Case Histories of Six Consumers and Their Families in Cash and Counseling

Patricia M. San Antonio, Lori Simon-Rusinowitz, Dawn Loughlin, J. Kevin Eckert, and Kevin J. Mahoney

Objective. To examine how the lives of consumers and their caregivers were affected by making choices and controlling their own resources with the cash option, this paper focuses on six case studies from the Cash and Counseling Demonstration Program.

Data Sources. Twenty-one consumers, caregivers, and state consultants were interviewed about their experiences in the program.

Study Design. The data come from a larger study of over 200 interviews conducted from June 2000 to August 2004. Interview data were analyzed for themes about caregiving and program satisfaction.

Principal Findings. Cash and Counseling benefited consumers and caregivers by allowing consumers increased continuity and reliability of care, increased ability to set hours of care, more satisfaction with how caregiving is offered and more satisfaction with the quality of care.

Conclusions. The cash option allowed consumers to create, schedule, and manage their own model of care. Some consumers faced challenges in the program with paperwork, accounting, worries about receiving care, and some ineffective state consultants who could have been more helpful.

Key Words. Cash and Counseling, cash option, case history, qualitative case studies

CASE HISTORIES OF SIX CONSUMERS AND THEIR FAMILIES IN CASH AND COUNSELING

This paper examines the case histories of six consumers and their caregivers in order to better understand how individual lives were affected by the Cash and Counseling Demonstration and Evaluation (CCDE) Programs in Arkansas, Florida, and New Jersey. Each case history provides a close look at the process of using the cash option and ways in which making choices and controlling their own resources makes a difference in consumers' lives. The case histories

focus on consumers' previous care arrangements and how Cash and Counseling helped them to improve their care and services as well as challenges they faced in the program.

Background

Cash and Counseling Program. The CCDE was a policy-driven study of a consumer-directed approach to personal assistance services for elders and younger adults with disabilities and in Florida children with disabilities (Mahoney, Simone, and Simon-Rusinowitz 2000). Funded by the U.S. Department of Health and Human Services and the Robert Wood Johnson Foundation, the program examined the use of the cash benefit by Medicaid consumers and tested their ability to design services for themselves that best met their needs while maintaining overall program budget neutrality (Foster et al. 2003). Using their cash benefit, consumers chose and hired the persons providing them with personal and essential services, such as bathing, eating, and dressing, as well as when and how they were provided. Consumers could hire a friend, relative, or unrelated person to work for them as caregivers. Consumers were also able to use their benefit to buy other services that would increase their independence such as transportation, home modifications, and assistive devices. Counseling and assistance with bookkeeping helped consumers manage their services.

The case histories described in this paper were based on interview data collected by researchers from the University of Maryland Baltimore County (UMBC). The purpose of the qualitative study was to provide an in-depth view of how consumers, caregivers, and state consultants worked together. The UMBC study was designed to provide an understanding of the personal experience of some consumers and caregivers in the Cash and Counseling programs as told in their own voices, one of the benefits of qualitative research (Sofaer 1999). The qualitative research focused on understanding the experience of the consumers, their changing needs, the choices they made in their use of the cash option, and the challenges they faced in the program. The case history, or case study method was used to understand how and why

Address correspondence to Patricia M. San Antonio, Ph.D., CSR, Incorporated, 2107 Wilson Blvd, Suite 1000, Arlington, VA 22201. Lori Simon-Rusinowitz, Ph.D., and Dawn Loughlin, Ph.D., are with the Department of Health Services Administration, and Center on Aging, College Park, MD. J. Kevin Eckert, Ph.D., is with the Erickson School of Aging Studies, University of Maryland Baltimore County, Baltimore, MD. Kevin J. Mahoney, Ph.D., is with the Graduate School of Social Work, Boston College, Chestnut Hill, MA.

the cash option worked for consumers in a real life context (Yin 1994). The importance of flexibility in the use of the cash option unites the cases discussed below (Gillham 2000; Stake 2000). This evaluation-driven project included both quantitative and qualitative evaluation components. This article reports findings from the qualitative studies.¹

Methodology

The data for this paper were collected as part of a larger qualitative study of the Arkansas, Florida, and New Jersey CCDE Programs (Eckert, San Antonio, and Siegel 2001; San Antonio et al. 2003; San Antonio and Niles 2005). The purpose of the UMBC study was to provide detailed information about the experiences of various types of participants receiving the “cash option” in the three state programs. The study focused on how “care units,” composed of consumers and/or representatives, paid workers, and state consultants interacted around issues of consumer-directed care. The study addressed five broad research questions: (1) Has the program made a difference in the lives of consumers, representatives, and workers, and if so, how? (2) How does participation in the program compare with previous arrangements? (3) In what manner are services provided? (4) How does the program work? (5) And what challenges do consumers face in the program?

