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CDC Seeks to Protect Health of Family Caregivers

Did you know...

- ✓ More than 34 million unpaid caregivers are providing care to someone age 18 and older who is ill or has a disability (AARP, 2008).
- ✓ For Alzheimer's disease alone, there are an estimated 9.8 million caregivers providing 8.4 billion hours of care each year (Alzheimer's Association, 2008).
- ✓ An estimated 21% of households in the United States are impacted by caregiving responsibilities (NAC, 2004).
- ✓ Half (53%) of caregivers who said their health had gotten worse due to caregiving also said the decline in their health has affected their ability to provide care (NAC, 2006).

Unpaid caregivers provide an estimated 90% of the long-term care (LTC) provided at home and fill an important role for their families and provide cost savings to the nation (IOM, 2008). Most of these caregivers are caring for someone age 50 and older, and many caregivers are older adults themselves. The average caregiver provides 20-25 hours of assistance per week, according to the National Alliance for Caregiving (NAC), a non-profit coalition of national organizations focusing on family caregiving issues. Many caregivers provide far more hours of care.

"Old age" was the most common reason given for caregiving needs for older adults, according to a survey of 1,247 caregivers in the United States (NAC, 2004). About 15% of caregivers gave "old age" as the reason for their caregiving. Other conditions that were cited as reasons for needing to care for someone age 50 and older were: cancer (9%), diabetes (9%), heart disease (9%), Alzheimer's (8%), stroke (6%), mobility limitations (6%), arthritis (5%), mental illness (3%), and vision problems (3%). For caregiver of younger adults, mental illness was the most common reason (23%) cited for the need for assistance.

While unpaid caregivers often say they get satisfaction from their efforts, caregiving can be stressful and burdensome and can contribute to depression and eventually to negative health effects for the caregiver, according to researcher Richard Schulz, PhD, Professor of Psychiatry at the University of Pittsburgh School of Medicine.

In addition to the stress or strain that caregivers face, they often avoid getting routine care for their own health and may have an impaired ability to recover from an illness, said John Crews, DPA, an epidemiologist at the U.S. Centers for Disease Control and Prevention (CDC). A decline in the caregiver's health often leads to institutionalization of the care recipient. The chronic health impact of caregiving on health may last longer than the caregiving itself.

While caregiving is primarily a family concern, society has a vested interest in keeping these caregivers healthy, effective, and able to continue their caregiving duties. Experts estimate that the economic value of family caregivers' unpaid contributions was approximately \$375 billion in 2007—more than the \$311 billion in total Medicaid expenditures for that year (AARP, 2008).

“Most people think of LTC as something that happens in nursing homes, assisted living facilities, other types of professional facilities, or through aging network services[such as senior centers, local agencies on aging], when in fact most of LTC is done in the home, by the family member, untrained, and unsupported,” said Carol Levine, Director of the Families and Health Care Project for the United Hospital Fund in New York City. “If the family caregivers are not able to carry out this function, then there will be an incredible drain on the formal caregiving system. So there is a very strong interest that is benevolent, but also pragmatic, that we have to keep these caregivers on the job, or we are going to be in very big trouble,” Levine said.

“If you are in poor health yourself and trying to provide care to your spouse, for instance, that is not going to be a very good situation and you may end up with two patients instead of one,” according to Lynn Friss Feinberg, deputy director of the Family Caregiver Alliance (FCA), a community-based nonprofit organization. In addition, “For anyone doing personal care, for example, if you are not healthy, then quality of care would most likely be compromised.”

“Family caregivers are pretty heroic in terms of what they do,” said Crews. “But the way we've fashioned long-term care is that we wear caregivers out and then put the care recipient into a nursing home when the caregiver becomes exhausted and can't take another step.”

“Our awareness of caregiving as a critical public health issue is growing, especially as the U.S. population continues to age and as dementia-associated health, economic, and societal challenges become even more pronounced,” said Janet Collins, PhD, Director of the National Center for Chronic Disease Prevention and Health Promotion at the Centers for Disease Control and Prevention.

All of these factors make caregiving a major public health issue. Most caregiver support has traditionally focused on emotional or social support for caregivers, and those are indeed important, but there is an important role for the public health system to play in maintaining the health of caregivers and encouraging them to maintain preventive health activities.

WHO ARE THE CAREGIVERS?

