack his suitcase.

Sam was ready to go early on September 1. The ride to the apartment was filled with anticipation. On the way, they decided to stop for a few groceries. The day at the apartment was busy. Furniture arrived and around dinner time, Sam's first support staff person arrived. Sam also had visits from the home health agency nurse and the landlord. With Anne there, Sam signed a timesheet for the first time. Everything went as planned.

Two weeks later, Sam took the bus alone for the first time from his apartment to the grocery store. Sam took his new computer with him in case he needed it. Sam was the proudest looking person getting off the bus that day at the grocery store. Mr. Radzins asked Sam if he was ready to work and Sam reported yes. Mr. Radzins said they would need to set up a schedule. Before Sam left that day, he had his schedule for work.

Claudia checked in with Sam several times over those first few weeks. Sam was lucky because everyone loved working for him. Anne and Sam decided to buy the computer that helped Sam communicate. The cost was already included in his budget. By the time Sam participated in his first consumer satisfaction survey, he reported that he loved everything. He loved having Anne visit, he loved his staff, he loved his job and he loved his apartment. Now that he had his own place and a job, he planned on finding a wife.

During the first year, Sam had quarterly contact from his case manager to reassess his needs and assure that risks for Sam in the community were addressed. Anne was present each time and special attention was given to how Sam's plan addressed potential areas of concern. Sam did not see the risks as everyone else did. Sam loved everything about his new life and felt very safe on his own. At the end of the demonstration year, services continued under the DDS Individual and Family Support Waiver with no apparent change to Sam.

Transition of ABI Population

In 2004 at age 28, Bill was working for his father in his carpet laying business and part time as a stock clerk at Target. This was not the first time that Bill had worked for his father over the past few years. Bill hated the work and the thought that once again he was dependent on his father. But he just could not seem to find that one thing that he really enjoyed doing long enough to stick with it. He did not have any money in savings and he needed to pay his rent, so once again it was back to his father's store. This seemed to be a cycle that Bill could not break.

While laying carpet in a church basement, he suddenly became violently ill and was admitted to the intensive care ward of a local hospital. After hours of testing, his condition continued to worsen and he was diagnosed with multi-organ failure. His problems included intracerebral hemorrhage, aspiration pneumonia, respiratory failure, sepsis, infections at multiple sites, acute renal failure, and hepatitis. The cause could not be identified, but he sustained severe hypoxic brain damage.

Bill remained in the hospital for more than two months. While he had been medically stable for some time, he had limited control of his limbs and trunk. His long-term prognosis for neurological recovery was not good. He also had uncontrollable seizures. His healthcare team was working to determine a drug regimen that would minimize both the frequency and the intensity of the seizures. Bill was referred to an ABI rehabilitation program for more intensive treatment and follow-up for his condition.

A year and ½ after his accident, Bill has regained most of the control of his legs and feet but still has limited control of his hands. He requires assistance with several ADLs and IADLs. He regained all of his memory from prior to the accident but his working memory is that of a 15 year old. Bill's personality also drastically changed. He went from a mild mannered guy to someone that is very volatile. He is easily angered and becomes out of control without any warning and at the slightest provocation.

Following the accident, Bill's family was unable to give him the care that he needed at home. He has been in a nursing facility for more than three years. He hates it there. He feels so out of place. All of the other people around him are sick and very old but he is not. He does not feel that he should be there and yet he understands that it would be very difficult for his parents to take care of him at home. Perhaps things would be better if he was able to make friends but he has a very hard time relating to the people there. 'Many of them cannot even talk!' Bill has one very good friend, Kelly, an older gentleman who is very different from the rest. He is fun and likes a lot of the same things that Bill does, like watching karate movies and playing video games. Kelly does not treat Bill like a kid.

One day when they were talking, Kelly shared very sad news with Bill. He, Kelly, would be leaving the nursing home very soon. He had applied for a new program called Money Follows the Person and was accepted. This program had helped Kelly find an apartment. This made Bill very sad. He became very upset, knocking a lamp on the floor and began to stomp out of the room. Kelly was able to calm Bill down. He was one of the very few people that could do this.

Kelly told Bill that if the MFP program could help him get out of the nursing home that it might be able to help Bill as well. Kelly helped Bill call the MFP office to get an application package.

As much as he hated it, Bill had assumed that he would always live in the nursing home. In the beginning he had thought a lot about leaving the nursing home, but as time went on he stopped thinking about it because he felt it was a dream that would never come true, so why waste time and energy thinking about it. Over the next few days he became very agitated thinking about possibly moving out. He would not admit it to anyone but he was afraid. He could not take care of himself, alone, he needed help. Would he have the help that he needed? Where would he live? Would he be able to see his parents when he wanted to? He had so many questions. He had a hard time sleeping and focusing. His behavior was, at times, out of control, he had several time outs in his room.

The application packet arrived by the end of the week. The next day when Bill's parents came to visit, Bill shared the application packet with them. Bill had told them about the program. They also knew about Bill's recent behavior and knew their son well enough to know that his behavior was because he was afraid. They spent a lot of time talking with him and assuring him that no matter what happens, they would make sure that he was o.k.

Bill's parents were very curious to find out more information. They were also cautious. "Could this program really give Bill all the supports he needs to live in the community?" With Bill, they read through all the materials. There were a few things that they needed to get clarification on, such as did they have to pay anything for Bill to participate in the program. Even though the materials did not say this was the case, they wanted to be sure. Could anything this good really be free? They would do anything to help Bill but financially things were not going well for them. Business at the store had been very slow for quite some time. If they needed to come up with additional funding in order for Bill to participate in the program they would do so, but they wanted to know as soon as possible in order to prepare. The office was still open for the day, so they called and were relieved to find out that if Bill was determined eligible for the program there was no cost to participate in the program.