For the larger study, approximately 25 consumers, their representatives when appropriate, their primary caregivers, and state consultants were interviewed in each of the three states. The consumers were chosen to provide a sample that included diversity in four selection criteria: age, race/ethnicity, type of worker hired (family/nonfamily), place of residence (rural or suburban/urban), and whether they had a representative. The selection criteria were determined through discussion with the Cash and Counseling Management Team and the state program staff to explore a range of possible experiences in the program. The selection criteria were identified based on initial results from the quantitative evaluation.

Data collection took place from March through June 2000 in Arkansas, in July and August of 2001 in New Jersey, and in July and August of 2002 in Florida. Face-to-face, semi-structured, open-ended interviews lasting 1–1.5 hours were conducted with consumers and their caregivers. The tape-recorded interviews were conducted by two interviewers and took place in the consumers’ homes. Each consumer or representative had participated in the Cash and Counseling Programs for at least 6 months. Consumer or representative interviews included questions about previous care experiences, rea-

sons why they decided to enroll in the program, type of help they needed, services their caregiver provided, the schedules and tasks of caregivers, qualities they looked for in a caregiver, the greatest benefits and/or drawbacks to their participation in the program, and comparisons between their experience in Cash and Counseling experience with previous services. Caregiver interviews included questions about; their previous caregiving experience, services they provided to cash-option consumers, their schedules, and their experiences in the program. State consultants acted as advisors and mediators in the program, and worked with consumers to devise a care plan and budget. Interviews with state consultants focused on their work with cash option consumers and caregivers and differences in their work with Cash and Counseling personal assistance versus other programs.

This paper is based on a subset of the interviews conducted for the larger qualitative study, focusing on interviews with six adults, or their representatives, who need personal assistance with daily activities, their family or nonfamily paid caregivers, and state consultants. The original sample for the larger study was a quota sample. Twenty-five consumers were chosen who fit into categories of interest developed in consultation with the funders, state staff, and researchers in order to understand the personal experiences of a variety of consumers and caregivers in the program. The six cases presented here have all the elements of our original quota sample with a variety in the cases of age, gender, race/ethnicity, cognitive ability, severity of disability, type of caregiver, use of representative, and use of the cash option.

Data Analysis. Each interview was tape recorded and transcribed verbatim as a *Word* document. Each interview was coded for a priori items corresponding to the semistructured, open-ended protocol questions. For example, all data were coded that pertained to the question about consumers' experience with care before enrolling in Cash and Counseling. The transcripts were then coded for themes that emerged from the texts of the three interviews. For example, the importance of choosing the time care is provided emerged from how consumers, representatives, and caregivers discussed what they considered "good" care. The data analysis resulted in narratives for each "consumer triad" based on the related interviews with the consumer/representative, paid caregiver, and consultant. The case histories discussed below are based on data from the transcripts with introductory background information culled from the larger study's narratives.

Case Histories

Each of the six case histories was chosen to illustrate how consumers use the Cash and Counseling option to meet their needs. Each case history describes how the cash option has helped consumers solve problems with the care and services received, and how they plan to use it in the future. The title chosen for each case history represents one of the main benefits of the Cash and Counseling Program for not only that particular consumer and their family, but for similar cases in all three states as well.

Finding a Caregiver with the Flexibility to Match the Hours Needed by the Consumer and Family

The Consumer. Mrs. Nora Bennett is a 98-year-old white widow who lives with a granddaughter, her granddaughter's husband, and a great-granddaughter in a house in suburban Tampa, Florida (San Antonio and Niles 2005). She suffers from mild dementia, has vision problems, and takes medication for high blood pressure, but is otherwise healthy. Mrs. Bennett's granddaughter Mary is her representative.