These unpaid caregivers—who are also referred to as informal or family caregivers because they work outside of the formal professional caregiving field—are relatives, friends, or neighbors who provide assistance to someone else due to that person’s physical or mental limitations. The typical caregiver is a 46-year-old woman who has a job and spends more than 20 hours a week taking care of her mother, according to a survey conducted by NAC and AARP (NAC, 2004).

There are about 34 million informal caregivers providing care at any given point in time, and 52 million providing care at some time during the year (AARP, 2008).

The need for family caregivers has increased with the health care system’s trend toward shorter hospital stays, medical advances that allow for complex home care, and the shortage of nurses and paraprofessional workers.

One study found that, among older adults age 65 and older with disabilities, the percentage of care recipients relying on informal caregivers rose from 57% in 1994 to 66% in 1999 (Spillman, 2005).

Family caregivers may be less available in the future as more women enter the workforce, generations of a family may live further apart, families have fewer children to support them in their old age, and caregivers themselves are getting older. For example, one study found that the proportion of spousal caregivers who are age 75 and older rose from 38% in 1989 to 47% in 1999 (Wolff, 2006).

WHAT CAREGIVERS DO

Caregivers may be providing around-the-clock care, be unable to leave the care recipient alone, and may be dealing with their own chronic illness or depression.

The U.S. Department of Health and Human Services’ (HHS) National Long Term Care Survey and Informal Caregivers Survey found that caregivers commonly assist with household management, bill paying, shopping and meal preparation, chores and repairs, and many other aspects of a frail older adult’s life. These are known as Instrumental Activities of Daily Living or IADLs. Caregivers may also transport the care recipient to the physician, provide information on the patient’s medical history, listen to the clinician’s assessment, write down instructions for the patient, help make decisions about the patient’s care, and administer medications.

Other caregivers provide more hands-on care, assisting an older adult with Activities of Daily Living (ADLs), such as bathing, eating, dressing, and toileting, especially for patients with Alzheimer’s disease and other dementias. There is a dearth of programs to help prepare informal caregivers for the work entailed in caregiving. Therefore, most of these caregivers have not been trained on how to properly lift, turn, dress, or feed someone who needs assistance with ADLs. There also is little training available to

help those caregivers who provide more medically intensive caregiving, including cleaning ventilator tubes, changing catheter bags, changing bandages, administering IV medications, etc.

A recent report on the health care workforce issued by a committee of the esteemed Institute of Medicine (IOM) recommended more opportunities for training informal caregivers to improve the care received by older adults and also ease the strain on informal caregivers, who often feel unprepared for the tasks they are required to perform (IOM, 2008). The IOM committee's report called on public, private, and community organizations to work to ensure adequate training is available in the community for informal caregivers (IOM, 2008).

"We recognize that not all caregivers have the same challenges, or respond in the same way, that there is a very individualized response," said Richard Birkel, PhD, Executive Director of the Rosalynn Carter Institute for Caregiving.

IMPACT ON CAREGIVER HEALTH

"Caregivers are at risk for a whole host of ill effects, and the research is pretty clear about that. We see rates of 30-40% of clinical depression among Alzheimer's disease caregivers." — Richard Birkel

Caregivers often have or develop their own health problems during the course of caregiving (Schulz, 1995). Evidence gathered over the last two decades on the health effects of caregiving has helped convince policymakers that caregiving is a major public health issue, according to Schulz. He noted that researchers use caregiving as a model for studying the health effects of chronic stress. The health impacts include the very real risk of the caregiver becoming a "patient" themselves, due to the physical and mental health effects of caregiving (Reinhard, 2008).

"There is a large body of evidence to show that caregiving has negative impacts on mental health, particularly depression," Feinberg said. "It is really the emotional and mental health effects that are most severe for caregivers, but there are also physical health effects that are severe as well," Feinberg explained. "There are a number of studies that show elevated blood pressure among caregivers of older family members with chronic conditions, lowered immunity, back pain from trying to turn someone who has had a stroke. The health effect on families is quite profound," she added.

The negative health effects "are a result of long-term exposure to the suffering of someone close to you," Schulz explained. Caregiver depression "is driven not only by the work of care, but also by the fact that you are in daily contact with someone who is depressed, disabled, and feeling they are a burden to others. It is that exposure to the suffering of somebody close to you that contributes to your own suffering. That is one of the factors that we haven't paid a lot of attention to."

Research indicates that prolonged distress, the physical demands of caregiving, the sense of loss in watching a loved one suffer, and the fragility of older caregivers often affects their physiological

functioning and increases their risk for physical health problems, leading to increased mortality (Schulz, 1999). A study of older spousal caregivers found that those who reported caregiver stress had a 63% higher mortality rate than noncaregivers of the same age (Schulz, 1999).

