News from the Trenches: Consumers Speak out on Medicare Needs

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Medicare Rights Center
Consumer Action Board

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Acknowledgments

This report would not have been possible without the dedication and real-life experiences of the Medicare Rights Center's Consumer Action Board (CAB). The experiences of these 52 people with Medicare provide invaluable insight to the staff of the Medicare Rights Center, and their insights should be instructive to the policy makers in the federal government. In addition to the contributions of the CAB members to this report, Ross Kessler and Eva DuGoff, health advocacy fellows at MRC, served as the authors of the report, and MRC Washington director Karen Davenport and communications director Deane Beebe provided helpful comments.

Medicare Rights Center

Medicare Rights Center (MRC) is the nation's largest independent source of health care information and assistance for people with Medicare. Founded in 1989, MRC helps older adults and people with disabilities get high-quality, affordable health care. MRC provides telephone hotline services to individuals who need answers to Medicare questions or help securing coverage and getting the health care they need. MRC brings the consumer voice to the national debate on Medicare reform.

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Executive Summary

The experience of older adults and people with disabilities—the 42 million Americans with Medicare—should be the guiding light as legislators and policy makers debate and change Medicare, a national treasure for nearly 40 years. In this report, the Medicare Rights Center (MRC) turns to the experience and wisdom of its Consumer Action Board (CAB) to highlight consumer concerns with the Medicare program in 2005. The CAB is a national board of people with Medicare who serve as advisers to MRC while playing active advocacy roles in their home communities and states.

In this report, CAB members share their personal and professional experiences on a wide range of issues from the Medicare-approved drug discount cards, transition to Medicare drug coverage, mental health coverage, and wheelchair coverage. Some CAB members draw on their personal experience: "Just about everyone I've spoken to about Medicare is confused and will not know what to do in 2006," says a retired nurse who is a CAB member from New York's Rockland County. "I can be included in that group."

Others speak from both their personal and professional experience in assisting low income people with Medicare: "Our nearest Medicaid office is 60 miles away and Medicaid always tells people to use the toll-free hotline. Even I have trouble getting an answer when I try to call for my clients' questions. It is difficult to imagine what will happen in 2006," says MRC's CAB member from Wichita County, Kansas.

Specifically, this report reviews the major concerns of CAB members—often through direct quotes—to illustrate policy issues, and offers concrete administrative and legislative solutions to bolster the Medicare system that so many Americans know and trust. The Medicare debate is too often dominated by abstract statistics and political ideologies that fail to convey how policy impacts the reality of people's lives, especially the daily struggle with health care. This report focuses on the consumer voice to humanize the statistics and politics driving the Medicare debate.

Over the course of several months CAB members identified six principal issues of concern that people with Medicare face. Each of these issues was identified by Medicare consumers in each of the regions of the United States.

1. Meeting the great unmet need for effective consumer education about the new Medicare drug benefit is a massive challenge given the needlessly complex Medicare prescription drug benefit.
2. Transitioning "dual eligibles"—people with both Medicare and Medicaid—from their current Medicaid benefit to the Medicare Part D prescription drug benefit on January 1, 2006, increasingly looks like a human disaster waiting to happen.
3. Eliminating the 24-month Medicare eligibility waiting period for people with disabilities under age 65 is necessary to avoid the cruel plight of people going without health coverage when they most need assistance due to severe disability.
4. Ensuring mental health parity with other Medicare benefits is essential if Americans with psychiatric illnesses are to receive vitally needed care.
5. Modifying the "in the home" requirement for wheelchair coverage is necessary to avert the unnecessary isolation of people with mobility limitations in their homes.

6. Eliminating the managed care “lock-in” that is set to begin on January 1, 2006 is necessary to allow people access to needed care given the historic undependability of private Medicare plans.

Background

As the implementation of the Medicare Part D outpatient prescription drug benefit looms, the Medicare Rights Center (MRC), a national consumer service organization, turned to its Consumer Action Board (CAB) for insight into how people with Medicare view the state of the Medicare program and the most substantial changes in Medicare benefits since Medicare’s enactment in 1965.

The Consumer Action Board is a national voice for people with Medicare that works hand-in-hand with MRC staff to strengthen the voice of consumers in local and national health care policy. Over the past two years, CAB has grown into a 52-member board, representing 34 states from Maine to California. CAB members represent a diverse range of Americans from executive directors of senior organizations to practicing nurses, urban to rural residents, and older adults to younger people with disabilities. In addition to serving as the eyes and ears for MRC across the country, CAB members communicate practical policy positions to local communities, the media, policy makers, and elected officials. Some examples of CAB member’s activities include writing to their Congressional representatives and editors of local newspapers, testifying before Congressional committees, writing op-ed pieces, and building relationships between MRC and state and local organizations.

The Medicare Rights Center (MRC) was established in 1989 to ensure that older adults and people with disabilities get good, affordable health care. Since that time, MRC has become the largest independent source of health care information and assistance in the United States for older adults and people with Medicare. MRC is uniquely attuned to consumer needs. Every year, MRC helps tens of thousands of people get good, affordable health care through its telephone hotlines and its educational programs which serve to professionals across the country. MRC's policy department uses the information gathered from people with Medicare, their families, caregivers and the professional who serve them to analyze trends and recommend systemic policy changes to improve the Medicare program on both a regional and national level. In addition, MRC publishes policy briefs and reports addressing major issues affecting access to good, affordable health care services for people with Medicare.

The following report is based on regular regional conference calls with CAB members and in-depth interviews by CAB members of men and women in their own home communities. As noted, the six main issues raised by CAB members are:

1. Developing effective consumer education about the new Medicare drug benefit;
2. Transitioning "dual eligibles"—people with both Medicare and Medicaid—to the Medicare Part D prescription drug benefit;
3. Eliminating the 24-month Medicare eligibility waiting period for people with disabilities under age 65;
4. Ensuring mental health parity;
5. Eliminating the "in the home" requirement for wheelchair coverage; and
6. Eliminating the managed care "lock-in."

Developing Effective Consumer Education About the New Medicare Drug Benefit

Despite the fanfare surrounding the signing of the Medicare Prescription Drug, Improvement and Modernization Act of 2003—commonly called the Medicare Modernization Act (MMA)—CAB members report an absence of informative education efforts around its flagship programs: the Medicare-approved drug discount card program and the Medicare Part D drug benefit. Because of the lack of adequate consumer education, CAB members throughout the country report widespread anxiety, frustration and confusion.