Help Needed. Mrs. Bennett needs help with getting up in the morning, showering, dressing, and grooming. She is still able to use the toilet on her own, but she needs help walking to the bathroom. She also needs to have her meals prepared and must be supervised at home.

Paid and Unpaid Care Received before Enrollment in Cash and Counseling. Mrs. Bennett has been cared for by her granddaughter Mary for 7 years, but has lived with Mary and her husband for the last 2 years since she could no longer live alone. Mary provided unpaid care to her grandmother. Once a year Mary's sister would take care of Mrs. Bennett for a week when Mary and her husband go on vacation. The family started getting paid help for Mrs. Bennett after she fell in the shower. Mary continued to provide personal care to her grandmother, but because Mary has a bad back and could no longer help Mrs. Bennett in the shower she hired an agency. Mrs. Bennett received agency workers for 5 days a week from 8 A.M. until 2 P.M. from Medicaid.

Problems with Care and Services before Enrollment in Cash and Counseling. Mary described problems with the care received before enrollment in Cash and Counseling. For example, agency hours were set and workers started at 8 A.M. even though Mrs. Bennett does not get up until 10 in the morning. Mary felt that she was paying workers for sitting. Owing to a worker shortage, Mrs. Bennett often had different workers. On one occasion, she had a different worker every day for 2 weeks. Mary felt that this was an intrusion

on her grandmother's sense of privacy and modesty as the workers provide intimate personal care. The agency workers were unreliable and often did not show up for work. Mary is a self-employed accountant. She almost lost her business because workers did not show up, preventing her from meeting with clients because she could not leave her grandmother.

Mary finally found Sylvia, a reliable worker from the agency who she liked to have care for her grandmother. Sylvia enjoyed working for Mrs. Bennett, but had scheduling difficulties with the agency. She often received phone calls at the last minute to work somewhere else. Sylvia was also required by the agency to provide care following a set schedule. For example, the agency required Sylvia to give Mrs. Bennett a shower once a week within a 45-minute period, which Sylvia thought was too rushed for the older woman.

How Cash and Counseling Helped the Consumer Improve Services. Mary heard about the Cash and Counseling option from her grandmother's consultant. She was happy to participate because she was able to hire Sylvia as a nonfamily caregiver. Mary pays Sylvia more per hour than the agency. Sylvia works from 10 to 4, 4 days a week, which is more convenient than the previous agency-dictated schedule. Mary works at home 1 day a week. Mrs. Bennett's great-granddaughter also lives with the family and helps provide care in exchange for room and board. Mary feels that Mrs. Bennett knows and is comfortable with Sylvia and the family trusts her. Sylvia even has a key to the house. Mary is especially grateful that she is able to continue working.

As the nonfamily caregiver, Sylvia also benefited from the enrollment in Cash and Counseling in several ways. Sylvia wants to keep her work to 23 hours a week because she receives widow's social security. She is able to work for just one consumer, not two different clients as she did before. Sylvia can also rely on a set schedule and knows what her hours are going to be. She can shower Mrs. Bennett every day at her own pace and because of this freedom to do her tasks as she sees fit she feels that she can do a better job caring for Mrs. Bennett. Her work is more flexible and she coordinates care with Mrs. Bennett's granddaughter and great-granddaughter. Sylvia also feels that she has developed a good relationship with Mrs. Bennett and the family appreciates her work.

Problems Encountered in Cash and Counseling. The family encountered some accounting problems at the beginning of Mrs. Bennett's enrollment in the program. Mrs. Bennett's granddaughter found it difficult to keep track of the number of caregiver hours expended. If the family reviewed the number of caregiving hours in the cash plan and found that they had used more hours

than allowed, they would only learn about the problem when they received a notice from the bookkeeping services. The family would then have to reduce their caregiving hours until they made up the difference in their overspending. As Mrs. Bennett still needed the same amount of care, the caregiver's pay would have to come out of her granddaughter's pocket. The Florida fiscal agency did not catch problems with use of the cash plan sometimes for several months, which resulted in expensive repayment plans.