Self-Reported Health. NAC conducted caregiver surveys in 1997, 2004, and 2006, with funding from the Metlife Foundation and other sources. NAC added the questions about caregiver health to its recent survey at the suggestion of CDC, according to Gail Gibson Hunt, NAC's President and CEO. "The CDC was influential in getting us to collect those data," Hunt said. The NAC surveys have found a wide range of reported health effects but clearly caregivers who provided more intense levels of care, such as assisting with ADLs, had more negative health outcomes.

Many surveyed caregivers reported that they have at least good physical health—25% said their health is excellent, 30% said it is very good, and 28% said it is good (NAC, 2004). However, 17% reported their health as fair or poor, compared to 9% of the population as a whole. Among those doing the most intense caregiving, 35% said they have fair or poor health, NAC found.

More than one-third (35%) of surveyed caregivers reported emotional stress, yet 27% said caregiving was not stressful.

The highest level of strain is reported by caregivers who are in poorer health, perform a more-intense level of caregiving, or feel that they had no choice in becoming caregivers (NAC, 2004). Factors contributing to emotional stress include the caregivers' own reported health, being a woman, and living in the same household with the care recipient.

Self-Care. Although there are only a few studies looking at the link between caregiving intensity and the caregiver's self-care, researchers have found evidence of caregivers neglecting their own health care appointments and eating a poor-quality diet when they are providing assistance with ADL activities such as toileting and eating (Burton, 2003).

Caregivers often lack the time and energy to prepare proper meals or exercise, NAC said in its 2006 survey. Caregivers also frequently have interrupted sleep, especially for those taking care of dementia patients who may wander or have other needs in the night. These declines in good eating, exercise, and sleep habits are more prevalent among caregivers who do the most intense caregiving or spend the most time caregiving. Self-care habits also decline among caregivers who said their health was worse.

Among those reporting that their health was in decline, the 2006 NAC survey found:

- 82% said their sleeping is worse than before they were caregivers
- 72% did not go the doctor as often as they should since they began providing care
- 63% said their eating habits are worse
- 58% said their exercise habits are worse

- 52% did at least one less preventive care practice than they used to, such as getting their teeth cleaned, vision checked, or having a routine medical examine
- 51% were taking more medications as a result of caregiving

The top reasons that surveyed caregivers said they do not go to the doctor is that they put their family's needs first (67% said that is a major reason), or they put the care recipient's needs over their own (57%). More than half (51%) said they do not have time to take care of themselves and almost half (49%) said they are too tired to do so.

Positive Aspects of Caregiving. There is emerging research on some positive effects of caregiving. Schulz and his research team found in large population-based samples that about one-third of caregivers report neither strain nor negative health effects, especially in the early stages of caregiving (Schulz, 1999). Caregivers report positive outcomes such as feeling important, learning new skills, and feeling that they are contributing something to someone else's life. "Paradoxically, what you often see is that caregivers who are the most distressed are also the ones who report these benefits," Schulz said.

"In the early stage of a caregiving experience, to the extent that you perceive yourself as doing something to alleviate the suffering of the person you are caring for, it makes you feel good, feel positive about yourself and what you are able to do for others," Schulz said. However, it is difficult over time to maintain that state. "Eventually you run into the situation where you are no longer effective as a caregiver, where you are no longer able to address the difficulties and the challenges that you are facing." This is an important distinction for future research to look at, he said.

Other Impacts on Caregivers. The 2004 survey by NAC found that caregivers report that they have difficulty finding time for one's self (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%). About 30% said they need help keeping the person they care for safe and 27% would like to find easy activities to do with the person they care for.

In addition to health impacts, caregivers may spend their own money to take care of the care recipient, have to cut back on work hours or quit their job altogether, which means they may lose income or their health insurance and reduce their retirement savings and Social Security benefits (AARP, 2008). The out-of-pocket costs for caregivers who are caring for someone who was age 50 or older averaged \$5,531 in 2007, AARP estimates. About 37% of caregivers for someone age 50 and older reduced their work hours or quit their job in 2007 (AARP, 2008).

SUPPORTING CAREGIVERS

NAC urges caregivers to take breaks from caregiving; to take care of their own health and well-being through good diet, exercise, and preventive health habits; and to join a support group.

