

Jean¹

Jean is a Caucasian woman in her late 50s. She has received her bachelor's degree and she enjoys painting, which she has not done for a while but hopes to resume. Jean's personal belief is that it is very important to maintain a healthy diet and keep up one's physical appearance.

Jean is an assertive and outspoken individual. She is also fiercely protective of her independence and as a result, is a strong self-advocate. This skill is invaluable since Jean currently has virtually no family supports that she considers reliable.

Jean suffers from osteoarthritis and has a psychiatric disability. For several years, Jean was living in a rehabilitation center. It was here that Jean became even more protective of her independence because she came so close to losing it. Jean recounts disliking having another person control what she could and could not do. It was also the rehabilitation center who unsuccessfully sought a Roger's guardianship over Jean.

Supports prior to the Real Choice Pilot Enrollment

According to Jean, her dissatisfaction with the rehabilitation center's psychiatric treatment led her to seek alternative psychiatric help. In addition, Jean wanted to have more control over her psychiatric care. She said she located a new psychiatrist by looking in the phone book and eventually connected with this psychiatrist. The social worker at that psychiatrist's office introduced her to her local independent living center (one of the two support brokerage agencies for the Real Choice Pilot). This connection became instrumental in helping Jean move back into the community.

Use of Real Choice Budget

The local independent living center referred Jean to the Real Choice Pilot. At the time she enrolled in the Real Choice Pilot, Jean was still living in the rehabilitation center. Before Jean could move back into the community, she needed to put in place a host of supports, some of which required significant resources. She needed to find an apartment, pay first and last month's rents, and buy household necessities. Therefore, Jean's first task was to plan her transition, with the assistance of her community liaison and other staff at the local independent living center. To that end, Jean used the budget to pay for transportation necessary to take her to various housing communities where she applied for housing. In addition, the budget was used for one-time transition costs, such as rental deposit, furnishings and other household necessities.

¹ The names on these case studies are fictional to protect the identities of the Real Choice Pilot participants.

After some intensive work, Jean secured an apartment and moved out of the rehabilitation center with the assistance of the independent living staff. Although the move was not without glitches and more planning could have been beneficial (e.g., getting groceries and connecting a telephone line),² Jean was ecstatic with the move and expressed great gratitude to these individuals for helping her.

Once Jean started living in her apartment, she used her budget to hire a worker for homemaking and transportation. Jean also planned on obtaining aquatherapy, orthopedic shoes (MassHealth did not cover this item for Jean), and cold packs for hips to help alleviate her osteoarthritis. Also, Jean planned to use her budget to obtain a computer and necessary equipment as a form of communication, information, and entertainment since she did not have a television or radio.

Benefits and Challenges in the Real Choice Pilot

That Jean left the rehabilitation center is a huge accomplishment of which she is exceptionally proud and for which she is grateful to the community liaison and the support brokerage agency's staff. However, soon after her transition, Jean did not feel adequately supported in her right to make decisions about her life. As a result, she requested a change in community liaison. Currently, Jean reports feeling in control of her life while being able to meet her needs. She has even obtained homemaking support, even though she had initially wanted to do the work herself. She currently reports feeling capable of self-directing and therefore needing and wanting only minimal help from her community liaison.

² These transition challenges have culminated in the development of processes and policies on using the self-directed budget for the purpose of transitioning from institutions.

Lisa

Lisa is a Caucasian woman in her early 60s, living in Southeast Massachusetts. She is an outgoing and social person and likes meeting new people. Lisa also likes engaging in productive work, paid or unpaid. Prior to her visual impairment, Lisa was a beautician and is also currently doing some volunteer work, e.g., at the senior housing complex where she lives. She had also expressed interest in finding paid work.

Lisa is legally blind due to macular degeneration, an age-related disorder. Although macular degeneration does not affect her peripheral vision, it adversely affects her ability to see details; making reading, driving, and doing detail work virtually impossible. In fact, Lisa's mother had the same condition. Lisa's visual impairment has made it challenging for her to perform household and other tasks without assistance. For example, because she cannot read fine print or see details, she has difficulty shopping, because it requires reading labels and distinguishing between different currencies.

Recently, Lisa had a heart attack and as a result, has been feeling sad and worried about her well-being. In addition, Lisa was divorced about two years ago, which further increased her emotional distress. She has also recently lost her puppy. Lisa's primary source of support is her sister Suzanne. Suzanne lives in the same town as Lisa and, prior to the Real Choice Pilot, was providing Lisa with transportation to do errands, shopping, and attend her medical and other appointments. Suzanne, however, has a terminal illness and has her own medical needs. Providing Lisa with the necessary support was increasingly stressful for Suzanne.

Supports prior to the Real Choice Pilot Enrollment

Prior to the Real Choice Pilot, Lisa was connected to one of the support brokerage agencies and was receiving home care services from an agency. The homemaker was coming to Lisa's home every day for an hour. In addition, a visiting nurse came to see Lisa twice a week for an hour each. Lisa also has a personal emergency response service. This service allows an individual who wears a medical device to access emergency response when necessary. These services have been arranged by Lisa's local elder services case management agency, one of the 27 agencies throughout the state. Nevertheless, Lisa wants the type of supports that she thinks would increase her quality of life, e.g., transportation.

Use of Real Choice Budget

Lisa learned about the Real Choice Pilot from her local independent living center (also one of the Pilot's support brokerage agencies). In a sentiment echoed by another individual in the Real Choice Pilot, Lisa thought such a program was too

good to be true. Lisa's goal for the Real Choice Pilot was to obtain individualized supports to address her needs resulting from her blindness, as well as to find ways to improve her quality of life. To Lisa, the most important support she needed was transportation. Although her sister had been able to drive her, she knew this was not a long-term solution. Therefore, her major goal was to obtain transportation support.

With the assistance of her friend at the local independent living center, Lisa hired a worker whose service she has been pleased with. In addition, Lisa replaced her agency homemaker by hiring a friend's daughter to help her around the house. To support her volunteer work as well as increase her independence, Lisa purchased a computer and accessories appropriate for individuals with visual impairments, e.g., screen reader and special keyboard. To go outside more, Lisa used part of her budget to participate in social activities sponsored by her housing complex.

