Summary of National Caregiver Health Promotion Summit

Department of Health and Human Services
December 16, 2003
10:00 am-12:00 pm

I. Michael O'Grady, Assistant Secretary, ASPE
Call to Order and Welcome

Dr. O'Grady welcomed the audience, and stated that supporting caregivers is important to the Department of Health and Human Services (HHS). He mentioned several efforts under way, including the CMS-sponsored Systems Change Grants, his research program in ASPE, and the work being conducted by the Administration on Aging.

II. Claude Allen, Deputy Secretary, HHS
Welcome

Mr. Allen related that as the chief operating officer for HHS he manages over 300 programs and a budget of $458 billion in 2002. He recognized the caregivers in attendance for their service, and acknowledged that it is hard to tell caregivers to work out, relax, and eat right given the competing demands on their time. He also acknowledged that there is no 'one-size fits all' approach that will work for all caregivers. He said that there is a need to develop tailored programs or approaches for caregivers that work for them at particular points in time. Mr. Allen said that caregivers need to know that it is not selfish for caregivers to focus on their own needs; it is just another 'job' for them as caregivers.

He went on to say that, while there are several federal programs under way to help caregivers such as the National Family Support Program, federal dollars only go so far. Public health and state programs are also needed to help caregivers improve their own health. Mr. Allen mentioned several organizations that are also helping caregivers, including the National Family Caregiver Alliance, National Council on Family Caregivers, AARP, the Alzheimer's Association, Easter Seals, and the National Council on the Aging. Mr. Allen concluded by reading a letter written by Nancy Reagan. Mrs. Reagan acknowledged the government for its efforts, thanked those attending the Summit meeting, provided advice on how caregivers can take better care of themselves physically and emotionally, and encouraged caregivers to accept help from family and friends.

III. Three Caregivers Provided Testimony About Their Personal Experiences, with Follow-up Questions Provided by Claude Allen

Mr. Donald "Mac" Showers talked about his experiences in caring for his wife after she was diagnosed with Alzheimer's disease, and emphasized the importance of maintaining quality of life for patient and caregiver alike. He strongly recommended that caregivers take care of themselves and maintain a healthy lifestyle. Among his specific recommendations were to: (a) get adequate rest (he felt that this was the hardest item on the list); (b) regularly exercise to maintain physical health; (c) eat a healthy diet; (d) have a sense of humor; and (e) arrange for respite from the rigors of caregiving. While it may seem impossible to do all of these things, he said that it is as necessary to care for the caregiver as it is to care for a loved one.

His partial solution was to hire some substitute caregivers, which proved to be a challenging task. In his experience, some of them were very good; others were not good. Only through a process of trial and error was he able to find good helpers who were compatible with his wife. He also recommended that people use respite services. He felt that it is easiest for caregivers to feel comfortable with respite when the person watching their loved one is trusted and qualified. But, Mr. Showers acknowledged that it is costly to use this service, and transportation must be available.

His most difficult decision came with the recognition that he could no longer care for his wife, and the need to put his wife in a nursing home. He spent most of a year researching locations and finding one that was qualified.

Mr. Showers said that there are many resources and knowledgeable people to help but caregivers need to reach out and ask for help. He said that there are many chronic disease associations, faith-based support groups, and other provider associations that can help.

While he was initially resistant to joining an Alzheimer's support group, he was asked to speak at one and he never missed a meeting after that. Soon afterward, he was diagnosed with prostate cancer. He wanted to join a support group but could not find a useful group so he started his own group. The group still meets at the Arlington VA hospital, and he still manages and leads it.

He concluded by saying that the most important point to take home is the need to put caregiver well-being and health first. In his words, "you cannot be a good caregiver if you don't take care of yourself."

Ms. Katryna Gould began serving as a caregiver in 1990. Since that time, she has taken care of her mother-in-law and then of her two parents, while also being a mother to her young son. She described herself as the "resident manager" of a multi-generational housing unit. When her mother-in-law moved in, she realized that her mother-in-law needed some social interaction so she signed her up for Adult Day Care services in the DC area. She also went to a caregiver support group herself, where she found that 1.5 hours/week of interaction with other caregivers was a great help. At that time, however, she declined additional help from a social worker.