Future Plans. Mary saves part of the cash allowance so she can hire caregivers for a week of respite care during her yearly vacation. She has returned to work in her own business as an accountant. She also invited her niece to live in her house and help with Mrs. Bennett's care as part of her room and board.

Cash Option Offers Consumer Flexibility to Pay for Nontraditional Services Including Respite

The Consumer. Adam Connolly is a 26-year-old single white man with developmental disabilities who lives with his mother and father in a rural area near Tampa, Florida (San Antonio and Niles 2005). Adam has cerebral palsy and a seizure disorder as a result of encephalitis. He has both cognitive and physical disabilities. Adam's mother acts as his representative and he has a nonfamily caregiver at a daycare center for adults with disabilities.

Help Needed. At the time of the interview Adam was making great strides in both his physical and cognitive condition. At his mother's insistence, a neurologist had reassessed his treatment and changed the medications Adam took for his seizure disorder. The change in medication had alleviated many of his problems including his sleepiness and mental foggiess, his incontinence, and inability to walk. Adam was in the process of learning to take steps and did not have to spend all his time in a power wheelchair. Before his medication change, Adam needed help with all activities of daily living (ADLs) and instrumental activities of daily living (IADLs). He is now able to eat and drink on his own, and is beginning to toilet himself. He was able to participate in center training classes and was learning to use computers and the Internet. Although his condition was improving, his care was still physically demanding.

Paid and Unpaid Care Received before Enrollment in Cash and Counseling. Adam's mother and father have always provided care to their son. Adam's parents also used a daycare center for adults with developmental disabilities, which was paid for by Medicaid.

Problems with Care and Services before Enrollment in Cash and Counseling. Mrs. Connolly could not choose the workers she wanted for respite care. Medicaid did not pay for all of the therapy she thought her son needed.

How Cash and Counseling Helped the Consumer Improve Services. Mrs. Connolly used the cash option to pay for therapy not allowed under Medicaid. For example, she pays for horseback riding which Adam loves and which allows him to participate in Special Olympics. The Connolly's also use the cash option to help pay for service to the van they use to transport their son to the center and to other events. In order to save money, Mr. Connolly does as much of the van upkeep as possible, but they need a skilled mechanic for some of the work. Mrs. Connolly hires a local couple she knows and trusts to provide respite care for Adam.

Problems Encountered in Cash and Counseling. Mrs. Connolly complained that the state consultant was ineffective at helping them find services such as transportation to Adam's daycare center. Mrs. Connolly had long experience in finding services and advocating for her son. She resented having to work with a state consultant who had less experience than she at finding resources, and thought the consultant was an unnecessary middleman.

Future Plans. The Connolly's save money from the cash option to pay for respite care. They are focused on providing support and increased therapy to Adam while he is making large strides in his physical and cognitive abilities. As his care was still physically demanding and his two brothers were no longer at home to help, Mrs. Connolly was trying to find ways to reduce their caregiving load.

Consumer Chooses Cash and Counseling for Improved Access to a Reliable Family Worker

The Consumer. Regina Erdman is a 55-year-old white woman who lives with her husband and son in a suburb of Tampa (San Antonio and Niles 2005). Mrs. Erdman suffers from prednisone-induced osteoporosis, emphysema, and chronic obstructive pulmonary disease. She has 30 fractures in her spine and ribs and has been confined to bed for the last 7 years. She leaves their apartment only to see the doctor. She is in great pain and uses a Duragesic pain patch.

Help Needed. Mrs. Erdman needs help with dressing and bathing. She also needs skin care and massage for her legs, feet, and back. She needs help getting and managing her medication schedule. Her bed linen needs to be changed once a week and she needs all housework, shopping, and cooking

done for her as well. She has no cognitive impairment, but is almost always confined to bed, in pain, or sleepy because of her pain medication so she needs help with all IADLs.

Paid and Unpaid Care Received before Enrollment in Cash and Counseling. Mrs. Erdman took part in a phone interview about her interest in the Cash and Counseling program before the program started. She remembered that she was not interested in the cash option at that time because she had good agency people who came in the afternoon. Shortly after the interview, she said that her agency help began “to go downhill.” And due to worker shortages she was no longer receiving the help she needed. In her case, the cash option became attractive when agency help was no longer readily available.