An overwhelming majority of CAB members tell of uncertainty regarding their future health coverage and say that little is being done to prepare them for the enormous changes to the Medicare program. These sentiments are echoed in survey results released by Republican pollster Linda DiVall, which reports that only half of people with Medicare are even aware of the Medicare prescription drug benefit and just one-third say they are likely to sign up for the new benefit in 2006.[1] CAB member Betty Sicher, a retired nurse active with the Rockland County Health Care Coalition in New York, states, "Just about everyone I've spoken to about Medicare is confused and will not know what to do in 2006. I can be included in that group."

In accordance with the MMA, in June 2004 the Centers for Medicare and Medicaid Services (CMS) launched the Medicare-approved drug discount card program—an interim program intended to provide people with Medicare discounts for prescription drugs, and to provide people with low-incomes $1,200 over two years in "transitional assistance" to pay for prescription drugs until 2006. Over 38 companies, including pharmacy benefit managers (PBMs), pharmacies and health insurance companies offered these drug discount cards through the Medicare program.

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[1] *CQ HealthBeat*, December 9, 2004.

Despite a massive publicity effort, enrollment numbers for the temporary discount cards have lagged far below initial expectations. Even though 6.2 million people (15 percent of people with Medicare) enrolled in a Medicare drug discount card, almost half of these people were automatically enrolled by their Medicare HMO or by their state pharmacy assistance program.[2] Only 25 percent of the seven million low-income people with Medicare who qualified for transitional assistance enrolled for the $1,200 credit toward their prescription drugs.[3] The low number of voluntary enrollment illustrates how confusing the Medicare-approved drug discount program is, and how many people with Medicare are finding more substantial discounts through other programs or by buying drugs abroad. The low number of voluntary enrollment also illustrates how consumer education efforts can be of only limited value in the face of complex benefit programs such as the 2004 discount care program and the 2006 prescription drug benefit.

MRC's CAB members confirm that a lack of credible information about the drug discount cards has contributed to the low enrollment. Dolores Hubert, chair of the Oregon Health and Long Term Care Committee of the Governor's Commission for Senior Services, describes the communication breakdown around the discount cards: "It is a complicated program and most seniors or their advocates are unable to access credible information from either Medicare or their health care providers. Most seniors are not computer literate and education about the benefits of the program are woefully lacking."

CAB members agree that the hesitation to enroll in the Medicare-approved drug discount card program is a sign that there is growing apprehension toward the new Medicare Part D benefit and that educating people with Medicare will be a hefty task requiring concise, simple and clear education messages for the public. CAB member, Barbara Kreml of Illinois, an

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[2] Congressional Research Service, "Beneficiary Information and Decision Supports for the Medicare-Endorsed Prescription Drug Discount Card," March 24, 2005.

[3] Ibid.

American Hospital Association retiree and an expert in the health care labor market, asserts, “I have found that most people do not know what Medicare Part D is. Trying to provide information that is understandable to all eligible participants is a daunting task. Medicare needs to consider that most Medicare recipients have not gone online to www.medicare.gov and are unaware of this web site.”

Similarly, Richard Lynch, a retired lawyer active on the West Virginia Governor’s Council on Aging, explains, “Medicare should go out of its way to retain the services of individuals to translate the bureaucratic and unnecessarily complicated language into, say, fourth-grade vocabulary. There is no reason that complexity needs to be further obfuscated with opaque language.”

CAB member, Gloria Samuels, a lawyer for Legal Services in Tennessee, sums it up by saying, “Confusion is the rule regarding the Medicare drug benefit. What happens when a provider changes the formulary? Individuals can only change drug providers once yearly. Does an individual have to then buy his own drug? These questions have no answers at this time, and I am not sure that there will be answers by January 1, 2006.”

Medicare Rights Center Recommendations

In the face of Administration and Congressional refusal to simplify the Medicare prescription drug benefit, CMS can take important steps to alleviate anxiety and concern among people with Medicare because of the lack of education around the drug benefit.

First, CMS must work aggressively with community-based organizations, health care providers, pharmacies and other information intermediaries to ensure that people with Medicare have up-to-date information on the implementation of the Medicare Part D drug benefit. The small increase planned for consumer education and counseling funding pales in comparison with the evident need.

Given the short time-frame that many people with Medicare will have for making these decisions—plans will begin advertising in mid-October, the Part D benefit begins January 1, 2006, and the Part D initial enrollment period will expire May 15, 2006—it is particularly important that consumer education efforts begin immediately. Outreach and enrollment experience—as well as private-sector marketing experience—demonstrates that individuals generally require multiple contacts before making significant personal financial decisions.

Transitioning "Dual Eligibles" to Medicare Part D

The Medicare Modernization Act eliminates Medicaid prescription drug coverage for 6.4 million "dual eligibles"—those enrolled in both Medicare and Medicaid—and automatically moves them into Medicare drug coverage on January 1, 2006. Because Medicaid drug coverage ends on the first day that the Medicare drug coverage is effective, the transition leaves no margin for computer error, system failures, postal delays or the inevitable disruptions and confusion involved in moving millions of the frailest older adults and people with disabilities from Medicaid to Medicare Part D. Using the existing MMA time frame, CMS will have 10 to 12 weeks to accomplish transitional tasks that the Medicare Payment Advisory Commission (MedPAC) suggests require at least six months.[4] Even if there was a 99 percent success rate in this transition—a rate that no one, including the CMS leadership, thinks is achievable—64,000 of the poorest and sickest Americans will lose their existing drug coverage on January 1, 2006, with nothing to replace it.

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[4] Medicare Payment Advisory Commission, "Report to the Congress: New Approaches in Medicare," Ch. 1, June 2004.

CAB members across the country have reported a considerable sense of anxiety and apprehension about this change. Harold Engelman, a former area director of the AARP Workforce in North Carolina and retired insurance executive, asserts, “Everyone I speak to is concerned about the people with Medicare who also have Medicaid. Too many of this population may be without lifesaving drugs in January 2006 and many are afraid that the present agenda is to totally dismantle Medicaid as we know it.”

Jacqueline Ridley, a retired college professor and active member of the Nevada Advisory Council for the Severely Disabled, concurs: “Our Medicare counselors have already struggled with trying to help those wanting to enroll in the low-income drug card. It is so confusing to seniors, especially those of low-income and not computer literate. I am very concerned about what will happen to those people on Medicaid in 2006.”