Personal Experiences in the Real Choice Pilot

To Lisa, her quality of life has significantly improved. Prior to the Real Choice Pilot, Lisa had experienced major losses. She had just undergone a divorce and a heart attack. The Real Choice Pilot enrollment was good timing for Lisa and became an opportunity to meet new people and learn new skills for independent living. Furthermore, by virtue of being in the Real Choice Pilot, Lisa met Real Choice Pilot staff people whom she considered to be friends. Also, her new computer and the equipment to make it more accessible as well as the social activities purchased through the budget have allowed Lisa to connect to her peers, decrease her isolation, and be more productive in her volunteer work.

Early on, Lisa had some difficulty finding someone who was able and willing to provide transportation. Because transportation was so crucial to be independent, finding someone to provide transportation was essential. Although Lisa had identified two possible workers, these two individuals eventually declined to work for Lisa because they found other employment that offered more hours and more pay. Fortunately, Lisa's friend who worked at the local independent living center helped her find someone who could assist Lisa when necessary.

The Real Choice Pilot has had a tremendously positive effect on Lisa's sister Suzanne as well. Prior to the Real Choice Pilot, Suzanne was Lisa's primary caregiver and provided any and all assistance Lisa needed. This assistance was extremely stressful for Suzanne. Once Lisa enrolled in the Real Choice Pilot, Lisa's worker was able to take over many of Suzanne's responsibilities. As a result, Suzanne can care for her own needs more. The Real Choice Pilot has lifted the burden off of Suzanne who feels she can truly enjoy her time with her sister when they are together, as they continue to visit each other several times a week.

Anna

Anna is a Caucasian woman in her 70s. Anna currently lives alone in her apartment. Anna's husband passed away recently and Anna is still coping with this loss. Fortunately, she has considerable family support. Her late niece's husband and their children—all of whom live nearby—make up Anna's primary circle of support.

Due to her emphysema, Anna uses portable oxygen which limits her ability to engage in any physical activity independently, including performing household chores and some personal care. In addition, she has a seizure disorder; her seizures and the unpredictability of their occurrence further limit her mobility inside and outside her home. As a result, Anna relies on both her family and formal supports to help her perform work at home and to help her go out. However, Anna is protective of her privacy and seeks to be more independent. For example, Anna yearns to have the freedom to leave the house or be alone as she pleases—which she feels she cannot always do because her family is concerned about her physical safety in those circumstances.

Supports prior to the Real Choice Pilot Enrollment

In addition to her emphysema, Anna has some sensory impairment. She is hard of hearing and uses a hearing aid. Anna's vision is also impaired to the point where she cannot read large print without her glasses. Prior to the Real Choice Pilot, Anna's glasses' prescription needed to be renewed. Although Anna had connected with her local independent living center, she received very little formal support prior to the Real Choice Pilot.

Use of Real Choice Budget

Anna was enrolled into the Real Choice Pilot with the assistance of her skills trainer at the local independent living center. She was somewhat unclear about the purpose of the Real Choice Pilot when she was first enrolled. When this was clarified, she chose her late niece's husband as her community liaison, although Anna knew several skills trainers at this local independent living center.

After Anna was assessed and enrolled, her skills trainer asked her whom she wanted as her workers. Anna wanted to hire her two nieces to assist her in homemaking and transportation for errands. In addition, she used her budget to purchase personal supplies such as glasses and dentures (not covered by MassHealth at the time) because they no longer fit properly and were causing her some pain. When Anna later moved to a more accessible apartment, she used her budget to pay for movers and to buy an air conditioner to cool her new space.

Experiences in the Real Choice Pilot

To Anna, the Real Choice Pilot has had tangible benefits that have improved her quality of life. For example, she is able to pay her family members—people who are close to her—to help her with homemaking. Although Anna likes having family, instead of strangers, come in her home to help her, Anna expresses that she does not feel as independent as she would like, partly due to her family members' protectiveness. However, Anna also recognizes that her level of independence is partly hampered by her condition. Specifically, Anna was advised by family members that she should not go to the store by herself or at will because of the unpredictable nature of her seizures. Furthermore, she is advised not to perform certain household chores because they would be too physically strenuous, given her emphysema. However, Anna *wants* to be able to go to the store at will or perform basic household chores such as vacuuming.

During her enrollment in the Real Choice Pilot, Anna was hospitalized several times, resulting from her blood sugar fluctuations. Subsequently, Anna's physician recommended that Anna further limit her physical activities, including climbing stairs. Because Anna's current apartment building did not have an elevator, Anna had to find another place to live. With the assistance of her nephew/community liaison, Anna visited potential housing complexes to find one that would best suit her needs and preferences. Once a new residence was identified, Anna and her community liaison used the budget to help finance the move.

Susan

Susan is a Caucasian woman in her 50s living in Central Massachusetts. Susan has Down's Syndrome, requires tube feeding, and has a host of other medical conditions, including seizures. Susan has experienced the gamut of institutional and home-based supports. She spent the first 30 or so years of her life in an institution. The next subsequent 10 years were spent in a group home. Susan has made many friends, whom she still visits from time to time.

During the last 10 years, Susan has been living with Leslie, Leslie's husband, and two children. Leslie provides adult foster care to Susan on behalf of Susan's guardian, who visits Susan at least once a month. Because she lacks verbal communications skills, Susan relies on Leslie and her guardian to communicate and advocate for her. Nevertheless, Susan is aware of her environment and can be understood by those close to her. When she is not out, Susan spends her time in the family room in the company of Leslie and her children.

Supports prior to the Real Choice Individual Budget

As her foster care provider, Leslie provides all hands-on personal care for Susan as well as all homemaking, supervision, and recreation to support Susan in the community. Given that they live together, Leslie essentially provides care around-the-clock. A visiting nurse sees Susan about once a week to monitor her medical needs, such as ensuring proper tube feeding and monitoring other potential medical complications. Susan also participates in group adult foster care about once every 3 months, which enables Leslie some respite time.