Encouraging a caregiver to be proactive with their own health care should be based on more than urging them to stay healthy so they can continue to take care of the care recipient, Levine said. People would take better care of themselves if they felt valued for their own abilities and personalities, not just based on what they provide to other people, Levine said. “Caregivers tend to develop the attitude that, ‘I’m only here to take care of Mom’.” But, Levine said, “Caregivers need to develop their own sense of independent existence, to recognize that there will be a life after caregiving, and that they will want to have as good health as possible,” Levine said.

“Those are not the kinds of messages that I think are out there in the public health or in the caregiving world,” Levine said. “It is an incredibly important subject and I think that it is important that the public health community is looking at this as an issue. CDC has certainly played a major role in that, but it has to come down to the clinical settings and community support as well, so there is a general understanding that this is important and we can play a part in making it better for caregivers.”

One good measure of how well caregivers take care of themselves is whether they are engaging in preventive health activities, such as an annual physician visit, mammograms for women, and flu shots. Caregivers have difficulty finding time to go to their doctor’s office. “This is a huge challenge,” Feinberg said. “When we make home visits, we use a structured caregiver assessment tool. We ask ‘Have you been to see your doctor in the past six months?’ Most caregivers do not get asked that question, because we are so focused on the care recipient instead of the caregiver. So that is an example of a public health approach, to make sure that the caregiver gets care.”

Helping Caregivers Cope. About 73% of surveyed caregivers said praying helps them cope with caregiving stress, 61% said that they talk with or seek advice from friends or relatives, and 44% read about caregiving in books or other materials (NAC, 2004).

Many caregivers also need professional assessment, training, and respite. Attendees at a consensus development conference hosted by FCA concluded that few home and community-based services assess caregiver well-being and the need for support (FCA, 2006). They concluded that a good assessment program should look at the caregiver and the care recipient as a whole, should result in a plan of care that is periodically updated, should include cultural competency, and should be covered by government and third-party payers as part of care for older adults.

The IOM committee recommended that health care providers, community groups, and other public and private entities make training available for informal caregivers on providing care and alleviating stress (IOM, 2008).

Respite services give the caregiver a break by providing someone to stay with the care recipient for a brief period of time, or allowing the care recipient to stay a few hours in an adult day care program or a few days in a nursing home.

Some of these caregiver services are offered under the Older Americans Act's National Family Caregiver Support Program (NFCSP), established in November 2000. The NFCSP provides support for states, area agencies on aging, community service providers, and tribes to provide a continuum of caregiver services, including information, assistance, individual counseling, support groups, training, respite, and supplemental services. Funding is distributed to states by the U.S. Administration on Aging (AoA). Priority must be given to low-income people and those with the greatest social and economic need, and older adults caring for persons with severe disabilities, including children with severe disabilities. The NFCSP has served more than 2 million caregivers nationwide.

The NFCSP has been "extremely successful," commented Rick Greene, who directed the program at AoA before going on a temporary assignment to the Department of Veterans Affairs. Prior to the NFCSP, only a few states had caregiver programs, Greene said. "Now there is a program in every state."

Under Medicaid's home and community-based care program, states can apply for waivers to provide respite care, training, and family counseling for caregivers. States also can elect to offer the Program of All-Inclusive Care for the Elderly (PACE), which provides comprehensive services for frail elders and may include caregiver services and respite in the care plan. PACE is a permanent part of the Medicare program. There were 61 PACE programs operational in 29 states in 2008, according to the National PACE Association.

The Medicare program can cover respite care through the hospice benefit. In 2006, Centers for Medicare and Medicaid Services (CMS) launched a demonstration program on Medical Adult Day Care Services that provides respite to caregivers while the care recipient attends adult day care. Medicare also has a web site (www.medicare.gov/Caregivers/) providing information for caregivers on how to access and navigate the Medicare system. "We are trying to help people understand how to help their loved one, friend, family member or spouse to access and better use the benefits they are entitled to," explained Susie Butler, Director of the Division of Provider Affairs, who is leading the caregiver effort for the CMS.

The Department of Veterans Affairs has a pilot program for caregiver assistance to improve health care education and provide needed training and resources for caregivers who assist disabled and aging veterans in their homes. Last year it provided \$4.7 million for these services.

Caregivers can also receive assistance from hospital discharge planners, the national Eldercare Locator service (800-677-1116, www.eldercare.gov) that connects users with local aging services, respite care services, stress reduction programs, and help from family, friends, and the community.