Gloria Samuels from Tennessee comments, “The needs of the ‘dual eligibles’ are being met with a heavy hand. To avoid any break in coverage, some ‘dual eligibles’ are going to receive membership in a random drug plan without any thought as to whether that plan has a formulary to meet their needs. I am unaware of any steps to ease the 10 to 12 week window of time for them to pick a drug provider.”

Moreover, based on their own experience with Medicaid’s bureaucratic obstacles, CAB members expect there to be problems with “dual eligibles’” transition to Medicare Part D. Bertie Evans, a retired nurse and current community case manager of Wichita County, Kansas, recalls, “Our nearest Medicaid office is 60 miles away and Medicaid always tells people to use the toll-free hotline. Even I have trouble getting an answer when I try to call for my clients’ questions. It is difficult to imagine what will happen in 2006.”

Medicare Rights Center Recommendations

To ensure the safe and smooth transition of individuals with Medicaid drug coverage to the Medicare Part D benefit, Congress should extend the Medicaid drug coverage as a safety net for a reasonable transition period.

Maintaining Medicaid coverage through the transition would prevent the nation's most vulnerable from falling through the cracks. Medicaid coverage would protect people who will lose their Medicaid coverage but are not enrolled in a Part D plan because of a transition error; people who have not received notice of their plan assignment or do not know how to obtain medications using their Part D plan; and people who must be evaluated for, and stabilized on, new drug regimens to comply with their Part D plan formularies.

Eliminating the 24-Month Waiting Period

While most of the 42 million Americans covered under Medicare are age 65 and older, nearly six million qualify for Medicare because of severe and permanent disabilities. Unlike older Americans, who typically enroll and become eligible for coverage within months of turning age 65, people with disabilities must wait 24 months from the date their Social Security Disability Insurance (SSDI) begins before their coverage takes effect. When added to the mandatory five-month delay for SSDI benefits to begin, the total waiting period is 29 months.

At a time when the need for health coverage is most dire, close to 400,000 Americans with disabilities are uninsured and many more are grossly underinsured.[5] Not surprisingly, death

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[5] Dale and Verdier, "Elimination of Medicare's Waiting Period for Seriously Disabled Adults: Impact on Coverage and Costs," Mathematica Policy Research Inc., The Commonwealth Fund, July 2003.

rates among SSDI recipients are highest during the first two years of enrollment, when they are often forced to choose between needed medical care and other life-sustaining needs.[6]

In each of the CAB regional conference calls, those with personal experience in the two-year waiting period gave heartfelt and passionate pleas for the elimination of the waiting period. Mary Troupe, executive director of the Coalition for Citizens with Disabilities in Mississippi, recalls, "As an individual who became disabled at the age of 25, I was lucky that I had worked enough quarters to qualify for Social Security Disability. The shock came when I was told I would not have medical coverage until I was disabled for 24 months.

"Ask yourself how you would feel—recently disabled trying to raise a family, coping with a huge life change and wolves at your door. Not only that, when you can't afford to pay the bills, the hospitals and doctors stop serving you. Imagine the time and expense it took to get back on track financially and physically. . . . Come roll a day in my chair and see what I see—you will understand the urgency to change this policy," she said.

A disability activist from Nebraska, Kathy Hoell, agrees, "Many persons with disabilities die from lack of care. While they wait, they cannot afford their everyday expenses of living and their medical costs so they do without food and medical care."

From across the country, CAB members who work with individuals with disabilities report powerful stories of those struggling—both financially and medically—to survive during the 24-month waiting period. Dolores Hubert, chair of the Oregon Health and Long Term Care Committee of the Governor's Commission for Senior Services, expresses the hardships facing people in the waiting period: "It has been my experience that having to wait increases the acuity

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[6] Mauney, "Medicare Benefits for Social Security Disability Recipients," Reports of Council on Medical Service, American Medical Association, June 2002.

of medical needs and calls for higher cost outlays at the time of eligibility. Mentally the toll is greatest when you are just trying to hang on until help can arrive.

"I don't think that is the way to treat people who are having a hard time keeping families together; it is wearing and usually ends with a divorce that is hard on the client and children. Scars extend over the balance of the lifetime of all players. For some death comes before benefits. Where is the value here?"

In addition, Pearl Lewis, founder of the Crohn's and Colitis Foundation of Maryland, says, "The lack of health care for 29 months can be a death sentence for those with cancer, HIV/AIDS, Crohn's disease, indeed the myriad of diseases that are listed in the Social Security Blue Book. If one does survive those 29 months, that person is breaking under the weight of tens of thousands of dollars in medical bills. . . . Until we eliminate the 29-month waiting period imposed on those our government has judged to be disabled, we have lost our humanity."

Medicare Rights Center Recommendations

Congress must eliminate the waiting period for Medicare coverage for people who qualify for SSDI. Legislation introduced in the 108th Congress would have phased out the waiting period over 10 years; other approaches would eliminate the waiting period more quickly.

The Medicare Payment Advisory Commission estimates that eliminating the 24-month waiting period would cost some $8.7 billion, or roughly 3 percent of current Medicare spending.[7,8] At the same time, the Medicaid program would save an estimated $4.3 billion annually because approximately 40 percent of people in the waiting period have Medicaid.[9]

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[7] Dale and Verdier.

[8] Medicare spending was $252.2 billion in 2002. "National Health Care and Medicare Spending," *Data Book: Health Care Spending and the Medicare Program*, MedPAC, June 2003.

[9] Ibid.

States who shoulder nearly half of Medicaid costs would save some $1.8 billion per year. Thus the net cost for the federal government for eliminating the 24-month waiting period would be $6.2 billion.

Mental Health Parity

Today, an unparalleled number of treatments for mental illness exist, but limitations in Medicare's mental health coverage prevent many Americans with Medicare from receiving the treatments they need. Many people with Medicare live with anxiety disorders, severe cognitive impairment and mood disorders such as depression. In fact, one in five older adults has a mental health condition, as do over half of the people who qualify for Medicare because of a disability.[10] Ultimately, untreated mental health conditions can lead to poor health and quality of life, a reduction in the ability to function and higher mortality rates.

