

# **MEDICARE TRENDS AND RECOMMENDATIONS:**

## **AN ANALYSIS OF 2012 CALL DATA FROM THE MEDICARE RIGHTS CENTER'S NATIONAL HELPLINE**

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*Disclaimer: All names and identifying details have been changed to protect the privacy of individuals.*

## I. INTRODUCTION

Today, nearly 50 years after its enactment, the Medicare program is a lifeline for more than 50 million older adults and people with disabilities, increasing access to needed health care and reducing strain on families. Yet for too many people with Medicare, the cost of health care remains burdensome. Most callers to the Medicare Rights Center's National Consumer Helpline are living on low and fixed incomes, a reality that reflects the Medicare population overall. Today, half of all people with Medicare live on annual incomes of \$23,500 or less and one quarter live on \$14,400 or less.<sup>1</sup>

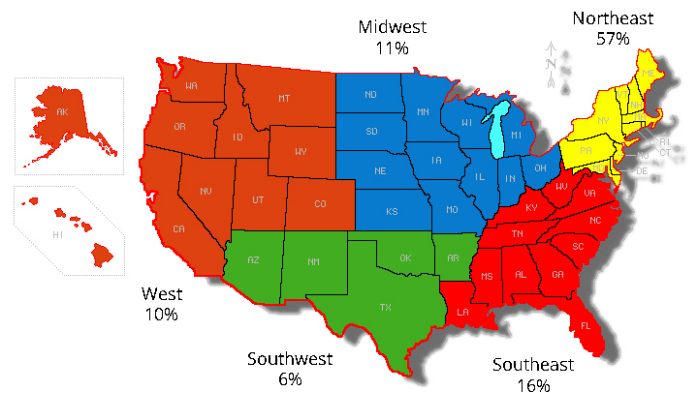
Adding to the financial burdens of a significant portion of the Medicare population is the reality that Medicare can be difficult to navigate, and securing needed coverage and care can require knowledge and perseverance. Challenges aside, Americans like Medicare. About two-thirds of Americans think Medicare offers good value for what is paid into the system, while fewer than half of Americans say the same for federal government services as a whole.<sup>2</sup>

Still, accessing and navigating the Medicare program is difficult for many beneficiaries. A 2011 Roper poll of 1,000 people over age 60 found that just 46 percent of respondents said they understand how Medicare works.<sup>3</sup> Other studies have found that nearly half of all seniors tend to stay enrolled in their current drug and health plans year after year, even though networks and formularies change and comparison shopping can reduce beneficiaries' out-of-pocket costs while improving access to care. Additionally, numerous studies have found that people who might be eligible for financial assistance through the Medicare program are not aware of this aid.<sup>4</sup>

The Medicare Rights Center has witnessed all of these problems firsthand on its national helpline. In

2012, the helpline answered more than 14,000 Medicare-related questions posed by older adults and people with disabilities, their family members and the professionals serving them. Their stories fill an extensive, carefully curated database that presents an emblematic cross-section of the problems encountered by people with Medicare and their families. An analysis of these questions offers a unique window into the challenges faced by Americans with Medicare as they seek to obtain and afford coverage, understand their benefits and contest potentially erroneous coverage decisions.

### 2012 National Helpline Calls per Region



In the coming year, as the Affordable Care Act's (ACA's) Health Insurance Marketplaces continue to be implemented, new managed care programs are introduced, and other new policies take effect, people with Medicare will face decisions and potential confusion as they navigate an evolving landscape. This report's analysis of the current challenges faced by people with Medicare is intended to shed light on the need to preserve and improve the program for a population that can scarcely afford to pay more for care, and to suggest reforms, discussed in Section VII, that would strengthen the program for current beneficiaries and future generations.

## II. TOP ISSUES IN 2012

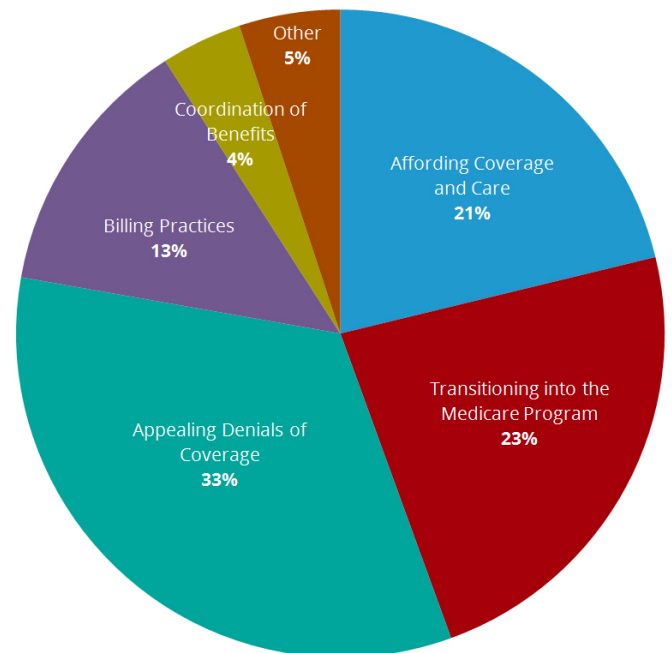
A Florida woman who thought she was having a heart attack discovers that her Medicare Advantage (MA) plan will not pay for her emergency room care. A New York man in a skilled nursing facility must use an ambulance to go to the doctor—but his insurer will pay only for one-way transportation. Ten years after a heart transplant, a blind woman learns that copayments for her anti-rejection drugs have soared, and she cannot afford them. A stomach cancer patient wants a second opinion from a specialist in his network, yet the insurer will not cover the visit.