Problems with Care and Services before Enrollment in Cash and Counseling. Because of the medication she takes for pain, Mrs. Erdman is very groggy in the morning and does not feel well enough to move around or bathe before 1 in the afternoon. Agency workers preferred to work in the morning and Mrs. Erdman could not find agency workers who were willing to start at 1 P.M. Agency workers often called her to try and arrange an earlier start time. Mrs. Erdman said that one worker called her multiple times the night before her shift to change the time. Even when agency workers agreed to start at 1 P.M. they often arrived at 11 in the morning. Agency workers often cancelled at the last minute and Mrs. Erdman had no help at all. Sometimes she had no agency worker because of a worker shortage. An agency supervisor came to help her with a shower several times because the agency did not have enough workers to send.

How Cash and Counseling Helped the Consumer Improve Services. Mrs. Erdman hired her son Ron as a caregiver because she trusts him and he is a reliable worker. He works the hours she needs and helps her with a bed bath when she is feeling well enough to take one.

The consultant helped Mrs. Erdman with the program paperwork, especially with the purchasing plan. The consultant also checks receipts.

Ron uses his caregiver salary for his monthly car note. He attends community college and works part time at a local hospital. The job he has with his mother helps him financially and also makes him feel that he is helping his mother.

Problems Encountered in Cash and Counseling. Mrs. Erdman is overwhelmed by the program paperwork. Even though she does not need a representative, her husband and son have to do the paperwork for her because she does not feel well enough to handle it. Mrs. Erdman also feels that

there are problems inherent in hiring your child to work as a caregiver. She has instituted strict rules for her son so that she will receive the care she needs from him, and she feels that she must be vigilant because she hired a family member. Her son worries about his mother and has an emotional involvement in her care, which is sometimes difficult.

Future Plans. Mrs. Erdman uses part of her cash option for skin care products. She is also trying to figure out how to pay for an extremely expensive medication. She plans to continue employing her son as a caregiver.

The Cash Option Offers an Independent Consumer the Ability to Create Backup Systems and Obtain Important Services Prohibited under the Previous System

The Consumer. Ms. Angela Grasso is a 39-year-old single white woman who lives with her parents in a house in suburban New Jersey (San Antonio et al. 2003, 190). Angela is quadriplegic and is suffering from a progressive neuromuscular wasting disease. She is slowly losing both her sight and hearing, but she has no cognitive impairment. She is the Director of a local disability rights and advocacy organization.

Help Needed. Angela needs help with all activities of daily living including transferring, bathing, dressing, and eating, as well as food preparation, homemaking, and other physical tasks. She also needs help with range of motion exercises.

Paid and Unpaid Care Received before Enrollment in Cash and Counseling. Angela's mother and father have always provided Angela with informal care. Angela also received 40 hours a week of care through an agency paid for by Medicaid.

Problems with Care and Services before Enrollment in Cash and Counseling. Angela had difficulty with previous care arrangements because of her special needs. Angela has speech difficulties, and many agency workers were not native English speakers and could not understand her. Angela also wants caregivers to provide secretarial help for her in her disability rights organizational activities. It is important to Angela that her care be provided a certain way, and because she had so many different workers, Angela did not get the care she wanted. The workers followed agency practices by expecting to dictate the tasks and schedule for Angela, and doing range of motion exercises the way the agency trained them to do so rather than follow Angela's directions.

How Cash and Counseling Helped the Consumer Improve Services. The reliability and training of caregivers is very important to Angela so she uses the

Cash and Counseling option to hire six caregivers, none of whom are related to her. With six caregivers she is not overly dependent on any one caregiver and they can also act as back-ups to each other for vacations or in case of illness. Her father serves as an emergency back-up caregiver. Angela prefers caregivers without much experience so she can train them to provide care the way she wants.

The consultant taught Angela how to do the cash plan and how to figure employee taxes and balance her checkbook. Angela can call the consultant for help.

Problems Encountered in Cash and Counseling. Angela prefers to do her own accounting, but has been using a fiscal intermediary. She felt that the intake worker for Cash and Counseling was not clear about the fact that consumers can do their own accounting, and she was steered toward using the fiscal intermediary. Angela discovered that she could do her own accounting at a conference, and she is trying to set up the training and support she needs to do this.