Special Groups of Caregivers. Caregiver support systems must be prepared to address different groups of caregivers. Male caregivers, and some ethnic caregivers, may view asking for help as a sign of

weakness and may not be comfortable in support groups. Rural caregivers may not be aware of services if they exist, or may be unable to travel to them. Caregivers of persons with dementia may simply be unable to leave the care recipient for even a minute. “For dementia caregiving, interventions that focus on information, support, and self-efficacy lead to lower depression in the caregiver, lower burden, and lower perception by the caregiver that the person has problem behaviors,” explained Katie Maslow, MSW, Associate Director for Quality Care Advocacy at the Alzheimer’s Association.

Selecting Interventions. “Not all caregivers require the most intense interventions,” Birkel said. “Some interventions are expensive and time-consuming and should be reserved for the caregivers with the most intense needs. In addition, the requirements for staff training and knowledge may be more advanced than what agencies typical have,” he said.

The Rosalynn Carter Institute for Caregiving is looking for ways to match a caregiver’s risk with interventions that will provide the most benefit. A literature review by its Evidence-Based Caregiver Intervention Resource Center found that there have been 60 randomized controlled studies—the gold standard for research—of various caregiver interventions. “No one realized the volume of research because most of the work was done in silos,” Birkel explained. “There was research on support for caregivers of someone with Alzheimer’s disease, research on cancer caregivers and stroke caregivers, but these researchers had never met.” While there are some unique sources of caregiver strain related to the type of caregiving they are doing, looking at the various research studies revealed many similarities in how to address caregiver needs, he said.

There are numerous programs that focus, for example, on caregivers of persons with dementia—who generally provide the most intense level of care. Dementia caregiver programs include the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) program that provides education and support to family caregivers in their own homes; the New York University Caregiver Intervention that counsels and supports spousal caregivers of persons with Alzheimer’s disease to improve the well-being of caregivers; the Environmental Skill-Building Program (ESP), which focuses on the home environment; and the Savvy Caregiver program, which teaches Alzheimer caregivers to think about their situation objectively and obtain the knowledge, skills, and attitudes they need to manage stress and carry out the caregiving role effectively.

“There are interventions with strong evidence-bases available to support a variety of needs and challenges that caregivers encounter,” said Lisa McGuire, PhD, Health Scientist in CDC’s Healthy Aging Program. “Some include facets to support not only the well-being but also the health of the caregivers and subsequently the care recipient. We should not only applaud the programs recognizing the importance of health but also encourage all interventions to include a health promotion component. One of the challenges for public health is finding strategies to link caregivers to preventive services that will keep

them at their highest level of functioning. This will help to ensure that caregivers have the best health outcomes possible under the circumstances.”

Similarities among these dementia care programs are that they focus on behavioral disturbances of the person with dementia, try to make the physical environment less risky, teach the caregiver to problem-solve, and break problems down into small parts that can be accomplished, explained Louis Burgio, PhD, Harold R. Johnson Professor of Social Work at the University of Michigan.

Funding Caregiver Support. Once the public health system figures out how to match a particular intervention with an individual caregiver, the next challenge is to find ways to sustain caregiver support programs once they have left the research laboratory. “We need to take these clinically proven interventions and put them in a community setting without the grant funding that got them through the clinical trial stage,” Birkel said. While setting up these programs may be initially expensive, in the long run, “there are great cost savings, because of the high cost of caregiver ill health,” he pointed out.

As part of a study of the ESP program, the Rosalynn Carter Institute for Caregiving is funding occupational therapists, who are working with Medicare Part B patients, to provide training for the family caregivers as well. The institute also is funding work with the REACH II caregiver support program in hospitals and the aging services network, and implementation of the NYU Caregiver program in a primary health care setting and in a Medicaid managed care environment. “We really are trying to determine which systems are best suited to support caregiver programs and to figure out how to overcome institutional and funding barriers,” Birkel said.

Getting to Care. Physicians and health care providers can also play a role in reaching caregivers. The NAC survey found that caregivers turn most often to their own doctors (28%) and the Internet for information (29%). Yet, 22% of caregivers said they need help talking with doctors and other healthcare professionals. Some 20% also want help with end-of-life decisions.

“The physician needs to be proactive and ask patients if they are caregivers,” Levine suggested. The family caregiver can take the initiative if the physician does not ask and volunteer that they are taking care of someone and that may be why they are feeling so tired, Levine said. Staff in a physician’s office could also identify caregivers and flag them for the doctor’s attention.