At the time of Susan's enrollment in the Real Choice Pilot, Leslie expressed significant financial constraints in meeting some of Susan's needs. With Susan's various medical conditions, she needed certain medical equipment and supplies. However, Leslie was not able to pay fully for these needs and this deficit, according to Leslie, was compromising Susan's health and quality of life. Specifically, because Susan has a feeding tube 24 hours a day, Susan requires certain supplies, some of which MassHealth does not cover. Leslie thought that a hospital bed with rails would be very beneficial for Susan's safety, particularly during her seizures. Leslie had previously been renting a hospital bed to meet this need. Leslie also wanted, but could not afford, a regular supply of bed pads to prevent Susan's skin irritations. In addition, although MassHealth paid for Susan's wheelchair, it did not pay for the wheelchair padding, which would have made Susan more comfortable, given its frequent use. Going outside was very difficult and limited because Leslie needed another person to help move Susan and her wheelchair. Compounding all of these needs was Leslie's need for additional respite or worker support because Susan sometimes does not sleep for long periods of time.

Real Choice Individual Budget

A Department of Mental Retardation service coordinator applied to the Real Choice Pilot on Susan's behalf. Leslie was interested in the Real Choice Pilot because she hoped that it could help her obtain the additional respite and worker support for Susan. She also wanted to obtain the medical equipment and supplies as well as a ramp inside the house that would make Susan more comfortable and allow her to go outside more easily. These items would not only increase quality of life for Susan but would also alleviate the financial and emotional burden on her caregiver.

With the Real Choice budget, Leslie, Susan's guardian, and the community liaison made a list of items they thought would be necessary to improve Susan's health. In addition to the hospital bed, items related to the hospital bed, and a chair lift, they identified other miscellaneous items not covered by MassHealth and other financial sources that could add significant comfort and safety to an individual and increase quality of life. For example, Leslie bought wheelchair accessories—wheelchair backpack, seat cover, pole for the IV stand, and soft seatbelt. These items made it more comfortable for Susan to be in a wheelchair and in turn, allowed both Susan and Leslie to go outside for longer periods of time. In addition, Leslie purchased items to aid transfers in and out of the bed and wheelchair and items related to the hospital bed. The budget also helped Leslie to pay for personal care supplies for Susan, such as wipes and syringes. In addition, Leslie was able to use the budget to obtain additional worker support.

Personal Experiences in the Real Choice Pilot

Susan's caregiver has been extremely satisfied with the support available through the Real Choice Pilot. The Real Choice Pilot has allowed both Susan and her caregiver to go outside more frequently. In fact, Leslie said that Susan went outside more in one month during the Real Choice Pilot participation than the two years prior to the Real Choice Pilot participation. It is not hard to imagine that these recreational opportunities reinvigorated Leslie as a caregiver as well as Susan. Being able to finance Susan's necessary supplies relieved Leslie of significant financial burden, especially since she had two children of her own. For example, Leslie has been able to stretch the individual budget by purchasing supplies in bulk or at discount prices.

Susan has strong advocates among family and friends. Both Leslie and Susan's community liaison have been working with Susan for the past ten years and understand her needs well.

Recently, Susan has undergone throat surgery, which has diminished her mobility because transfers in and out of her wheelchair need to be limited. As a result, Susan's physician is making home visits and notes, as others have done previously, that Susan is doing very well.

Sally

Sally is a Caucasian woman in her early 60s. She has some college education and one of her favorite hobbies is reading. In fact, she had been an avid reader in the past, reading about a book a day. Sally also enjoys volunteer work and has volunteered in a clubhouse in the past.

Sally has strong supports in her life. She has a son who lives out-of-state. She is very close to her sister and her sister's family, with whom she lives. Sally's sister has been instrumental in helping Sally cope with cancer and its treatment. For instance, her sister was there to assist with personal care as well as accompanying her on recreational activities.

Supports prior to the Real Choice Individual Budget

Prior to enrollment in the Real Choice Pilot, Sally had accessed agency-based services contracted through the local elder services agency³ (one of the support brokerage agencies). Specifically, this agency had enrolled Sally in a program where Sally was able to hire her own personal care worker/homemaker. Sally was also receiving transportation and companion services. In addition, Sally's sister was providing significant help with bathing and dressing as well as household chores such as housework and meal preparation.

Even with the help of her sister, Sally felt that she had some needs that were currently unmet. For example, Sally found that she had no way to pay for the special scooter she needed, her dentures, or her glasses, all of which MassHealth traditionally does not cover, or that she did not qualify for under MassHealth. Sally was feeling very dependent on her sister, who was providing her with a home as well as with personal care and emotional support but was not being compensated in any way. Although she was very close to her sister, it was difficult on Sally to feel so dependent on someone else. Furthermore, although Sally was already hiring her own worker, the Pilot offered additional flexibility, e.g., equipment, and additional technical support, i.e., the community liaison. Recognizing these needs and seeing the potential benefits, her local elder services agency suggested that Sally apply for the Real Choice Pilot.

Real Choice Individual Budget

In the spirit of being more independent, Sally wanted to replace her agency-based supports with a worker of her choosing whom she could supervise. With agency-based supports, Sally had a separate worker for personal care and homemaking and another worker for companion services. The Real Choice Pilot provided Sally with the flexibility to obtain the assistance she needed while making it more individualized to her personal preferences. Since Sally's sister

³ ASAP

was able to provide a mix of supports at flexible hours, Sally would be able to have one worker for all her needs, rather than having separate workers.

Once Sally received her individual budget, she used part of the budget to hire her sister to provide more inclusive care: personal care, homemaker, transportation, and companion services. In this way, Sally was able to receive more hours of formal worker assistance than she was previously receiving from agency providers. So, while she was receiving 10 hours a week of agency-based support, she was able to receive up to 13 hours of formal worker assistance with Real Choice Pilot. Still, Sally's sister continued to provide many hours of unpaid assistance beyond the allotted 13 hours as formal caregiver.