Together Bill and his parents filled out the application. The next few weeks were very hard for Bill. He could not understand why it was taking so long to hear back from the MFP office. This was also the time when his friend, Kelly, was discharged from the nursing home. Kelly invited Bill to visit him in his new apartment but he refused to go. He was angry at Kelly for leaving him all alone. He did not have anyone else to talk to at the nursing home. He spent most of his days after Kelly's discharge in his room watching T.V.

On May, 22, three and ½ weeks after Bill and his parents mailed the application, Bill received a letter from the MFP program office telling him that he was eligible for the program and assigning him a transition number of '20.' The letter stated that the transition coordinator's name was Rick and that he would receive a call within three days. Also included in the packet of materials were a transition guide, a self-assessment tool, and a description of Bill's rights and responsibilities as an MFP participant. Bill did not have to wait long for Rick to call; he called the next day and scheduled an appointment to talk with Bill and his parents the following week.

Bill started filling out the self-assessment form the day Rick called. But there were many things on the form that he did not understand and was not sure how to answer, so he asked his parents for help. They were more than happy to help Bill. Since the accident, this was the first constructive thing that Bill had focused on. They would do anything to help him get out of the nursing home. The nursing home is not where they wanted their son to spend the rest of his life.

The night before the meeting with Rick, Bill did not sleep. He was too excited. The next day, he called his parent's several times to make sure that they would be on time for the meeting. Bill was dressed and ready for the meeting at 7:00am. The meeting was not until 1:30pm. Alan arrived a little early for the meeting. Bill looked at him, studying his face before saying anything. Bill liked Alan right away, he had a friendly face.

Alan talked with Bill and his parents about the program. He shared with them a housing guide, medical release forms and informed consent document. He talked with Bill about the different housing options. He asked Bill what things he liked doing, his dreams and goals. Bill liked that Alan talked to him like he was an adult and directed questions to him and not just his parents. They reviewed the self-assessment that Bill and his parents had completed. Alan also shared with them the 24-hour back-up triage system available to people who participate in the program. Before leaving, Alan told Bill that for their next meeting he would need to gather several personal documents such as his social security card and birth certificate. Alan also asked Bill to sign the informed consent. Based upon this first meeting, Alan knew that the nursing home was not the right environment for Bill but was not sure what was. He sensed that Bill was a very angry young man and lonely man. The second meeting was scheduled for the following week.

For the next meeting Bill made sure that he had all of the information Alan had asked for. Again, Bill's parents participated in the meeting. Bill wanted them to be apart of the meetings and they wanted to be there as well. They spent more time talking about the housing options available to Bill. Alan explained to Bill what to expect and what would happen next. He felt that it was very important for Bill to understand all the steps in the process. Alan also explained to Bill that a social worker from CCCI would be scheduling an appointment with the next three days to assess Bill's level of need for community services. Alan also worked with Bill on completing the paperwork for rental assistance.

As Alan said, the CCCI social worker called and scheduled a meeting for the end of the week. The CCCI social worker completed the assessment and told Bill that he was eligible for the ABI waiver. The CCCI social worker told Bill that he had the option to self-direct his care. He did not really know what this meant, but after it was explained to him he thought it was great. Bill chose to select a fiscal intermediary who would help counsel him on developing a budget.

A third meeting was scheduled for the next week. Alan and the CCCI social worker both participated in this meeting. Bill's parents were also there, once again. Alan had reservations about Bill living alone. But he also was not sure how well he would do with roommates. He wanted to try to use this meeting as an opportunity to try to figure out the best option for Bill. Alan remembered that during their first meeting Bill had mentioned his friend Kelly. Perhaps it was possible for Kelly and Bill to live together. He would bring this up as a possible option at the meeting. Bill's face lit up when Alan mentioned the idea of living with Kelly. Kelly was his

best friend and although he was angry at him for leaving him behind, he missed him terribly. He would love to live with him. He hoped that Kelly was not mad at him for not coming to visit.

Within the next few days, Alan was able to reach Kelly. Kelly had been lonely since leaving the nursing home and missed Bill. He really liked the idea of the two of them living together. But Kelly's apartment was a one bedroom unit. They needed an apartment with two bedrooms. Alan immediately contacted the housing coordinator who discovered an available two bedroom apartment in Kelly's building.

Bill could not believe how everything was working. He was going to get out of the hateful old nursing home and spend all day with Kelly playing games. He could not remember when he was so happy. During their next meeting, Alan shared with Bill that he would have a budget of \$525 to cover apartment set up costs and by furniture. The CCCI social worker talked with Bill and his parents to make sure that transition to the community would go smoothly, including making sure that Bill had the necessary doctor appointments and referrals in place.

Bill was scheduled to be discharged on August 25. He crossed each day off his calendar to mark what he called "Getting Out Day." When he arrived at the new apartment, it was so good to see Kelly again. He had not seen him since he left the nursing home.

Over the next few months, Bill adjusted to living on his own and being the boss of his staff. This was not easy, but he was learning and getting a lot of help from his case manager, his parents and Kelly. At the three month interval when Bill completed his consumer satisfaction survey he said that sometimes things were hard, but he was much happier than when he was in the nursing home. His parents noticed that his outbursts were fewer.

At the end of the first year in the community, Bill was doing very well and thinking about getting a job. During his annual assessment he was informed that he was no longer in the demonstration but that he was now formally enrolled in the ABI waiver. His services were not affected.