Future Plans. Angela is saving some of her allowance each month to purchase voice-directed software for her computer so she can do administrative work more independently. Directing her own care takes tremendous energy and organization and Angela takes her role as an advocate for disability rights seriously. In order to facilitate hiring she wants to set up an emergency pool of careworkers that could be called on by any of the consumers with disabilities in her county.

The Cash Option Offers Ethnic Elders and Their Families the Ability to Obtain Culturally Appropriate Care

The Consumer. Mrs. Teresa Moreno is an 80-year-old widow of Ecuadorian descent (San Antonio et al. 2003). Mrs. Moreno lives with her daughter-in-law, two granddaughters in their twenties, and two small grandsons in a three-bedroom apartment in a city in New Jersey. Mrs. Moreno has Parkinson's, Alzheimer's, osteoporosis, and depression. Mrs. Moreno's representative is her eldest granddaughter who works as a health aide in a nursing home.

Help Needed. Mrs. Moreno needs total care and supervision. She has a cognitive impairment. She can walk a little with assistance, but she is usually in a wheelchair. Mrs. Moreno needs help with all activities of daily living such as toileting, washing, and dressing, and instrumental activities of daily living

such as laundry, meals, and exercises. Her family never leaves Mrs. Moreno home alone.

Paid and Unpaid Care Received before Enrollment in Cash and Counseling. Mrs. Moreno's daughter-in-law Anna is a licensed home health aide who works for an agency. The agency does not allow workers to care for their own family members although Anna feels that there is no one better to care for her mother-in-law than herself because of their close relationship. Anna quit her job with an agency in order to care for her mother-in-law. Anna and her two daughters always provided unpaid care for Mrs. Moreno. In addition, agency workers provide 40 hours of paid care per week for Mrs. Moreno.

Problems with Care and Services before Enrollment in Cash and Counseling. While Anna herself is an agency worker and respects agency care, Anna had problems with several agency workers who came to care for her mother-in-law. Several of the workers did only a minimum amount of work and only what they wanted to do. They became angry when Anna complained. Some of the caregiving work was sloppy. For example, one worker bathed Mrs. Moreno and applied talc to her wet feet so that Mrs. Moreno developed a crust on her feet. As a licensed homemaker herself, Anna was very offended by sloppy work and expected her mother-in-law to be cared for well and treated respectfully. The issue of respect for an elder was especially important to this Hispanic family.

How Cash and Counseling Helped the Consumer Improve Services. Anna and her daughter Clara provided care for Mrs. Moreno. Clara was saving money to attend school. The pay from her grandmother allows her to stay home with her small son. Anna is also able to spend more time with her mother-in-law and enjoy their personal relationship, which was not possible when she worked outside the home. The family liked working with a Hispanic consultant who spoke Spanish.

Problems Encountered in Cash and Counseling. Mrs. Moreno's family did not have a good experience with their intake meeting for the program. They did not feel like their questions were answered or that the state worker understood Mrs. Moreno's needs. For example, when Anna told the worker the number of hours they needed to care for her mother-in-law, the staff member told them that Cash and Counseling did not pay for babysitting. Anna was offended that her assessment of Mrs. Moreno's needs were described as babysitting. The family was happier with Cash and Counseling once they started working with a Spanish speaking consultant. They felt that they were treated more respectfully and were able to understand the program more clearly. The issue of respect is important not just for elders, but is an

important aspect of the family's satisfaction in their interaction with the consultant. While Anna likes working with her mother-in-law, she does not get paid time and a half on holidays as she does for an agency so she suffers financially as a paid caregiver in the program.

Future Plans. When Clara attends school, Anna will have to find another caregiver for Mrs. Moreno. The family plans to continue to rely on the extended family to provide care and support each other as caregivers.

Cash Option Offers Services That Allow Family to Expand Involvement in the Community

The Consumer. Mr. Jim O'Brien is a 23-year-old, single, African-American man with developmental disabilities who lives with his mother and father in Little Rock, Arkansas (Eckert et.al. 2001). Jim has cerebral palsy and a seizure disorder and cannot speak. He is cognitively impaired. Jim's mother acts as his representative and his father is his paid caregiver.