Although Medicare pays 80 percent of most covered Part B services, Medicare pays only 50 percent of covered mental health services, leaving the balance to be paid by the patient. As a result, people with Medicare who do not have supplemental coverage must pay a larger proportion of their mental health care costs out of pocket than they pay for general outpatient services. This cost burden prevents many men and women from seeking mental health care and causes many patients to forgo needed therapy that would improve their quality of life, permit more active and independent involvement in the community, and prevent costly hospitalizations. It also discourages psychiatrists and other mental health professionals from accepting patients with Medicare since coinsurance is often left unpaid by the patient.

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[10] Bartels, "Prevention, Treatment and Intervention for Mental Disorders in Older Persons: Priorities for Health Policy and Research," Comments from a Congressional Briefing: "Addressing the Unmet Needs of America's Elderly—A Briefing on Mental Health and Aging," June 5, 2001

CAB members report grave hardships caused by Medicare's discriminatory and limited coverage for mental illness. Mary Angus, a disability activist and member of the Mental Health Association of Nebraska, avows, "In a post-Americans with Disabilities Act world, it is inexcusable not to have parity for mental health in Medicare."

In particular, CAB members point out that the lack of mental health parity perpetuates the stigma of mental illness as less worthy of treatment than other physical illnesses. Howard Gochberg, a member of the Board of Directors for the Metropolitan Region of the Minnesota Senior Federation, explains, "Mental health inequity should not be continued as it implies that seniors with mental health problems are second-class citizens."

In addition, CAB members believe that the effects of a lack of mental health treatment are profound. As Gene Smith, president of the Senior Statesmen of Virginia, sees it: "Seniors experience loss of parents, spouses, siblings, friends and even children. They also experience loss of mobility, loss of hearing and vision, loss of a driver's license, loss of a home and loss of independence. If depression lasts very long without medical help, poor mental health can drastically impact the physical health by the individual's failing to eat, bathe, exercise or socialize.

"Early medical assistance can stabilize the individual's mental and emotional behavior without the negative effects on physical health. On behalf of seniors nationwide, I urge the members of Congress and the Centers for Medicare and Medicaid Services to cover mental health medical assistance at 80 percent," she said.

While inequitable mental health coverage is a long-standing concern, the exclusion of benzodiazepines from Medicare Part D coverage is a new issue. Under the new Medicare Part D prescription drug benefit, benzodiazepines—medicines used for the treatment of anxiety disorders, insomnia, panic disorder and other forms of mental illness—are not required to be covered by prescription drug plans. As a result, patients will have to pay out of pocket to maintain their benzodiazepine regimens.

Medicare Rights Center Recommendations

MRC urges Congress to establish parity between mental health services and other Medicare benefits by raising Medicare coverage for mental health visits to 80 percent of Medicare rates for covered visits.

CMS should evaluate and revise the list of medications states may exclude from Medicaid coverage. Benzodiazepines and other medications that are commonly used in medical practice and are of significant value to people with Medicare, such as medications that promote weight gain for people undergoing chemotherapy or body wasting, should no longer be excluded by Medicaid. This change would enable Part D plans to cover these important medications.

Eliminating the "In the Home" Requirement for Wheelchair Coverage

Over the last two decades, society's perception of disabilities and people's ability to live with them has evolved. Technological advances, such as wheelchairs and motorized scooters, enable people with severe physical disabilities to live independent and active lives. Federal initiatives like the Americans with Disabilities Act of 1990, signed into law by President George H.W. Bush, and President George W. Bush's New Freedom Initiative, illustrate a growing awareness among lawmakers that disabilities can be overcome and should no longer be grounds for isolation or discrimination. In addition, to prevent seclusion, the Older Americans Act provides federal funding to encourage older Americans to meet outside of their homes in public facilities for meals and conversation.

However, Medicare's standard for covering such assistive mobility devices does not reflect this societal shift. To receive coverage for a wheelchair or a scooter, a person with Medicare must need that equipment in order to function within his or her home. This coverage standard is CMS's interpretation of the 1965 Medicare statute, which defines durable medical equipment (DME), including mobility devices, as equipment "used in the patient's home."

In practice, the "in the home" standard confines many Americans to their homes, preventing them from actively and meaningfully engaging in the community. For example, if Mr. B requires a power-operated wheelchair to go down the street to the grocery store, but only requires a manual wheelchair to navigate through his home, Medicare will only cover a manual wheelchair. This effectively disqualifies Mr. B. from leaving his home without the assistance of others.

CAB members in each region of the country, especially those with disabilities, have expressed their own feelings of isolation and frustration stemming from Medicare's "in the home" requirement for wheelchair coverage. Kathy Hoell from Nebraska said, "The wheelchair policy for Medicare is archaic at best. There are some individuals who are capable of walking short distances in their homes but are unable to go out of the front door safely. However, the system forces them to isolate themselves in their homes and makes them unable to participate in society or access medical service outside their homes."

Other individuals with disabilities feel that Medicare's "in the home" requirement creates a cruel sense of seclusion. Peggy Coster, founder of the Coalition of Disability Concerns in San Francisco, said, "Seclusion is considered a form of torture when applied to prisoners and has been considered torture throughout history. Why would imposing isolation on people with disabilities be different? Isolation produces both physical and mental repercussions. . . . Most people who could use wheelchairs, even if only to get out of their homes because their ability to walk is so limited, cannot get wheelchairs."

Medicare Rights Center Recommendations

CMS should revise its proposed National Coverage Determination for durable medical equipment, such as motorized wheelchairs, under Medicare to consider the needs of individuals both **inside and outside** of the home and incorporate functionally based criteria into the assessment of an individual's mobility needs. These changes would enable individuals who need power wheelchairs and other mobility devices to engage in a fuller range of day-to-day domestic, vocational and social activities.

Eliminating the Medicare Managed Care "Lock-In"

Presently, people with Medicare who enroll in a private Medicare Advantage Plan, such as a health maintenance organization (HMO), a preferred provider organization (PPO) or a private fee-for-service (PFFS) plan, may disenroll from the plan at any time during the year and return to Original Medicare. Because of the medical and financial vulnerability of the Medicare population, this open enrollment and disenrollment period for Medicare private plans allows older Americans and people with disabilities the opportunity to make choices about how and where they get their health care as their needs change. In addition, it allows people who have chosen a Medicare private plan that does not include their doctor the opportunity to return immediately to the Original Medicare fee-for-service system. Routinely, health care providers enter and leave various private plans during the course of a given year.