In addition, Sally used the individual budget to increase her mobility, functioning, and comfort. Specifically, she purchased a scooter, glasses, and dentures. Sally used the remainder of her budget to purchase a shower rail and a bench to allow her to be a little more independent while bathing.

Personal Experiences in the Real Choice Pilot

Sally is very satisfied with how the Real Choice Pilot is going. The Real Choice Pilot gave Sally the control over how to improve her quality of life and to obtain what was truly important to her. For example, with the new scooter, Sally was able to go outside by herself, often with her dog on her lap—something she was unable to do previously. As she said, “sometimes you have to change the scenery.” This allowed her to do something without her caregiver's assistance, a significant boost in her sense of independence. Furthermore, the scooter enabled her to resume volunteer work and she was able to go on social outings with her family. Even the process of directing her budget was a boost to Sally's confidence. In purchasing her scooter, Sally shopped around and found a scooter with a strong warranty plan. She “felt good about it, a little independence.” With her new glasses, she resumed reading. Once her dentures were purchased, Sally was able to eat a piece of steak, which she had been long anticipating!

In general, Sally faced no major challenges in directing her budget. Upon entering the program, she had a good sense of the specific supports she would need to increase her quality of life. She wanted and was able to have her sister be her main direct worker using the budget. In her community liaison's opinion, the program has worked wonderfully for Sally, mainly because Sally was clear about her needs and took the initiative and followed through with the program's expectations, all of this with minimal support from her community liaison.

In the process of self-directing her individual budget, Sally has had to watch her spending really closely as she used more of her budget allotted for workers than originally planned. This is perhaps due to her sister providing far more hours of assistance than what Sally's budget could cover. To make up for this, Sally had

to modify the hours spent weekly as she approached the end of the year. She was able to do this without any major problem.

Matt

Matt is a Hispanic man in his late 50s. Matt is currently living with his significant other. He has two sons who live out of state but do not visit him as much as he would like. Matt speaks only Spanish and does not read or write Spanish or English. Many know Matt as a smart person with a good memory.

Matt has Parkinson's disease and diabetes. He receives a great deal of help from his wife with household chores and personal care. However, Matt reports that his wife has severe depression and other health concerns of her own. He also has a history of falls but does not always use his walker. Matt's medical conditions have made him feel persistently worried and saddened. At times, he has had temper outbursts which affect both his relations with his family and workers. Matt acknowledges his part and has been responsive to others who point this out to him.

Supports prior to the Real Choice Pilot Enrollment

At the time of his enrollment in the Real Choice Pilot, Matt had been connected to his local independent living center. A visiting nurse was also seeing him twice a week to help manage his medication and other medical issues. However, Matt was interested in receiving the support he needed without adding undue stress on his wife, who acknowledged that her caregiving responsibilities were becoming more than she could handle. In fact, Matt's wife felt so overwhelmed with caring for Matt that she applied for support for herself (She was ineligible).

Use of Real Choice Budget

Matt and his wife learned about the Real Choice Pilot from their local independent living center. After he enrolled in the Real Choice Pilot, Matt used part of his budget to hire a worker to provide him transportation to do errands and another worker to help him with household chores. In addition, Matt also purchased an over-the-bed table.

Personal Experiences in the Real Choice Pilot

According to Matt, the biggest benefit from the Real Choice Pilot is having the worker support, with which he is very pleased. The worker helps Matt with errands and other household tasks, which makes Matt less dependent on his wife and alleviates her stress level. In addition, the budget will help him obtain some equipment to increase his quality of life by increasing his comfort and mobility.

Although Matt has found a worker who has proven to be dependable, Matt had experienced some worker issues. Specifically, his original worker, whom he liked a lot, quit working for Matt. This worker quit because Matt was not treating her

respectfully and was in fact, reprimanding her needlessly. When this issue was brought to the community liaison's attention, the community liaison and another staff person at the local independent living center discussed the matter with Matt. Matt was responsive and acknowledged his responsibility with the issue.

Matt also experienced some frustration because he felt he did not have adequate information regarding the Real Choice Pilot in the early months of his enrollment. Due to his illiteracy, he was unable to read his consumer guidebook. Although Matt's first few community liaisons spoke Spanish, Matt also reported not understanding the Real Choice Pilot as much as he needed. Information, e.g., in audio format, was important for him to be able to make decisions. As the Real Choice Pilot moves into its second year, Matt has a new community liaison who is also bilingual and has proven to be a strong advocate on his behalf.

John

John is an African-American man in his 50s. He presently lives with his wife in Central Massachusetts. John has had some college education. He is a sociable person and enjoys going out and visiting with friends.

John has recently had several heart attacks. Consequently, he is experiencing some speech, visual, and memory loss as well as mobility impairment. John requires large print to read and occasionally uses a hand reader given his visual impairment. John also uses a walker to help him move about. John's other diagnosis include renal failure and asbestos poisoning of the lungs. As a result of these conditions, John has been having difficulty with performing necessary tasks such as shopping and household chores and has often been homebound. Because his wife has physical difficulties of her own, she is unable to help John fully. Therefore, his cousin has been helping with household chores, although her time is limited because she has her own family and job.

Supports prior to the Real Choice Pilot enrollment

Prior to enrollment in the Real Choice Pilot, John was receiving various services from a local mental health/case management organization. Perhaps the most consistent has been John's social worker of three years, Mark, with whom John has a very strong relationship and whom he sees or talks to about once a week. In addition, John was receiving medical transportation and attending a day program for rehabilitation set up by this case management organization. This organization was also serving as a representative payee, perhaps due to John's symptoms of depression/anxiety and possibly substance abuse (for John and his wife), at the time when he enrolled in the Real Choice Pilot. A visiting nurse was also providing post-acute care for John following his hospitalizations.

The combination of his physical and medical conditions and the lack of resources to obtain additional help for himself and his wife was a major strain on John. He often could not leave his apartment due to physical weakness. However, the lack of transportation or resources to do the things he likes further dampened his motivation to be out. For example, going to a restaurant would have provided much-welcomed diversion but this was sometimes not feasible.