Churches, senior centers, and community organizations also could be part of public health awareness campaigns to urge caregivers to take care of their health and access preventive health services, Levine said.

CDC’S ROLE

“There is growing awareness about the importance of caregiving across CDC’s programs addressing issues such as aging, cancer, disability, heart disease, and injury,” according to Lynda

Anderson, PhD, Director of the Healthy Aging Program in CDC's Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion. "At the same time, there are increasing concerns about caregivers' physical and emotional health and a recognition of the need to identify programs that ensure that caregivers emerge from these responsibilities in the best health possible."

"The question is how to create a systems approach that encourages caregivers to get access to health care, to take care of their own health, and find support, so that they don't just wear their health out," Crews said.

CDC's Healthy Aging Program in partnership with Kimberly-Clark Corporation developed a monograph, *Assuring Healthy Caregivers, A Public Health Approach to Translating Research into Practice: The RE-AIM Framework*, an effort to provide a framework to better understand how to promote the translation of evidence-based programs and policy for caregivers into public health practice (CDC, 2008). As a follow-up to that monograph, CDC is developing a "how to" guide for area agencies on aging, churches, senior centers, and other entities, to highlight what they might need to consider when deciding to implement a caregiving intervention.

BRFSS. The heart of public health data collection is the Behavioral Risk Factor Surveillance System (BRFSS). BRFSS is the largest ongoing state-based telephone survey in the world that gathers state-level data on the leading causes of morbidity and mortality related to chronic disease. This information is used to track ongoing and developing health risks of adults (18+ years old) in the United States. States implement the 12-month survey beginning in January of each year, and the data is made available to the public by the following spring, in what Crews described as an "incredible turn around." The survey collects information about topics such as health risk behaviors, clinical preventive practices, and health care access and use. There is a basic set of questions, called the "core," used by all states, the District of Columbia, and three territories. States can then choose to add approved optional modules to their BRFSS survey and additional questions of relevance to the state.

In 2000, two questions about caregivers were added to the basic BRFSS administered by all states and the District of Columbia. The questions asked whether someone provided regular care or assistance to a person 60 years old or older and who they would contact about arranging short-term or long-term care for someone.

CDC supported the University of Florida in 2004 to develop an expanded caregiver module to collect data on the characteristics of caregivers. Since then, the set of caregiver questions were pilot tested in North Carolina in 2005. Pilots have also been conducted in several other states, including Florida, Hawaii, Kansas, and Washington. In 2009, one question from the module is being asked as part of an emerging core. The rest of the module, which consists of nine additional questions, is now available for

adoption by all states and is being rolled out in the BRFSS for Illinois, Minnesota and New York. The module addresses the age and gender of the care recipient; the relationship between the caregiver and the care recipient; the duration of caregiving; the major health problem, long-term illness, or disability of the care recipient; the types of assistance needed by the care recipient; the average hours of caregiving per week; the most difficult problem facing the caregiver; and whether the person has had more difficulty with thinking or remembering in the past year. Response from the optional module can then be paired with information from the core BRFSS to learn about many currently unknown facets of the health and well-being of caregivers.

“The BRFSS optional module on caregivers can provide information at the national, state, and local levels that otherwise may not be available,” McGuire explained. “For example, we will have information available on a variety of modifiable health risk behaviors, preventive services, chronic health conditions, and mental health of caregivers.”

“When that information comes out, I think that other states will see the value and want to use the module,” Maslow said. “We will use the Washington state data to get our Alzheimer’s chapters excited about getting similar information for their states.”

How States Can Use BRFSS Data. The data from the states can be broken down to the metropolitan and micropolitan statistical areas (MMSA) level. “The caregiver module will allow states to do more specific strategic planning,” Feinberg said. Having good data about caregivers at the local level means that “public health agencies, the aging services network, and caregiver support programs can analyze the data and see what makes most sense in terms of public health response,” she explained. “One outcome could be a state campaign on the importance of taking care of yourself, as a family caregiver.” Examples might be a public awareness campaign encouraging caregivers to go to their doctor or get their blood pressure checked.

“That surveillance is going to make this more real and more understood at the state level, and lower down, and state legislators and policymakers and program directors can start to target interventions to the real need,” Maslow said.

The North Carolina department of aging is working on action plans for programmatic changes to better support caregivers. The department will use the data to document caregiver support needs for state policymakers, said Ronda Talley, PhD, MPH, a health scientist on CDC’s Disability & Health Team. “Having the data puts a little more oomph behind it,” Talley added.