However, beginning in 2006, people with Medicare will be able to change plans, or move between a private plan and Original Medicare, only during the open enrollment period—November 15, 2005 to May 15, 2006. The following year, the open enrollment period when people can enroll or disenroll from a private plan will be limited to January 2007 to March 2007. Under "lock-in," older adults and people with disabilities in Medicare HMOs will lose two critical protections: the ability to leave a plan that no longer meets their needs and the right to maintain continuity of care from doctors they know and trust as plan networks change with little warning throughout the year.

Because CAB members have had difficult experiences with Medicare private plans, the new "lock-in" requirements for Medicare private plans have left many members concerned. Shirley Genn, former executive director of Brooklyn-wide Interagency Council of the Aging in New York, said, "It is totally dysfunctional to keep Medicare recipients in a one year lock-in. It is absurd that HMOs are free to change their physicians and formularies during the course of a year at will, while beneficiaries are left in a defenseless position for a year if they require a doctor or drug that is no longer on their list."

Moreover, CAB members report that some specialists are inaccessible with Medicare private plans and are concerned that a one year "lock-in" will prevent people from gaining access to medically necessary treatment. Donna Ambrogi, a member of the California Senior Legislature and founder of the Consumer Advisory Council for Inter-Valley Health Plan, reports: "Many of our best specialists have pulled out of Medicare HMOs in our area. Some of those in an HMO consider dropping out of their HMO and going into regular Medicare when they need surgery and want one of these specialists." Starting in 2006, this type of movement will be impossible, leaving many without access to good, affordable health care.

Medicare Rights Center Recommendations

MRC urges Congress to repeal the "lock-in" provision. If Congress does not act to protect the rights of people with Medicare, CMS should establish meaningful exceptions to permit people with Medicare to disenroll from health plans as needed.

Conclusion

Since the passage of the Medicare Modernization Act, the debate about the future of Medicare has been dominated by statistics that do too little to convey the reality of people's daily struggle with access to health care in this country. In this report, we have attempted to amplify the often muted voice of the consumer. As illustrated, people who rely on Medicare and Medicaid for their prescription drugs and other medically necessary treatments are in a state of angst and frustration. Congress and CMS must take the necessary steps, both legislatively and administratively, to ensure that the most vulnerable population in the country is not left to fend for themselves during the most massive change in the Medicare program since its conception. The complexity of the MMA, the difficulty of the transition of "dual eligibles" to the Medicare drug benefit, the 24-month waiting period for people with disabilities, mental health parity, wheelchair coverage, and the Medicare managed care "lock-in" are all real problems with real consequences. Human lives, whose experiences are portrayed in this report, deserve affordable, accessible health care that is secure in the months and years to come.

Consumer Action Board

Jo Alison Taylor, Alabama
An attorney, Ms. Taylor has extensive legal experience dealing with elder law issues and health care management. She has recently served as general counsel of the University of Alabama Law School's Elder Law Clinic and as chair of the Elder Law Section of the Alabama State Bar. She has served as a board member for Alabama's Caring Days Senior Day Care and for the Tennessee Valley Home Heath Agency. Ms. Taylor is very concerned about the complications of navigating through the current health care system, the cost of prescription drugs, and the inconsistencies of health care coverage across the country.

Jessie Tehranchi, Alabama
A former elementary school teacher, Ms. Tehranchi is currently an active health advocate in a number of state and national organizations. Ms. Tehranchi is on the board of the Universal Health Care Action Network, an ambassador for the Alabama Chapter of the National Sclerosis Society, and a member of the Alabama Arise Health Caucus.

Donna Ambrogi, California
As a two-time Fulbright Scholar and Pew Fellow in health care policy, Ms. Ambrogi has devoted much of her life to health care education and advocacy. A retired elder law attorney and professor, Ms. Ambrogi is currently a member of the California Senior Legislature, serves on the board of California Advocates for Nursing Home Reform, and volunteers at a food distribution center for the poor and homeless in southern California. In addition, she started a Consumer Advisory Council for Inter-Valley Health Plan—a local non-profit Medicare HMO—to communicate problems that HMO members have with its services.

Peggy Coster, California
Disabled since 1989, Ms. Coster is involved in health care and disability advocacy. She founded the Coalition of Disability Concerns (later the Disability Community Democratic Club). She is also a producer and board member for Access SF, a public access television station.

Alan Eisenberg, Colorado
A graduate of University of Colorado, Mr. Eisenberg worked for 15 years as a pharmacist at Abbot Laboratories then Baxter International in Illinois. Returning to Colorado, he developed an institutional pharmacy practice providing health care to long term care facilities, assisted living facilities, penal institutions, the mental health population, and hospice programs specializing in pain management. Mr. Eisenberg currently serves on the board of Colorado Foundation for Medical Care and on the Executive Committee for Seniors Inc. He also is a legislative advocate for AARP and a former vice president for Rx Plus.

Lionel Williams, Connecticut
Raised in New York, Mr. Williams moved to Connecticut at the age of 25 where he worked for state and national unions negotiating contracts and representing unions in arbitration proceedings. He currently serves on the Connecticut State Board of Mediation and Arbitration as a labor arbitrator.

Beverly LeFleur, Florida
A former spokesperson for Miami Children's Hospital, Ms. LeFleur has become an outspoken advocate on a variety of senior issues. She was a member of the Florida Ombudsmen Council. Currently, Ms. LaFleur teaches illiterate adults to read and write. Always ready to listen, Ms. LeFleur is a great advocate for helping people with Medicare beneficiaries gain access to senior programs and educational materials.

Paul Severance, Indiana
Mr. Severance is the founder and executive director of United Senior Action of Indiana, a 15,000-member senior citizen public policy advocacy organization. For the past 25 years, he has built and led United Senior Action into a leading statewide senior organization that has had a major impact on both state and national senior health care policy. Prior to this endeavor, Mr. Severance did senior organizing in New York and later was the staff director for the Near East Side Community Organization in Indianapolis.

Barbara Bloom Kreml, MSIR, Illinois
For nearly 30 years, Ms. Kreml worked for the American Hospital Association (AHA) focusing primarily on the health care labor market. In various capacities, Ms. Kreml has used her expertise in professional credentialing, education and public relations with organizations such as the Professional Examination Service (PES), the National Consortium on Health Science and Technology Education (NCHSTE) and the League of Women Voters of Chicago.