Use of Real Choice Budget

John learned about the Real Choice Pilot through Mark, his social worker. John was told that the Real Choice Pilot could help him get out more and be less homebound. The Pilot could also help him purchase other necessary items to live healthier in the community.

Using the budget, John obtained additional homemaking and transportation support. Because of his medical conditions, John was advised not to overexert himself. To help address this need, John sought to purchase a washer and dryer

so he would not have to go to the laundromat, which had been requiring both transportation and lifting on his part.

During the first year of his Real Choice Pilot participation, John hired a homemaker. The homemaker was a referral from people John knew. John had difficulty performing employer-related responsibilities such as supervising and completing paperwork. Although his community liaison suggested using an agency-based worker to ease such responsibilities, this option did not appeal to John and he did not choose this option. John also purchased the washer and dryer as planned.

Another major, yet unanticipated use of the budget was assistance for moving into another apartment. During his participation in the Real Choice Pilot, John's apartment had a fire and he and his wife were temporarily living in a motel. Although some needs were met by the Red Cross, John had to start over and his Real Choice budget helped him during the transition. For example, he was able to use his budget for first and last month's rent as well as home furnishings after securing another apartment. This allowed John to avoid being homeless, further anxiety, and potentially another hospitalization.

Personal Experiences in the Real Choice Pilot

During his participation in the Real Choice Pilot, John has experienced some difficulties, some related and some unrelated to directing his budget. John was hospitalized five times. John also experienced financial stress when he was threatened with eviction and when the fire occurred. Additionally, John is still in the process of using his budget for community integration activities. Nevertheless, John expresses much gratitude for how the budget and support brokerage agency have helped him. For John, it is important that he can go to the movies or grocery shopping on his own. John notes that his quality of life and independence have much improved because he has access to more transportation from the Real Choice Pilot than before. Even his relatives have observed a noticeable difference in his demeanor. (About six months after John started to receive services from the Real Choice Pilot, John disenrolled from the local social services because he felt he no longer needed the service of the social worker and the representative payee). In addition, the fact that he was able to use the budget at times of crisis gave him some peace of mind.

Derek

Derek was a Caucasian man in his 60s. Derek has had some college education. In the past, Derek had engaged in horse riding, particularly race horses and as a result, had sustained many injuries, broken bones and fractures as a result of this hobby. Derek was divorced and had been living with his adult daughter, Mary.

Derek was diagnosed with colon cancer, cirrhosis of the liver, diabetes, and hepatitis. In addition, Derek suffered from arthritis, osteoporosis, and emphysema. These conditions significantly limited Derek's ability to perform household tasks and some personal care. Therefore, Mary took care of all his household needs and assisted him with personal care needs such as dressing, bathing, and outside mobility. She was also managing his finances and medication.

In providing care for Derek, Mary was unable to take certain jobs. Nevertheless, she needed to finance her own living expenses. Although Derek knows his daughter cares for him, the fact that she was looking for paid work was causing him anxiety. Derek appreciated wholeheartedly the care his daughter provided him and wished to compensate her for her assistance.

Supports prior to the Real Choice Pilot Enrollment

In addition to the help from Mary, Derek was receiving several paid supports. Specifically, he was receiving a personal care worker through the self-directed program at the local elder services agency. In addition, he was receiving medical transportation support. At the time of his application to the Real Choice Pilot, Derek's health had deteriorated further and therefore he needed more flexible support which included a personal care worker and equipment. Recognizing this benefit, the support brokerage agency suggested Derek enroll in the Pilot.

Use of Real Choice Budget

Because the support brokerage agency completed the application on Derek's behalf, Derek had only a vague recollection of his application to the Real Choice Pilot. During the spending plan development phase, however, Derek took an active role in deciding what purchases were important to him and, with Mary's assistance, obtained cost estimates for these purchases. Derek's budget was used to pay for worker support and obtain key equipment to support his mobility as well as other activities around the house. Specifically, Derek's budget was used to compensate Mary for the care she would be providing, to purchase equipment and home modifications such as a hospital bed, shower bench, and air conditioner as well as other items such as diabetic shoes and special eyeglasses. Although MassHealth covers hospital beds and diabetic shoes, Derek did not meet the eligibility requirements to obtain these items.

Personal Experiences in the Real Choice Pilot

According to Derek and his primary caregiver, Mary, Derek's participation in the program has helped to meet his needs as they arose. He appreciated the ability to pay Mary for her support. In addition, he said that the hospital bed was helpful because it helped him change position more easily.

In the early phase of the Real Choice Pilot, there was some confusion on Derek's part around the Real Choice Pilot's policies. Derek and Mary thought that he had a separate budget to pay for Mary's support and another budget for other items on the spending plan. Derek and Mary were surprised when they learned that the entire budget would cover both worker and equipment support. Consequently, Derek was not able to pay Mary as much as he had originally thought possible. This disappointed both Derek and Mary. Furthermore, it caused Derek some anxiety because he knew she was looking for another higher-paying job. In addition, Derek later wanted to purchase a brace along with his orthopedic shoes, which would have reduced his budget for worker support. Reducing his budget for worker support was not at all appealing to Derek, even though it was presented to him. Fortunately, Derek was able to increase his overall budget to allow for the brace, without reducing Mary's hours.

In early December 2005, Derek's health rapidly deteriorated and he needed hospice care. The budget was then used to meet Derek's increased need for support, e.g., worker support. Derek passed away in his home in December 2005. His daughter who was by his side during the entire time has expressed tremendous gratitude for how the Real Choice Pilot had supported her father during his final months.

Dana

Dana is a young African-American woman in her late 20s. Dana lives by herself in her own apartment. She is a self-sufficient woman and has a pleasant demeanor. She has had some college education as well. Dana is currently selling cosmetics on a commission basis. However, Dana wants to find work that offers more consistent pay. Dana is also engaged to be married.

Dana has spina bifida and uses a wheelchair as well as a leg brace. Dana's lack of balance on her feet has contributed to a significant number of falls over the past year. Her unsteadiness also makes it difficult for her to perform household tasks independently. In addition, Dana is diagnosed with a psychiatric disability. Although her therapist recommends that she takes an anti-depressant, Dana does not want to do so.