Help Needed. Jim needs help with all activities of daily living and instrumental activities of daily living. Jim must be bathed, dressed, fed, toileted, and transferred. According to his mother, Jim's physical condition is deteriorating.

Paid and Unpaid Care Received before Enrollment in Cash and Counseling. Mr. and Mrs. O'Brien have always cared for Jim. Mrs. O'Brien's mother helped until her health became poor. Jim's two sisters and his older brother also helped take care of Jim and provided respite care to his parents. Jim's elder sister helps him on the weekends. She brings her children with her when she visits, which Jim and his parents enjoy. If his sister cannot help, Jim's older brother may come to help. The O'Brien's really felt the loss of support when their children moved out so they received Medicaid home care agency services on weekends. Jim also attends a daycare center during the week paid for by Medicaid.

Problems with Care and Services before Enrollment in Cash and Counseling. The O'Brien's are more pleased with the cash option than previous services. One agency worker was unable to find childcare so she came to their house with her two children, ages 7 and 9. Mrs. O'Brien felt sympathy for her and allowed the worker to bring her children with her for 4-5 months, but she was never able to find childcare and Mrs. O'Brien did not feel she could do the job with her children there so she asked for another worker. A second agency worker was 70 years old and was not strong enough to transfer Jim or carry him upstairs to the toilet. The worker fell with Jim. The O'Brien's had to

be available to help with transfers and toileting so the agency worker was not a help to them, although they liked her and felt bad about asking for another worker.

How Flexibility in Cash and Counseling Helped the Consumer Improve Services. Jim attends a daycare center 5 days a week. Mrs. O'Brien takes care of Jim as an unpaid caregiver in the morning and gets him ready for the bus to the center. After work everyday, Mr. O'Brien takes care of Jim as his paid caregiver. Both Mr. and Mrs. O'Brien help him in the evening. On the weekends, Mrs. O'Brien takes care of Jim on Saturday and Mr. O'Brien takes care of Jim on Sunday for pay. Mrs. O'Brien likes the advantage of working with a consultant who she can call directly with questions about the program. Mr. O'Brien likes using his caregiver paycheck to purchase respite care. He and his wife are able to go out together, which they enjoy.

Problems Encountered in Cash and Counseling. The O'Brien's have had difficulty completing the caregiving timesheets correctly and have had paperwork lost in the mail. Tracking caregiving and getting timely responses from the fiscal intermediary is a problem.

Future Plans. The O'Brien's do not have any particular plans to change Jim's care arrangements, although they are beginning to think about how to care for him in the future when they are no longer able to do so themselves. Jim's sister has offered to care for Jim in the future, but Mrs. O'Brien does not think she appreciates the magnitude of this responsibility and does not want her children to have to shoulder their brother's care. Mrs. O'Brien realizes that Jim will require increasing levels of institutional care in the future. She continues to serve on state-wide advocacy groups for developmental disabilities.

DISCUSSION

The stories from the qualitative study support the CCDE quantitative evaluation findings on consumer and caregiver satisfaction, and illustrate the many ways in which the program's flexibility enabled consumers to make their care more responsive to their needs and desires.

The cases illustrate how consumers' lives were improved under Cash and Counseling. For example, the program enhanced the consumer's ability to communicate with the caregiver (Grasso, Moreno), provided increased continuity of care (Bennett) increased reliability of care (Bennett, Erdman), increased the ability to change care arrangements according to needs (Con-

nolly), and increased the ability to set hours of care (Bennett, Erdman). In addition, Cash and Counseling allowed for better coordination with family caregivers (Bennett) and more satisfaction with the ways in which the work is done and with the quality of care (Bennett, Erdman, Grasso, Moreno, O'Brien). The qualitative data presented here enhance our understanding of CCDE survey findings because they show us what kind of care is most helpful to consumers: care consistently delivered to consumers at the times it is needed and care that they control, so if they are dissatisfied they can change the arrangements. The consumers in our study chose consumer direction, because it enabled them to obtain care that meets these criteria.