Miriam Marx, Illinois
After teaching English in her community as well as abroad, Ms. Marx worked as a secretary at the University of Illinois until she retired. After retiring, Ms. Marx returned to graduate school for a master's degree in divinity. Ms. Marx currently volunteers with the Champaign County Health Care Consumers.

Terry Cunningham, Iowa
Mr. Cunningham worked as the vice president and human resources director for Goodwill Industries of Des Moines, Iowa, where he performed case management and counseling for selected clients in addition to his other administrative responsibilities. Mr. Cunningham is an active advocate for people with Medicare with disabilities. His current and past activities include the Governors Planning Council for Developmental Disabilities, the National Rehabilitation Association, the Statewide Independent Living Council, and the Mid-Iowa Workshops Board of Directors.

Nancy Nichols, Iowa
After teaching in public schools for 32 years, Ms. Nichols became very involved with elderly services as a P.E.E.R. (Prompt Elderly Emergency Response) Advocate for Polk County, Iowa. Currently, Ms. Nichols is a member of the Area Agency on Aging, a delegate to the Older Iowans Legislature, an Executive Committee member of the Iowa Women's Health Committee and president of the Iowa Aging Coalition.

Charlotte Brown, Kansas
Before retiring in 2004, Charlotte Brown worked for the National Association of Insurance

Commissioners (NAIC) and for the University of Missouri-Columbia Hospital and Clinics. She was a member of the mayor's FOCUS group—a cross section of Kansas citizens providing advice and direction on the how to improve the city's infrastructure. Mrs. Brown was a former executive director of the Women's City Club and a member of the Broadway Area Business Association. She created and owned her own business, Brown Baskets, Ltd, a computerized gift delivery system. She is an active member of her community in the Johnson County Leadership, Red Hat Society, Johnson County Community College's Brown and Gold Club and Cancer Action, Inc.

Bertie Evans, RN, Kansas
Ms. Evans was a nurse for nearly 50 years before retiring. She then started a Community Case Manager Program to help community members find solutions and access resources for their health care needs. Ms. Evans is currently the community case manager of Wichita County and an advocate for the seniors attempting to obtain prescription drugs from pharmaceutical companies. She is also an advisory board member for the Kansas Foundation for Medical Care, a not-for-profit organization focused on improving health care quality.

Hazel D. Schexnayder, Louisiana
A native of Louisiana, Ms. Schexnayder worked as a school food service manager for 24 years and then a child nutrition program supervisor for seven years. After retiring, she became involved with several health education initiatives in her community.

Margaret Ross, RN, Maine
Ms. Ross, a registered nurse, retired from state service as the director of Maine's Medicaid Surveillance and Utilization Review Unit. During her career, she participated in efforts to identify and deter misuse and abuse in the health care system, specifically in the Medicare and Medicaid programs. Currently, Ms. Ross participates as a volunteer at Maine Public Television, is a member of the Maine Medicare Education Partnership, and is a trustee of the Central Maine Medical Center School of Nursing.

Jane Scease, Maine
A social worker specializing in geriatric care for over 35 years, Ms. Scease has expansive knowledge of the current health care system and its effects on older Americans. She is an experienced presenter on social work with dementia victims and their families, and a field instructor for social work for the Worden School for Social Service and the University of Connecticut School of Social Work. She presently serves on the board for Maine's People Alliance and the Consumers for Affordable Health Care.

Pearl Lewis, Maryland
Ms. Lewis, an active educator and advocate, is the volunteer director and founder of the Maryland Patient Advocacy Group, an organization that advocates for the needs of Maryland citizens facing both acute and chronic medical conditions. In 1983, she founded the Crohn's and Colitis Foundation of Maryland, became its executive director, and then went on to serve as the national director of patient advocacy and government relations. Ms. Lewis has created access-to-care documents that cover everything from cradle to grave for special needs populations for

18 states and the District of Columbia. These pamphlets are currently being used in nonprofit organizations, hospitals, and dialysis centers across the country.

Marilyn Campbell, Massachusetts
A former licensed real estate broker, Ms. Campbell devoted much of her life to altruistic causes. In her former position as director of the Concord Council on Aging, she developed staff positions to include full time licensed social workers, part-time registered nurses, and an Alzheimer disease consultant to provide counseling and referrals. Ms. Campbell has also collaborated with the people of Massachusetts to provide jobs and health programs, intergenerational programs in public and private schools, and free medical transportation for older adults. She is now the founder and owner of Living Legacies, an organization designed to help people write their own ethical or heritage wills.

Lyn Legere, Massachusetts
Lyn Legere, a long-time advocate for people with psychiatric disabilities, works as a representative for people with disabilities seeking to obtain or maintain Social Security Disability Insurance (SSDI) and Supplemental Security Insurance (SSI) benefits. Ms. Legere also trains professionals, consumers, family members and supporters across the country on SSDI, SSI, Medicare and Medicaid issues. Since the passage of the Medicare Modernization Act in 2003, Ms. Legere has been actively training people about the law and voicing the needs and concerns of people with psychiatric disabilities. Ms. Legere will be receiving her master's degree of science in psychiatric rehabilitation from Boston University in May 2005.

Robert Tell, Michigan
Through a variety of professional and volunteer experiences, Mr. Tell has acquired expertise in health policy and regulation. He holds a graduate degree in hospital administration from Columbia University and has served as the chief executive officer for Menorah Medical Center in Kansas City, Missouri, and as the chief operating officer for the Greater Detroit Area Hospital Council. He has held adjunct academic appointments at Washington University, Wayne State University School of Medicine, and the University of Michigan and is currently involved in a variety of nonprofit elderly and community service activities.

Howard Gochberg, Minnesota
In 1992, Mr. Gochberg retired after 36 years working in the field of logistics management. Presently, Mr. Gochberg is extremely active as a member of the board of directors for the Metropolitan Region of the Minnesota Senior Federation (MSF), as a member of the Health Action Committee of MSF, and as co-chair of the Medical Justice Coalition (MJC).