However, state fiscal constraints are slowing down the adoption of the BRFSS caregiver module. “In the short term, I don’t think we are going to see states on the uptake for this, because there is no money,” Feinberg said. She noted that the state of California decided not to do the caregiver module on its

2009 BRFSS, due to severe budget constraints within the state. “But longer term, I think you will see more involvement, and that is a very good thing.”

FUTURE PUBLIC POLICY DIRECTIONS

The IOM committee concluded that the trend toward fewer caregivers—both formal and informal—at a time when the number of older persons is expanding underscores the importance of identifying effective strategies to support informal caregivers. Caregiver supports should include increased training opportunities, more respite opportunities, and the use of technologies that promote greater independent functioning among older adults and reduce their reliance on caregivers (IOM, 2008).

AARP, in its report, “Valuing the Invaluable: The Economic Value of Family Caregiving,” calls for expanding funding for the NFCSP, which received \$166 million in FY 2008. According to AARP, this represents less than one-twentieth of one percent of the economic value of caregivers’ contributions (AARP, 2008).

Research is revealing that caregiver support is not a one-size-fits all. From a public health standpoint, “we need to apply traditional public health thinking to that challenge,” Birkel said. Thus, one layer would involve universal interventions for caregivers, targeted to all members of a community. Activities might include talking to young people in high school about caregiving as a challenge. The next level is targeted interventions that could be illness-specific, such as educational programs just for dementia caregivers. The highest level of support would be to use the indicated intervention, tailored and individualized for a specific need.

Legislatures play an important role. In recent years, 13 state legislatures have passed 16 caregiver support bills. Congress passed the Lifespan Respite Care Act, which was signed into law by President Bush in December 2006 (IOM, 2008). The law will allow states to develop a network of respite care providers, but has not yet received federal funding.

Caregiver support needs to go beyond day-to-day assistance. The IOM committee said systems need to be in place to promote the financial, retirement, and health care security for informal caregivers who leave the workforce to care for an older adult (IOM, 2008).

Health policy changes could reframe both chronic and long-term health care to focus on the entire family instead of the individual. That model has been adopted successfully by the hospice system.

State attorneys general could recognize caregiver training as a way for non-profit hospitals to meet their requirement to provide community benefits, the IOM report suggested (IOM, 2008).

Healthy People 2010 calls for public health surveillance and health promotion programs for persons with disabilities and their caregivers in every state. Another way to increase awareness of these

issues would be to add more health goals for family caregivers to the Healthy People 2020 objectives now being developed by HHS.

The concept of caregiver support itself needs to broaden its scope. Much of the discussion surrounding caregiving has focused on those caring for older adults. But as persons with disabilities live to much older ages, a new cohort of caregivers, for younger persons with disabilities, has emerged. The recent increase in veterans with serious injuries also means more younger adults will need caregivers. At the other end of the spectrum, longevity means that there are now many people in their 70s caring for parents in their 90s. Many experts say caregiving should take a lifespan approach, starting with talking to kids in high school about caregiving and its impact on society.

This document is available online at www.chronicdisease.org. It was written by Nancy Aldrich. William F. Benson was senior editor and project manager.

STORY IDEAS FOR JOURNALISTS

- 1) Gather information on caregiver needs and supports in your area. The National Conference of State Legislatures has a good resource on state data (www.aoa.gov/PROF/aoaprogram/caregiver/careprof/resources/fcs.pdf). Talk with local aging services information and service providers (area agencies on aging, senior centers, local affiliates for advocacy organizations, etc.) and find out what resources are available locally for caregivers. Ask about information services, caregiver training, support groups, respite care, and other types of assistance.
- 2) Contact your state health department officials and find out if they are using the caregiver module on the next BRFSS survey or if they plan to do so at a later time. If it has already used the module, ask what the findings were.
- 3) Interview caregivers and tell their story. See if you can follow a caregiver through a typical day, and report on the positive and negative experiences. Ask caregivers about the benefits of caregiving and write about how it can be beneficial to a family member. Ask about the more subtle aspects of caregiving, like the suffering of the patient and how that affects the caregiver.
- 4) Provide information on resources that caregivers can use (see “Additional Resources” below).