Supports prior to the Real Choice Pilot

Prior to the Real Choice Pilot, Dana had been connected to the Massachusetts Rehabilitation Commission (MRC). Through MRC, Dana had received an employment evaluation a few years ago and had been connected to her local independent living center for other skills training. Another support she was receiving from MRC was a homemaker support for about four hours each day. Dana, however, prefers to hire and direct her own workers. In addition, she wanted to get out to do things like her peers.

Use of Real Choice Budget

Dana learned about the Real Choice Pilot from her case manager.⁴ Upon enrollment, Dana, her case manager, and her community liaison all met to help develop her spending plan. Dana started out by drafting a list of services and purchases that she needed and that could not be funded by other sources.

Using her budget, Dana replaced her agency-based worker with a worker she directly hired. In addition, Dana used the budget to purchase a computer to easily access information and connect to disability groups. She also used her budget to join a fitness club as well as purchase vitamins. Later, Dana added cooking classes and educational materials for self-study. Dana also regularly used her budget to purchase agency-based transportation to supplement her transportation needs.

Personal Experiences in the Real Choice Pilot

Dana enjoys the choice and control the Real Choice Pilot offers while taking on the responsibility that accompanies such choice and control. Specifically, she

⁴ Case manager for a local non profit organization providing education, rehabilitation, and social services for young people.

likes that fact that it is up to her to decide how to meet her needs. In the process of exercising her control over workers, Dana has had to learn to address worker related issues. For example, some of her workers did not abide by work hours. As a result, Dana has experienced some worker turnover in the process of identifying quality workers. Despite these worker difficulties, Dana's resolution to hire her own workers underscores her desire to have control over her own care.

In spite of the difficulty she has experienced in finding and retaining quality workers, the Real Choice Pilot has worked well for Dana and has helped her improve her quality of life. Dana is able to purchase new glasses and engage in structured recreation via her cooking class that would not have been possible previously. This also serves as an opportunity to get out and meet people in her community as well to increase her independent living skills.

Carrie

Carrie is a Caucasian woman in her mid 20s. Carrie currently lives with her mother and brother in an apartment. Carrie also volunteers at a local independent living center. Her hobbies include singing and cross-stitching. Carrie has never had paid work but is very interested in obtaining employment supports to help her find paid work. Carrie has completed some coursework at the local community college. Carrie is also engaged to be married.

Like other young women of her age, Carrie wishes to go out and do things on her own. She wants to be independent but does not always feel that way. Because Carrie has leukodystrophy and alternates between using her wheelchair and walker, accessibility is paramount in allowing her to be independent. However, her independence is currently compromised by several factors. First, doorways inside her apartment are narrow, making wheelchair use virtually impossible. Second, the porch of her apartment is not accessible because it has stairs which are very difficult for Carrie to maneuver with just her walker. Also, the transportation company she had been using told her that they would no longer carry her walker for her after the driver almost fell while carrying her walker.

Supports prior to the Real Choice Pilot Enrollment

Prior to enrolling in the Real Choice Pilot, Carrie was working with the local independent living center for skills training as well as financial support to make her residence more accessible. In addition to these paid supports, Carrie's mother was providing general homemaking and personal assistance to Carrie as needed. However, Carrie recognized that given her mother's full time work and other responsibilities, she was not able to provide all the support Carrie wanted at the time she wanted it. In addition, Carrie was interested in more intensive employment support.

Use of Real Choice Budget

Carrie learned about the Real Choice Pilot from the independent living center where she works. Her colleague/friend there became her community liaison.

Initially, Carrie used part of her budget to obtain transportation, some of which was provided by her mother and some by transportation companies. In addition, Carrie also bought a smaller and lighter walker to increase her mobility inside the house and which would be easier to transport. Her previous walker was bigger and bulkier to carry. Halfway into the program, Carrie decided to return to school and therefore redirected some of her budget to school-related supplies.

Personal Experiences in the Real Choice Pilot

During the course of her participation in the Real Choice Pilot, Carrie has changed her personal goals significantly. At the time of her enrollment in the Real Choice Pilot, she wanted to resume therapeutic horseback riding and to make modification to her apartment to make it more accessible. Later, Carrie decided to re-enroll in the local college, instead of pursuing paid employment, and to move out to live on her own. To follow through with these decisions, she would need a power wheelchair. Therefore, it became more important to adapt her mother's car to accommodate the wheelchair, rather than to modify her apartment. Given her new goal, Carrie and her mother are planning to use the budget to finance school supplies and possibly to obtain paid support for Carrie in her own apartment.

Betsy

Betsy is an African-American woman in her 40s living in Central Massachusetts. Betsy is separated from her husband and lives alone in her own apartment. Betsy is a resourceful and assertive woman. Her daughter, who lives in a nearby town, and other family members are largely uninvolved in her care. Until recently, Betsy had worked at a popular local bookstore and at the medical center. Betsy enjoyed working and wants to find paid work again. Betsy has her graduate equivalency diploma (GED) but also wants additional education or training.

Betsy has bi-polar disorder. Fluctuations in her mental health status have made it difficult to maintain consistent employment. It has, at times, kept Betsy from going out into the community and performing necessary household tasks as well as from caring for herself adequately. Recently, Betsy has been experiencing knee problems and is wearing a knee brace, making mobility outside even more difficult.

Supports prior to the Real Choice Pilot Enrollment

Prior to the Real Choice Pilot, Betsy was connected to a local mental health case management organization. Through this organization, Betsy was receiving weekly therapy. In addition, she was seeing a visiting nurse every other week. The nurse helped monitor her mental health and other medical conditions. Betsy's case manager at the case management organization was also available to coordinate services as necessary.

Although her mental health services organization was helping Betsy address her mental health disability, other needs were not being met. Betsy had little means to leave her house. She had no means of transportation other than the limited rides to go to her medical appointments. Furthermore, although Betsy is interested in obtaining employment support, such as skills training, she was not accessing employment supports. She has been attending a training program sponsored by the Department of Mental Health but wants more specific training. In addition, Betsy wanted homemaking support since her ability to accomplish these tasks fluctuated with her mental health status.