Mary Troupe, Mississippi
A former elementary teacher and critical care specialist, Ms. Troupe has devoted her life to advocating for those with disabilities. She served on the Governor's Commission on Disabilities and the Secretary of State's "Help America Vote Act" Advisory Committee, and she received the President's Committee on the Employment of Persons with Disabilities Advocacy Award. Ms. Troupe trains state and community providers on their responsibilities under the American with Disabilities Act (ADA) and educates professionals and policy-makers on the issues of health disparities. She continually promotes the independent living philosophy and involvement of

people with disabilities in all aspect of their communities. Ms. Troupe currently serves as the executive director of the Coalition for Citizens with Disabilities.

William R. “Bill” Anthony, Missouri
A native Missourian, Mr. Anthony has 31 years’ experience in education as a teacher and school administrator. He also worked at the Central Missouri Area Agency on Aging and as a certified fire investigator. Mr. Anthony is active in his community and currently volunteers as a Medicare and Medicaid counselor.

Mary E. Angus, Nebraska
Before becoming disabled, Mary Angus worked as a therapist with abused families and children, and as a child protective service worker. Presently, Ms. Angus is a state-wide volunteer activist on disability and mental health issues. She is on the state's Protection and Advocacy for Individuals with Mental Illness Advisory Council and is a member of the Region IV Behavioral Health Advisory Committee and co-edits the quarterly newsletter for the National Alliance for the Mentally Ill Nebraska (NAMI NE).

Kathy Hoell, Nebraska
A nurse by training, Ms. Hoell also holds her master’s degree in public administration. Ms. Hoell has Medicare because of a disability. She is a very active advocate for people with disabilities, particularly around the issue of independent living.

Jacqueline Ridley, Nevada
Ms. Ridley is a retired college professor and has been a senior advocate for over 30 years. She served a four-year term with the Nevada Commission on Aging, started one of the first community college gerontology programs in the country and helped in the development of numerous programs for older adults including senior centers and hospice programs. She is currently on the Nevada Advisory Council for the Severely Disabled and has been a State Health Insurance Assistance Program (SHIP) Medicare advisor for nine years.

Martha Bauman, New Hampshire
Martha Bauman is a free lance writer who writes a column on senior issues for the *Keene Sentinel* and senior profiles for *New Hampshire Magazine*. She chairs the Area Committee on Aging and is a board member of New Hampshire Housing Finance Authority. Prior to retirement, she was the director of Monadnock Volunteer Center and the Retired Senior Volunteer Program. She also directed long-term care services in substance abuse programs and mental health centers in New Hampshire and Massachusetts.

Krystafer Azur Francaux, New Jersey
Mr. Azur Francaux is currently an invaluable hotline counselor at the Medicare Rights Center and a part-time assistant at the Magee Rehabilitation Center in Philadelphia, Pennsylvania. In addition to his advocacy efforts, he is also chairman of the Speakers Bureau of the Master Gardeners of Union County.

John Glasel, New Jersey
A professional trumpeter, Mr. Glasel was president of the American Federation of Musicians

Local 802 in New York City, and served as the trustee of its health benefits plan. Since retiring in 1993, he has served as vice-chair of the Gray Panthers of Northern New Jersey and is presently secretary of Health Care for All/New Jersey.

Meyer Braiterman, New York
Mr. Braiterman has been an insurance broker/agent for 25 years specializing in medical insurance and is active with many health care advocacy organizations in New York. Prior to his involvement in health care issues, he worked for 30 years in the arts as consultant, publicist, theatre and concert producer and manager, technical director and lighting and sound designer.

Thelma Consuelo Correll, New York
Ms. Correll worked as a radiographer and union delegate for 21 years before teaching Labor Studies at the State University of New York at Old Westbury. As a retiree, she is still very involved with her union, Service Employees International Union local 1199, and with various health care advocacy groups.

Shirley Genn, New York
In 2003, Ms. Genn retired from the Brooklyn-wide Interagency Council of the Aging (BWICA) after 17 years of serving as executive director and director of public policy. Prior to that, she served as administrator at the New York City Board of Education in the Office of Equal Opportunity. Ms. Genn provided staff training in compliance and grievance procedures and mediated conflicts within the school system and with outside advocacy groups involved with equal opportunity issues.

Betty Sicher, M.S., RNC, New York
With an underlying dedication to the issues of geriatrics, mental health and social work, Ms. Sicher has been a registered nurse for over 50 years. Ms. Sicher has shown her commitment through involvement with the Rockland County Health Care Coalition and the Alliance for Retired Adults. Recently, her desire to advocate for seniors has led her to work for the preservation of Social Security and a viable Medicare prescription drug plan.

Jerry Edwards, North Carolina
A native of Asheville, North Carolina, Mr. Edwards worked for 30 years career in health care administration, management and regulatory compliance in the public and private sectors. Currently, he is active in health advocacy work in North Carolina, especially on HIV/AIDS issues.

Harold Engelman, North Carolina
A former Japanese language specialist in the U.S. Army and a vice president of nationally known insurance companies, Mr. Engelman has become very involved as a health advocate. He is a state representative for the National Committee to Preserve Social Security and Medicare and a former Area Director of the AARP Workforce. He also serves on the Arbitration Panel of the National Association of Securities Dealers (NASD). Mr. Engelman’s insurance expertise has proven to be an invaluable resource for the Consumer Action Board.

Thelma Clabbers, Ohio
A retired nurse, Ms. Clabbers has dedicated her life to the health care field. Ms. Clabbers served as the director of the Health and Wellness Program for the Hospital Corporation of America in Virginia and worked for 12 years as the assessment manager for the Medicaid Waiver Program for five counties in Ohio. Currently, she volunteers as a nursing home ombudsman and as medical researcher for Pro Seniors, an elder law firm in Ohio.

R. Dean Rinehart, Oklahoma
An attorney since 1956, Mr. Rinehart is a partner at the law firm of Rinehart, Rinehart & Rinehart, P.C. He is the chairman of the board for the Russell Murray Hospice and is a member of a National Fellowship and the First Christian Church Financial Board. Mr. Rinehart is a former president of the Canadian County Bar Association, and a founding member of the Organizational Committee of the Lawyers Helping Lawyers Committee of the Oklahoma Bar Association.

Dolores Hubert, Oregon
Ms. Hubert was born, raised and educated in Oregon, and after a career in nursing she pursued her studies in Health Care Administration. She worked as an ombudswoman in nursing homes, resolving complaint issues for residents. Ms. Hubert chairs the Health and Long Term Care Committee of the Governor's Commission for Senior Services and lobbies for senior issues in the Oregon legislature.