REFERENCES AND RESOURCES

JOURNALS AND REFERENCES CITED:

- AARP, 2008: Houser, A., et al., AARP Public Policy Institute, *Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update*, 2008, www.aarp.org/research/housing-mobility/caregiving/i13_caregiving.html
- Alzheimer’s Association, 2008: Alzheimer’s Association, *2008 Alzheimer’s Disease Facts and Figures*, www.alz.org/national/documents/report_alzfactsfigures2008.pdf
- Burton, 2003: Burton, L., et al., “Transitions in Spousal Caregiving,” *Gerontologist* 2003, 43(2), 230–241, <http://gerontologist.gerontologyjournals.org/cgi/content/abstract/43/2/230>
- CDC, 2008: Centers for Disease Control and Prevention and the Kimberly-Clark Corporation, *Assuring Healthy Caregivers, A Public Health Approach to Translating Research into Practice: The RE-AIM Framework*, 2008, <http://www.cdc.gov/aging/caregiving/index.htm>
- FCA, 2006: Family Caregiver Alliance, *Caregiver Assessment: Principals, Guidelines and Strategies for Change*, Report from a National Consensus Development Conference, held September 7-9, 2005, www.caregiver.org/caregiver/jsp/content/pdfs/v1_consensus.pdf
- IOM, 2008: Institute on Medicine, *Retooling for an Aging America: Building the Health Care Workforce*, April 2008, www.nap.edu/catalog/12089.html

- NAC, 2004: National Alliance for Caregiving/AARP, *Caregiving in the U.S.*, 2004, http://assets.aarp.org/rgcenter/il/us_caregiving_1.pdf
- NAC, 2006: National Alliance for Caregiving, *Evercare Study of Caregivers in Decline*, 2006, www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf
- Reinhard, 2008: Reinhard, S., et al., "State of the Science: Professional Partners Supporting Family Caregivers," *American Journal of Nursing*, 2008, 108(9 Supple.), www.nursingcenter.com/ajnfamilycaregivers
- Schulz, 1995: Schulz, R., et al., "Psychiatric and Physical Morbidity Effects of Dementia Caregiving: Prevalence, Correlates, and Causes," *Gerontologist* 1995, 35: 771-791, <http://gerontologist.gerontologyjournals.org/cgi/content/abstract/35/6/771>
- Schulz, 1999: Schulz, R., et al., "Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study," *JAMA* 1999; 282:2215-2219, <http://jama.ama-assn.org/cgi/content/abstract/282/23/2215>
- Schulz, 2008: Schulz, R., et al., "Physical and Mental Health Effects of Family Caregiving," in Reinhard (see Reinhard, 2008 above), pp. 12-26, www.nursingcenter.com/ajnfamilycaregivers
- Spillman, 2005: Spillman, B., et al., *Staying the Course: Trends in Family Caregiving*, 2005, http://assets.aarp.org/rgcenter/il/2005_17_caregiving.pdf
- Wolff, 2006: Wolff, J., "Caregivers of Frail Elders: Updating a National Profile," *Gerontologist* 2006, 46(3):344-356, <http://gerontologist.gerontologyjournals.org/cgi/content/abstract/46/3/344>

ADDITIONAL RESOURCES:

- AARP Caregiving web site, www.aarp.org/caregiving
- American Red Cross Family Caregiver Program, www.redcross.org/services/hss/care/family.html
- AoA caregiver links, www.aoa.gov/prof/aoaprogram/caregiver/careprof/resources/caregiver_resources.aspx
- AoA National Family Caregiver Support Program Resource Room, www.aoa.gov/prof/aoaprogram/caregiver/caregiver.aspx
- Caregiver Stress Check*, www.alz.org/stresscheck/overview.asp
- Caregiver Tip Sheet*, www.aoa.gov/prof/aoaprogram/caregiver/overview/docs/CaregiverTipSheet.pdf
- Caregivers Count Too! An Online Toolkit to Help Practitioners Assess the Needs of Family Caregivers*, www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1695
- Caregiving in the U.S.*, www.aarp.org/research/reference/publicopinions/aresearch-import-853.html
- Family Caregiver Alliance, www.caregiver.org/
- Family Caregiving*, www.redcross.org/services/hss/care/family.html
- Family Caregiver Support – State Facts at a Glance*, www.aoa.gov/PROF/aoaprogram/caregiver/careprof/resources/fcs.pdf
- Medicare caregiver information, www.medicare.gov/Caregivers/
- National Alliance for Caregiving, www.caregiving.org
- Rosalyn Carter Institute on Caregiving's Evidence-Based Caregiver Intervention Resource Center, www.rosalynncarter.org/dynamic_grid/

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