Use of Real Choice Budget

Once enrolled in the Real Choice Pilot, Betsy devoted part of her budget to obtaining homemaking and transportation supports. In addition, Betsy used the other part of her budget to enroll in computer and crafts classes which have assisted Betsy to get out and meet people in the community. About six months into the program, Betsy experienced some knee problems and was able to use her budget to make certain modifications in her apartment.

Personal Experiences in the Real Choice Pilot

Betsy describes her quality of life as significantly improved as a result of the Real Choice Pilot. She has been able to leave the house much more than before. She is able to take classes where she learns new ideas and skills and where she meets and mingles with classmates. Betsy noted that this kind of activity is far more interesting to her than the activities in a traditional day program.

A challenge that Betsy encountered during the Real Choice Pilot enrollment is finding quality workers. Betsy started out hiring some family members and friends and then agency-based workers. One worker who was assigned did not show up for work. When the agency assigned another worker, this individual also did not show up for work. Betsy then changed to another homemaking agency, without much success. Betsy is currently employing a homemaker who is not affiliated with an agency and who appears to be more reliable thus far. With this worker, Betsy is now able to receive the necessary support she was previously lacking.

Peter

Peter is an African-American man in his 60s. He has a high school degree, and some of his hobbies include listening to music and playing chess. In the past, Peter has volunteered with the Red Cross. He has virtually no family supports nearby and is widowed. Peter's primary diagnoses are schizophrenia, diabetes, and asthma. Because of his life experiences, Peter guards his decision-making power vigilantly.

Prior to the Real Choice Pilot

Peter was hospitalized approximately two years ago because of his inability to comply with treatment for his diabetes. He was subsequently admitted into a local nursing facility where he lived for about a year and a half. Prior to entering this nursing facility, Peter was living in his own apartment with specialized support set up by the local elder services agency. He was also receiving mental health and skilled nursing supports. .

Use of the Real Choice Budget

Peter had been living in the nursing facility when a representative from the Department of Mental Health told Peter about the Pilot and applied to the Pilot on his behalf. Through the Real Choice assessment process, Peter's needs were identified as some assistance with bathing and more extensive assistance with medication and financial management, as well as homemaking and transportation. At the time Peter enrolled in the Pilot, he had also been referred to a nursing facility transition Pilot project to assist him to move back into the community.

Prior to moving into the community, Peter spent several months looking for housing and working with his community liaison to draft his spending plan. His spending plan included necessary purchases related to the transition, including furniture, clothing, and the support to assist him to plan for the move. The spending plan also included an agency-based worker to assist him with bathing, preparing meals, homemaking, and transportation for after he moved.

During the planning stage, staff from both the nursing facility transition Pilot project and the support brokerage agency provided intense support to Peter by assisting him to complete the paperwork needed to move, locate housing, and identify supportive services. However, Peter had to accomplish certain tasks requiring decisions, e.g., identification of workers, purchasing food, and locating furniture for the actual moving day. Although Peter could have used his budget to obtain a worker to assist him with these tasks, his need for assistance with paperwork to initiate a worker was unforeseen. Also, his desire to make his own decisions appeared to have led to some unaccomplished moving tasks. As a result, certain household necessities were not purchased in time for the move

and were instead purchased by the support brokerage agency⁵ on the day Peter moved into his new apartment.

Once Peter was in the community, he used his budget to hire an agency-based worker for homemaking and personal care. He received worker support from the same homemaking agency for about one year after his transition. In addition to this worker, Peter started to receive home health and skill nursing support from MassHealth. Although Peter recognized that he needed help with financial management, he was not able to find a service with which he was satisfied, partly because Peter was very reluctant to give up his financial autonomy. As a result, the nurse who provided nursing assistance also helped Peter with minor financial tasks. In addition, a case manager referred by his support brokerage agency assisted Peter by referring him to various public benefits programs and helping him through their application processes.

Experiences during the Pilot

That Peter left the nursing facility is evidence of his determination to live on his own and his ability to take advantage of resources to meet his unmet needs. In fact, prior to leaving the nursing facility, he identified his needs for medical equipment, support workers, and back-up needs primarily on his own. Nevertheless, Peter appears to require intense ongoing support as a result of his chronic conditions. These supports ranged from personal care and homemaking to community integration to prevent social isolation.

Although some of his personal care and homemaking needs were addressed, his need for community integration (e.g., companions) went unaddressed. Peter became isolated in the community and his decrease in physical functioning went unrecognized. Consequently, Peter became medically unstable and was admitted to a hospital. Peter then decided to return to a nursing home rather than stay in the community. With support from his community liaison, Peter sold some of his medical equipment and gave up his housing⁶. Once he was stable in the nursing home, he regretted giving up his home and the items he had sold. It appears now that maybe his individual budget and his community liaison could have been used to avoid the hospitalization and the nursing home admission. Since then, Peter has received a better trained community liaison. Currently, Peter is working with his new community liaison on a plan to return to community living.

⁵ These purchases were eventually reimbursed by the fiscal intermediary using Peter's budget.

⁶ As a result of experiences with Peter, Pilot staff are working on new policies to prevent experiences like Peter's when possible and to retain items and housing in the community for when the individual is ready to return home.

Carolyn

Carolyn is a Caucasian woman in her mid 30s and is currently living in a rest home. Prior to her move here several years ago, Carolyn was living with her daughter in her parents' home nearby and was working as a home health aide. Because of her bi-polar disorder, Carolyn has had to move into the rest home, leaving her job and leaving her daughter with her parents. However, Carolyn wishes to move out and live on her own. She also wants employment training to resume working and eventually advance her career.

Supports prior to the Real Choice Pilot

The rest home (referred to by her state agency case manager) has been providing Carolyn with medication and finance management as well as with preparing her meals. Carolyn recognizes that she needs these skills to resume living on her own and has expressed an interest in learning to manage her own medication and finances to better position herself to live independently. Currently, her medication is being managed completely by the rest home staff. Occupational therapy and behavioral assessment conducted recently show that Carolyn knows her medications but would need assistance managing it in an independent living arrangement. Carolyn's father is her representative payee and manages her finances, although Carolyn had been previously unaware of this arrangement.