The case histories show how consumer-directed care and Cash and Counseling makes it possible for different types of consumers to meet their diverse needs with a variety of arrangements. For example, Mrs. Erdman prefers that her paid caregiver begin work in the afternoon, which agency workers were not able nor willing to accommodate. Jim O'Brien attends an adult daycare program, and his parents alternate his morning, evening, and weekend care.

Consumer-directed care allows consumers and their families to change their schedules and activities. Many consumers, like Angela Grasso whose vision and hearing loss are progressive, and Adam Connolly, who is beginning to learn to walk, are concerned with the ongoing process required for them to arrange and negotiate changes in their care quickly, as their needs change. The interviews' focus on the process of caregiving shows how directly hired workers develop their expertise over time through experience and feedback from the consumer. For example, the Connolly's and the O'Brien's have been intimately involved as caregivers throughout their sons' lives. On the other hand, Angela Grasso prefers to hire caregivers without much experience so she can train them herself to provide care the way she wants. However, we see in both situations that good care is not static, but instead is negotiated and adjusted over time between consumers and their directly hired caregivers.

Our interviews also illustrate that the program can benefit caregivers. Mrs. Bennett's paid caregiver (and former agency worker), Sylvia, is more satisfied working for only one consumer, with a set schedule. Mrs. Moreno's granddaughter is able to care for her grandmother, while saving money to attend school. A consumer's decision to enroll in a consumer-directed program may be based on the perceived benefits to both the consumer and the caregiver. The improved quality of life for both consumer and caregiver may also enable consumers to remain in the community for as long as possible.

Consumers face challenges as well and these issues are an important aspect of consumers' experience in the program. For example, problems with the statements and the timeliness of the fiscal intermediary services create problems. The amount of paperwork required for the program can be overwhelming to consumers like Mrs. Erdman who, otherwise, direct their own care. Parents of children with disabilities in Florida were often frustrated by having to work with consultants who were not as experienced as they. Such challenges may be especially frustrating to consumers who enrolled in Cash and Counseling hoping to avoid bureaucratic problems.

The case studies presented here provide a look at how different types of consumers and their families participate in Cash and Counseling. Consumers from many different backgrounds can use the program to address their specific needs and situations. Consumers and their caregivers often struggle to get the services they need while managing chronic conditions. The flexibility of the cash option provides an opportunity for program participants to choose both the type and the delivery of services and a means to achieving independence and satisfaction.

NOTE

1. Please refer to www.cashandcounseling.org for numerous articles reporting findings from the quantitative studies.

REFERENCES

- Eckert, J. K., P. M. San Antonio, and K. B. Siegel. 2001. "The Cash and Counseling Qualitative Study: Stories from the Independent Choices Program in Arkansas" [accessed on October 5, 2005]. Available at www.cashandcounseling.org
- Foster, L., R. Brown, B. Phillips, J. Schore, and B. Carlson. 2003. "Improving the Quality of Medicaid Personal Assistance through Consumer Direction: Findings from the Arkansas Cash and Counseling Demonstration." *Health Affairs* (March 26, 2003, web exclusive).
- Gillham, B. 2000. *Case Study Research Methods*. London: Continuum.
- Mahoney, K. J., K. Simone, and L. Simon-Rusinowitz. 2000. "Early Lessons from the Cash and Counseling Demonstration and Evaluation." *Generations* 24 (3): 41–6.
- San Antonio, P. M., J. K. Eckert, K. J. Niles, and K. B. Siegel. 2003. "The Cash and Counseling Qualitative Study: Stories from the Personal Preference Program in New Jersey" [accessed on October 5, 2005]. Available at www.cashandcounseling.org

- San Antonio, P. M., and K. J. Niles. 2005. "The Cash and Counseling Qualitative Study: Stories from the Consumer Directed Care Program in Florida" [accessed on October 5, 2005]. Available at www.cashandcounseling.org
- Sofaer, S. 1999. "Qualitative Methods: What Are They and Why Use Them?" *Health Services Research* 34 (5): 1101–18.
- Stake, R. B. 2000. "Case Studies." In *Handbook of Qualitative Research*, edited by N. K. Denzin and Y. S. Lincoln, pp. 435–54. Thousand Oaks, CA: Sage.
- Yin, R. K. 1994. *Case Study Research: Design and Methods*. Thousand Oaks, CA: Sage.