As her mother-in-law declined, however, Katrina realized that she needed more services and support and she called the social worker. From the social worker she learned not to feel ashamed to ask for help. The social worker reminded her that in her former career she was not expected to be an expert at everything; so too as a caregiver she should not be expected to know everything about caregiving. Instead, she should leave that to the experts and to ask for advice. Katryna said that was among the best advice she received.

Her mother-in-law died peacefully at home after a period of gradually failing health. Soon after, however, her parents were stricken with debilitating illnesses. After a hospitalization due to a fall, her dad was diagnosed with terminal pancreatic cancer and died 13 days later. He mother began soon afterward to slow down and was diagnosed with dementia. She moved in with Katryna, and later, to a rehabilitation facility, with Katryna then becoming a long-distance caregiver. Her mom's health improved and she moved to the Methodist Home, leaving Katryna with more time on her hands and a chance to experience a degree of freedom. She started walking, but unfortunately she broke her foot in two places from 'overzealous exercise.' Her caregiving responsibilities continue, with her mother having again being hospitalized last week, and then having returned to the Methodist Home.

Katryna concluded by saying that she was unsure what would happen next, but that she has learned to seek balance in her life as wife, mother, daughter, daughter-in-law and caregiver.

Bill Kays took care of his wife when she was afflicted with Alzheimer's disease until she died 2 years ago. He stressed that the importance of the health and wellness of caregivers cannot be overlooked.

He realized that he needed help several years ago, when, one morning, his wife left the house to go to Safeway, just 5 blocks from their home. He had recently retired and he waited home for her. Three hours later, she still was not home. He did not know what to do; if he left the house, he was afraid he might miss the police or others. Eventually, she pulled into the driveway. She stayed in the car. He went out to see what had happened and she said he had gotten lost. They both had a good cry and realized they needed help. Mr. Kays said he must have been in denial because when he called some of his closest friends, with whom they vacationed once each year, his friends said that they had seen his wife's decline for at least 5 years.

Mr. Kays reflected that he and his wife, who were high school sweethearts, planned all of his 34-working years that they would really live their lives once he retired. They never got the chance. So, he suggested that it is best to "enjoy yourself" now rather than waiting until it is too late.

He never told his wife that she had Alzheimer's Disease because he knew that there was no effective treatment and he did not want to upset her. He cared for her at home. His children called him daily and wanted to help but he did not want to worry them so he minimized her condition, and even when she had bad days, he said that everything was fine.

His children knew that he was lying and suggested that he get some help from agencies. Eventually, he called the Alzheimer Association's help line and he joined the support group there. He was told that "everything you are doing is wrong," and it was there that he learned about Adult Day Programs. He put Pearl in one and began looking for a nursing home. The day he put her in a nursing home was the hardest day of his life. He then joked that it hurt him a little after he put her in the home because "she liked it!"

Even so, he feels that placing her in a nursing home "saved my life". He had a heart attack 3 months later, and needed a quadruple by-pass operation. One month later, his son took him to the heart surgeon and asked why the father had the heart attack when he had never had symptoms (nor high blood pressure nor high cholesterol), and the physician said that "caregiver stress got you."

Mr. Kays said that it was really important for him to 'get his problems off his chest' and that the Alzheimer's Association's support group gave him the chance to do this. He said that his life as a caregiver started to improve once he realized that his wife could not help what she was doing. He recommended that all caregivers need to find out what resources are available in their community and to call them for help.

Question 1: to Mr. Showers: "What people did you meet at the Alzheimer's Support Group and how did you learn to care for yourself?"

Answer: At first, I did not want to spend the little free time I had going to meetings. "But, the social worker talked me into going to one meeting, where I was asked to speak about my experiences, so I went. There, I felt something going to the meetings and never missed another one."

Question 2: to Ms. Gould: "What is one thing you did or something that caregivers can do to be rejuvenated or refreshed to take care of themselves."

Answer: Each circumstance is different but it is important to recognize that "you are not alone and you don't need to rely on yourself. There is support in the community that can continue even after the caregiving role ends."

Question 3: to Ms. Gould: "How did you deal with caring for an older relative and your son at the same time?"

Answer: "I lectured my friends; this was hard but I told them 'don't feel sorry for me; support me, and listen, but don't tell me how it feels; let me tell you how it feels!'"

<u>**Question 4**</u>: to Mr. Kays: “Did you know that you had health challenges?”