Real Choice Pilot

Unlike a few other Real Choice Pilot participants who did not apply to the Real Choice Pilot themselves, Carolyn applied on her own initiative. At the time of her application, Carolyn's goal was to move out of the rest home and back to her parents' home. With the assistance of her community liaison, Carolyn drafted a comprehensive spending plan that included key items such as transition, respite, and medication management needs. However, after the spending plan was drafted, Carolyn's community liaison later learned that her parents, the rest home and case manager did not support this move. This resistance presented a major hurdle to accomplishing her goal to move to a less restrictive setting. In addition, both the community liaison and Carolyn herself noted that she had trouble maintaining her initiative and focusing to accomplish tasks, which in turn discouraged the community liaison.

Experiences during the Real Choice Pilot

Currently, Carolyn is undergoing an occupational therapy assessment for the most appropriate setting for community living. Transitioning into a shared living arrangement is one of the options that have been discussed with Carolyn. Concurrently, Carolyn has been attending a day program to help strengthen her independent living skills. Carolyn reported enjoying this day program because it

is an opportunity for her to mingle with her peers. Day program staff have also reportedly commended Carolyn's behavior at the day program.

For most of the first year of her Pilot participation, Carolyn has left her budget largely unspent. Although Carolyn's proposed use of the budget to fund the actual move was deemed premature by her formal and informal supports, no alternative use of the budget was identified for most of the first year. This impasse was partly due to the fact that Carolyn, her formal and informal supports were unfamiliar with non-traditional supports that could be purchased with the budget. As a result, during this time, Carolyn's formal supports have been learning about the Real Choice Pilot, since both Carolyn and her formal supports agree that the rest home is not the most appropriate setting for Carolyn. Recently, the budget has been used to pay for Carolyn's dental care as well as the previously mentioned occupational therapy and behavioral assessments to evaluate her independent living skills. It remains to be seen whether her goals of community living and employment can be met in the future and whether or not the Real Choice Pilot will play a role.

Marcy

Marcy is a Caucasian woman in her mid 40s. Marcy has a graduate-level degree and had been teaching at a local community college. She has a love for learning and reading and her major personal goal is the attainment of a doctoral degree.

Within the past few years, Marcy's vision and functioning have deteriorated due to a rare form of multiple sclerosis. During the same time, Marcy has been hospitalized multiple times and has been through rehabilitation at a nursing facility. Furthermore, her medical concerns have caused much stress and anxiety for Marcy to the point where she has been diagnosed with depression. Together, these health conditions have made it very difficult for Marcy to continue working. Nevertheless, she plans on achieving her educational goal and returning to the workforce.

Supports prior to the Real Choice Pilot Enrollment

Marcy had left the nursing facility before she applied to the Real Choice Pilot. At the time of her application, Marcy was living in her own apartment with various supports. These included an agency-based homemaker and transportation, visiting nurse service, and a personal emergency response system. These supports were financed by both the Massachusetts Commission for the Blind (MCB) as well as MassHealth. However, Marcy was interested in directing her own care workers.

In addition to these paid supports, Marcy relies on informal supports. Specifically, her son and her MCB volunteer help Marcy to write out her bills. Marcy also relies on a friend and her priest for significant emotional support.

Use of Budget

Marcy learned about the Real Choice Pilot from a staff person at a nursing facility transition project. Marcy recalls that when she was first told about the Real Choice Pilot, it was described as a way to "realize her potential" and dreams. Because the Real Choice Pilot was described to Marcy in these vague terms, Marcy thought the enrollment in the Real Choice Pilot could pay for her doctoral studies tuition. She believed that she could use all of her budget for tuition, while obtaining her worker supports from another source.

It took some time for Marcy to understand that her individual budget in the Pilot was intended to finance all of her home and community-based non-medical supports, including worker support. Although the Real Choice Pilot did not pay for tuition, Marcy was able to use a portion of her budget for various supports. Specifically, Marcy bought a computer and a closed circuit television, as well as some medical equipment not covered by MassHealth and kitchen supplies to help her prepare her own meals. Marcy was very excited to purchase an

accessible computer to connect to other individuals with her health condition. In addition, Marcy replaced the agency-based homemaker with three direct workers who were either acquaintances or referrals from her friends. Marcy's support brokerage agency also connected her to a case manager to help Marcy apply for public benefits programs due to her high medical needs.

Experiences during the Real Choice Pilot

Although Marcy was one of the first individuals to be assessed for the Real Choice Pilot, she had experienced several stumbling blocks that significantly delayed her use of her budget. Given Marcy's determination to pursue further education, she deduced that the Real Choice Pilot could do just that: pay for her tuition to go to school. When Marcy learned that she could not pay her tuition through the Real Choice Pilot, she was greatly disappointed. Marcy's confusion may have been attributed to the fact that program staff, i.e., the assessor and community liaison, were unclear themselves as to whether her tuition could be paid through the Real Choice Pilot and therefore did not correct Marcy's misconception early on. In addition to this confusion, Marcy was hospitalized for a significant period of time a few months after her spending plan was developed.

Because of her health conditions, exacerbated by the repeated hospitalizations, Marcy was preoccupied with medical concerns and wavered about whether to remain in the Real Choice Pilot. Marcy's physician also discouraged Marcy at one point, fearing that it would add more stress. After some discussion with the senior staff from the support brokerage agency, Marcy eventually decided to remain in the Real Choice Pilot. Even after this decision, Marcy delayed hiring workers and completing the fiscal paperwork for those workers. Marcy's community liaison offered to complete the necessary paperwork for her, and eventually provided Marcy much guidance in assisting with the fiscal paperwork.

Several months after her most recent hospitalization, Marcy has identified individuals she wanted for workers and has completed the fiscal paperwork and successfully hired these individuals. Furthermore, Marcy is in the process of identifying an individual who can provide support similar to that of a representative, a move that is expected to strengthen her ability to self-direct.