Martin Berger, Pennsylvania
Mr. Berger spent his career working in the labor movement with the International Ladies Garment Workers (now known as UNITE). In 1987, he joined the ILGWU headquarters in New York City where he opened the First Garment Workers Justice Center. Now retired, Mr. Berger continues to work as a lobbyist for UNITE in Pennsylvania. He is the president of the Pennsylvania Alliance for Retired Americans and chairs the local Democratic Party.

Daniel Schulder, Pennsylvania
Mr. Schulder has devoted much of his life to legislative and policy development on aging issues and programs. He served as the director for public policy and legislation for the National Council on the Aging, the director of the department of legislation and public affairs for the National Council of Senior Citizens, the director of legislation for the Alliance for Retired Americans, and as a delegate to the White House Conference on Aging. Presently, Mr. Schulder continues to advocate on behalf of seniors as a consultant for the Board of Pennsylvania Alliance for Retired Americans.

Mary Lou Mahan, South Dakota
Ms. Mahan has spent a lifetime working in business, agriculture, politics, and public service. For the past several years, she has worked extensively to provide health insurance and benefit packages to families through a partnership she formed with insurance providers. In addition, Mary Lou has an extensive and lifelong background in local, state and national politics. Ms. Mahan's commitment to public service explains her extensive background and experience in community involvement including longstanding service on several hospital and nursing home

boards, local and state health care associations, and a variety of educational enhancement positions.

John McIntyre, South Dakota
Before retiring in 1993, Mr. McIntyre spent 38 years as a middle school teacher and counselor. In recognition of his career, he was awarded the Marvin Kemp Award for Outstanding Contributions to the Field of Guidance and Counseling, the Orv Schmieding Award for Counseling Skills, and the Sioux Falls Education Assocation and South Dakota Education Association Human and Civil Rights Awards. For the past 10 years, Mr. McIntyre has served as an instructor in the 55 ALIVE Defense Driving Program for AARP and has been an active member of the Government Affairs Committee of AARP South Dakota. Mr. McIntyre has served one term as representative and one term as senator in the South Dakota Legislature and is currently chairperson of the Minnehaha County Democratic Party. He was elected to be a delegate for John Kerry at the 2004 Democratic convention.

Louise McKown, Tennessee
Ms. McKown has a rare, progressive neurological condition and had to go without health insurance during the 24-month waiting period because her COBRA coverage ended before her Medicare coverage began. She is very involved in disability advocacy, having worked for the East Tennessee Technology Access Center and chaired the Tennessee Disability Coalition.

Gloria Samuels, Tennessee
A lawyer, Ms. Samuels works for Legal Services, specializing in health law and representing individuals who have had their TennCare (Medicaid) services terminated, been denied a service or been overcharged. She is also active in educating people with Medicare about their rights and protections.

Charles Kelly, Texas
A retired consultant for the U.S. Office of Economic Development and president of his own highly profitable real estate company, Mr. Kelly has applied his business experience and organizational skills with a passion and a commitment to the education and well-being of seniors. He has provided care to seniors as an officer of the National Association of Professional Geriatric Care Managers and as the Director of Senior Care Management. Presently, Mr. Kelly volunteers as the Senior Outreach Coordinator for the Galveston County Health District in Texas.

Harriet M. Goodwin, Vermont
Ms. Goodwin is the former Executive Director of COVE (Community of Vermont Elders), a statewide advocacy and educational organization. She still works for them as a consultant and serves on a number of state task forces and nonprofit boards focusing on various aging and care issues. A licensed social worker with advanced degrees in gerontology, Ms. Goodwin spent 30 years in a variety of senior service organizations before joining COVE.

Gene Ecton Smith, Virginia
A former flight attendant and retired high school mathematics teacher, Ms. Smith is actively involved with aging issues in her community and at the state level, having been president of the

Virginia Council of Senior Citizens. She is currently the president of the Senior Statesmen of Virginia, a group that speaks for senior citizens in the Commonwealth. She is also on the board of Northwestern Virginia Health Systems Agency and is a charter member of the Alliance for Retired Americans and a former board member for Jefferson, Virginia, Area Agency on the Aging.

Thais Blatnik, West Virginia
Ms. Blatnik has spent a rewarding and distinguished career serving the people of West Virginia. In addition to being a former West Virginia State Senator and member of the House of Delegates, she also served as a commissioner and chair for the Department of Health and Human Resources and Commission on Child Support. She is presently a CASA Advocate for neglected and abused children and a co-founder of the Ohio Valley Health Right, Inc., which provides health care and pharmacy services to working poor and seniors. She brings with her invaluable experience in drafting legislation and implementing governmental agendas to the board.

Richard P. Lynch, West Virginia
A retired lawyer, Mr. Lynch directed the American Bar Association's Government and Public Sector Lawyers Division, its Standing Committee on Law and Literacy and its Standing Committee on Association Standards for Criminal Justice. He was the director of the National District Attorneys Association's Commission on Victim Witness Assistance and its national Economic Crime Project. He also served as deputy chief counsel of the U.S. House of Representatives Select Committee on Crime. As a volunteer he served as vice chairman of the Board of Literacy Volunteers of America, as president of Literacy Volunteers of America (West Virginia), as a long time board member of The Homeless Children's Tutorial Project in Washington, D.C., and as a member of the Kitchen Cabinet to the President of the Points of Light Foundation. He is a member of the West Virginia Governor's Council on Aging and serves as a volunteer to the West Virginia Silver Haired Legislature.

Harold DeVos, Wisconsin
Mr. DeVos is currently retired after having suffered severely disabling chronic pain for nearly 30 years. After losing the ability to work, he got involved in organizations to develop state and national pain policies that are sympathetic to those suffering intractable pain. He also spends several hours a day counseling others who suffer chronic pain with an internet group called "Pumpsters." Mr. DeVos is a strong advocate of a reformed health care system that offers increased accessibility.

Tom Frazier, Wisconsin
Tom Frazier is executive director of the Coalition of Wisconsin Aging Group (CWAG), a nonpartisan membership organization involved in education, training, leadership development and advocacy. Prior to that, Mr. Frazier worked for as a policy analyst at the Wisconsin Bureau on Aging, and as deputy director of the West Virginia Commission on Aging. Mr. Frazier is a member of the National Council on Aging (NCOA), president of the National Coalition of Consumer Organizations (NCCO), and holds a masters of public administration from Pennsylvania State University.