Answer: Mr. Kays said that he had had a previous heart attack but that it was small and left no residual damage. While he knew he did not have the heart of a marathon runner, he was so preoccupied that he did not notice or acknowledge symptoms like dizziness, etc. He also did not go to the doctor for himself while he was caring for his wife, Pearl. Now, he is on a speaker’s bureau, and is sure to get the word out that caregivers need to get their own health checked out. He said, “what would happen to your loved one if something happened to you [the caregiver]?”

IV John Hoff, Deputy Assistant Secretary, ASPE Introduction of Josephina Carbonell, Assistant Secretary, AoA

Mr. Hoff noted that his mother had been a caregiver for his father, who recently died of Alzheimer’s Disease. He reflected that the qualities noted in Nancy Reagan’s letter--love, devotion, caring, and humor, were displayed by the 3 caregivers who just spoke. He mentioned a few programs to support caregivers such as the Cash and Counseling Program, which was designed to allow consumers to hire their own people (relatives) and given individuals more control. He then introduced Ms. Carbonell.

Ms. Carbonell expressed her thanks to caregivers for their contributions, and added that as she travels around the world, she makes a practice of meeting with caregivers to stay attuned to the issues facing them. She is also a long-distance caregiver so she readily understands many of these issues first-hand. She said that family caregivers are the unsung heros and backbone of our long-term care system.

Ms. Carbonell then described the National family Caregivers Support Program, which is just under 3-years old. In its first full year of implementation, the program reached 3.8 million already and provided information and access to research and programs for these individuals.

She said the key is in getting the word out about services available. Her goal is for there to be access to information and support to seniors and caregivers regardless of income, and flexible services for all individuals in need of help.

Ms. Carbonell also said that health is a key component to caregiving. Health promotion/disease prevention is a cornerstone to the availability of caregivers. Caregivers need to know that they should not neglect their own health.

She said that it is important to sensitize the health system and health care providers as well. These systems and individuals need to promote programs that are effective in reducing disease and disability for caregivers. There is also a need to rebalance the long-term care system locally so that it allows more seniors to remain living independently (or with assistance) at home.

V. Panelist Discussion, moderated by Jonathan Ortmans, of PFI, with input by the Panel

Panelists:

- Richard Schulz, Professor and Director of the Center for Social and Urban Research, U-Pittsburgh;
- Suzanne Mintz, President and CEO of National Caregiver Family Association
- Carol Levine, Director of Families and Health Care Project at the United Hospital Fund, and
- Dr. Margaret Giannini, Director, Office on Disability, and advisor to the Secretary of HHS on assistive technology

Jonathan introduced each of the panelists, and then asked individual panel members to respond to specific questions. The questions and responses follow.

Question 1: "Dr. Schulz, what are some of the health effects of caregiving?"

Answer: Until recently, we knew that emotional problems, such as depression and anxiety, resulted from long-term caregiving, but only recently have we learned that physical health is also compromised. Caregivers are more susceptible to inflections, disease, and when caregiving is accompanied by emotional strain, the odds of dying are increased by 63%.

Question 2: "Ms. Levine, what are the primary sources of stress for caregivers?"

Answer: There are multiple sources of stress. Some are internal to the caregiving role, but many are external. Some external stressors include the amount of time spent on the telephone fighting with insurance companies, working out transportation for the care recipient. The biggest stressor is never knowing what challenge will come next from caregiving. There is chronic stress, which does not end while you are serving as a caregiver.

Question 3: "Dr. Giannini: what are some of the assistive technologies that may be used to help relieve stress?"

Answer: The goal of these devices is to provide more time for caregivers for themselves. Several devices have been developed to help reduce stress, such as special lifts and vans to help care recipients get into cars; and environmental supports in the home. Dr. Giannini also advocated that more women to go to the physician when they had symptoms of fatigue, which is a normal symptom for many caregivers. She said that heart attack symptoms, including fatigue, are different for women than men, and it is important for caregivers not to just think that they are tired. "Soft signs, such as fatigue, could be triggers of heart disease."

<u>Question 4</u>: " Ms. Mintz, what are other sources of stress, especially some financial challenges, facing caregivers?"

Answer: So many things that care recipients need are not covered by insurance, including special transportation (vans) to take care recipients to the doctors, and adult diapers (which cost her $1,800 per year). Ms. Mintz said that caregivers spend 11% out-of-pocket for services not covered by Medicare, and that a family with a disabled member had expenses 2 ½ times higher than those of a family without a disabled member.

<u>Question 5</u>: "Ms. Levine, why don't caregivers take better care of themselves?"

Answer: There are both practical and emotional reasons for this. Some reasons are: the lack of time; the money involved (particularly as many caregivers leave their jobs, lose their health insurance, and then do not want to pay out-of-pocket to visit a physician); the general attitude that "nothing I feel compares to what my husband/mother/father, etc is going through (i.e., the caregiver's needs seem insignificant); depression, which causes many caregivers to take action for themselves; and denial ("maybe I don't want to find out if I am sick").

<u>Question 6</u>: "Ms. Mintz, because many caregivers do not self-identify as 'caregivers', how can we reach them?"

Answer: The term "informal caregivers" is considered pejorative by most caregivers. Similarly, the word "caregiver" is thought to mean a formal caregiver by the caregiving community. Ms. Mintz thinks that caregivers prefer the term "family caregiver" since this term suggests an emotional bond between the caregiver and care recipient. Ms. Mintz suggested that in order to better reach caregivers, we need to provide better care coordination.

Dr. Schulz also suggested that system changes be made. For example, when caregivers take their relatives to the doctor, there is an opportunity for physicians to view both individuals as patients and to identify when "caregivers may be getting into trouble". He suggested that both units in the dyad be considered by the physician and offered help.

Dr. Giannini also stated that there is not enough training provided for caregivers. While some training programs exist, she said that they are voluntary. We need to increase the amount of education available to caregivers. As of now, most caregivers rely on other caregivers for help. They need an infrastructure to support them and provide immediate help.

Ms. Levine said that doctors also need to receive training to be more sensitive and to identify unstated problems among caregivers. She said that when she went to the doctor with her own hip problems, "there was a lot more going on with her" than just her hip. Although Ms. Levine did not mention any of her other health concerns, it would have been helpful had her physician been sensitive to her caregiving challenges and health needs, and offered more help. Ms. Levine hoped that the AoA-funded Making the Link program, which is designed to link both the caregiver and the care recipient to the medical care and AAA-networks, would help in this regard.

Question 7: Assistant Secretary Carbonell, what advice do you have for caregivers?"

Answer: First, get information ahead of time. Do not wait until you are in a crisis to obtain this information. Second, use the 800 toll-free lines for the Eldercare Locator in your area. The 800 (toll-free) number is 1-800-677-1116. Third, get immunized and obtain routine screenings. Fourth, do something for yourself. Fifth, do not try to do it all yourself (she suggested that some physicians are prescribing respite for caregivers to encourage them to take time off); Sixth, watch your diet and do not skip meals; Seventh; take time out for physical activity (including gardening and other home-based activity); Eighth, make sure that if you take medications, you take them on time; and ninth, if you are depressed, seek help.

Ms. Carbonell said that it is critically important for caregivers to know what services are out there. AoA is currently pilot testing a new concept where people will have 'one-stop shopping' and obtain all of their long-term care needs through Resource Coordinating Centers.

Question 8: "Ms. Mintz, what can we do to promote quality respite care?"

Answer: It is the primary thing that all caregivers want. Ms. Mintz recommended passing the Lifespan Respite Act to enhance programs that are already out there.

Carol Levine said that she agrees with Ms. Mintz but wants people to know that respite is not a panacea. First, respite services must be of a high quality for caregivers to be able to relax with leaving family members in their care, and assuring this quality can be difficult. Also, people will come home from their break and have to deal with the current pressing challenges of caregiving. So, while respite is very important, it will not 'fix things' for caregivers.

Dr. Giannini said that one of the weakest links right now is the poor training provided to respite providers. Since most of these individuals have no relation to the care recipients or caregivers, they generally do not feel confident about the care. We need caregivers to feel comfortable saying "others can do this too." If caregivers gain the confidence of respite providers, they will be more likely to use these services.

Question 9: "Dr. Schulz, what are some of the lessons learned from intervention studies?"

We have learned that consumer-directed care can be cost-effective (through the Cash and Counseling demonstration); but there is no one magic bullet that will solve the problem for all caregivers. Caregiving is a multi-dimensional challenge over time. We need to tap into caregivers where they are at a particular moment in time. One thing that Dr. Schulz has found useful is the development of a risk appraisal system that tracks and monitors caregivers' health, self-care, social support, and other factors over time. Interventions are then developed for each caregiver to target areas identified as at risk for that individual (this is the focus of the REACH II intervention).

Question 10: “Secretary Carbonell, looking ahead, what are some projected trends for the future?”

The Administration on Aging is building on the research and best science available at the community level in order to respond to the challenges of our time. AoA and HHS are taking the lead by providing information on-line (through Medicare.gov and other websites) and by providing resource centers for one-stop shopping. Given that the number of older people needing assistance will rapidly increase with the aging of the baby boom generation, HHS is testing strategies now so that they can meet the increased needs for caregivers.

Among the steps being taken are the: (a) increase in access to information and resources through the AoA Resource Centers; (b) development of best evidence-based science tested in the community settings (through awards from AoA and NCOA), (c) increase in medical professional training (through programs like the Making the Link project); (d) increase in education for Certified Nursing Assistants; (e) increase in preventive services covered by Medicare (she hopes that there will be opportunities to increase the number of prevention services covered by this new legislation); (f) efforts to provide additional transportation services to better support families; and (g) increase in the number of options for families.

Ms. Carbonell knows that 71% of all money spent on older persons currently is spent in the nursing home setting. Since most families want their relatives to remain at home, Ms. Carbonell feels that we need to rebalance the long-term care system and provide an infrastructure that supports family caregivers at home. She said that the ultimate goal of these efforts is to improve the lives of older Americans while supporting their families.

Question 11: “Finally, we have one last question for each of the panelists. If you could add one item to the wish list (one policy or program) to support caregivers, what would it be?”

Ms. Mintz: I would start with the health care system. We need to reform our health care system so that it recognizes that chronic care is different from acute care. In order to better serve patients and their families, we need to provide a system that balances chronic care with acute care and recognizes the differences between them.

Ms. Levine: I would work on improving the transitions from the hospital or short-term rehabilitation to the home. We say that we provide “safe and adequate discharges” but this is not done well. Ms. Levine would like HHS, CMS, and other agencies to focus on how to conduct a safe and adequate discharge, with the involvement and input of the family.

Dr. Schulz: As a researcher and policy person, the issue of quality of care provided by caregivers needs some attention. We need to enhance and monitor the quality of care provided by caregivers.

Dr. Giannini: We recognize the gaps in the system now. We hope and will test whether the New Freedom Initiative introduced by this administration also will provide necessary community-integrated services to caregivers. Her personal (non HHS) wish list item is to enhance the training provided to formal caregivers so that will can develop a qualified cadre of formal caregivers in the workforce.

VI. Josephina Carbonell
Brief Closing Remarks

"Our work has just begun!"

Related Links

- ➔ Event Overview (http://aspe.hhs.gov/daltcp/CaregiverEvent/overview.pdf)
- ➔ Event Agenda (http://aspe.hhs.gov/daltcp/CaregiverEvent/agenda.pdf)
- ➔ A Special Letter from Mrs. Nancy Reagan to Family Caregivers (http://aspe.hhs.gov/daltcp/CaregiverEvent/letter.pdf)
- ➔ One-Page Fact Sheet on Family Caregivers (http://aspe.hhs.gov/daltcp/CaregiverEvent/factsheet.pdf)
- ➔ Frequently Asked Questions concerning Family Caregiving (http://aspe.hhs.gov/daltcp/CaregiverEvent/faq.pdf)
- ➔ An Overview of Programs and Initiatives Sponsored by DHHS to Promote Healthy Aging: A Background Paper for the Blueprint on Aging for the 21st Century Technical Advisory Group (TAG) Meeting (http://aspe.hhs.gov/daltcp/CaregiverEvent/programs.pdf)
- ➔ A Compendium of Intervention and Descriptive Studies Designed to Promote the Health of Caregivers for Older Adults (http://aspe.hhs.gov/daltcp/CaregiverEvent/compendium.pdf)

NOTE: HTML versions of all Caregiver Event material is also available from http://aspe.hhs.gov/daltcp/reports-e.shtml#DALTCP5, or Hard Copies can be mailed to you by emailing your request to webmaster.DALTCP@hhs.gov.