Dozens of people like these call the Medicare Rights Center every day, seeking support in handling urgent, complex problems. Explored in their minutiae, calls to Medicare Rights begin to suggest systemic problems with the provision of public and private health coverage to older adults and people with disabilities. At the same time, these calls spotlight the widespread yet often hidden economic and health challenges facing our nation's older adults and people with disabilities. In fact—and because the helpline by its nature draws problems and complaints related to Medicare rather than success stories, of which there are also many—a year of Medicare Rights counseling sessions serves as a useful microcosm of challenges facing people with Medicare beyond those who call Medicare Rights for help. At the same time, an analysis of the helpline call record suggests ways by which the Medicare program can be reformed to more effectively meet the needs of beneficiaries and their families now and in the future.

Analysis of the helpline's extensive database reveals that three trends dominate:

- ✓ Affording coverage and care
- ✓ Transitioning into the Medicare program
- ✓ Appealing denials of coverage

### 2012 Top Trends on Medicare Rights' National Helpline



Of the 14,102 questions that Medicare Rights' helpline addressed in 2012, the majority came from individuals who in one way or another were experiencing challenges affording their health care costs. Specifically, one-fifth (21 percent) of calls related directly to enrolling in low-income benefits, one-quarter (23 percent) related to enrolling in the Medicare program, and one-third (33 percent) concerned appealing a denial in order to receive and afford needed care or medicines. Remaining calls were related to questions about billing practices (13 percent), coordination of benefits (4 percent), and a mix of other issues (5 percent).<sup>5</sup> Month to month, these patterns remained relatively consistent over the course of 2012, though there was a noticeable uptick in requests for help with low-income benefits in October, November and December versus the rest of the year, possibly in conjunction with the annual open enrollment period for changing coverage.

## PEOPLE WITH MEDICARE: JUST THE FACTS

- ✓ Half of all people with Medicare—nearly 25 million individuals—live on annual incomes of \$23,500 or less, and one quarter live on annual incomes of \$14,400 or less.<sup>6</sup>
- ✓ In 2010, Medicare premiums and cost sharing consumed 26 percent of the average monthly Social Security benefit, compared to only 7 percent in 1980.<sup>7</sup>
- ✓ Today, the average Medicare household spends 15 percent of their income on health care—three times that of non-Medicare households.<sup>8</sup>
- ✓ 80 percent of seniors have at least one chronic condition.<sup>9</sup>
- ✓ One in seven seniors struggles with hunger.<sup>10</sup>

While the top three trends identified in the national mix of calls also dominated in New York City and State, New Yorkers were much more likely to seek help affording coverage. For instance, 40 percent of calls from New York City and 34 percent of calls from New York State were related to low-income Medicare benefits. All together, New York State calls represented almost half of the helpline's inquiries, and New York City represented just over half of this amount, or about one-quarter of total inquiries. These figures are not surprising considering that Medicare Rights is located in New York and conducts significant community outreach throughout the state, particularly related to increasing enrollment in low-income Medicare benefits. That said, all callers to Medicare Rights' national helpline are screened for these benefits and, as appropriate, provided support in accessing benefits in their home states.

## III. AFFORDING MEDICARE

**PROBLEM:** With half of all Medicare beneficiaries living on less than \$23,500 a year, and the costs of medical care and prescriptions continuing to rise, it is more important than ever to help people bridge the gap between what their benefits cover and what they can afford to pay out of pocket.<sup>11</sup> For women and people of color, who live on even less, such bridges are even more vital. Consider, for example, that among older African Americans and Hispanics, the poverty rate is more than twice as high as it is among non-Hispanic whites. Further, medical expenses are far higher for older Americans and those with disabilities than for the rest of the population: Medicare households devote 14 percent of their budgets to health care, compared with just 5 percent for non-Medicare households.<sup>12</sup>

Fortunately, a variety of state, federal and nongovernmental programs exist to help low-income Medicare beneficiaries with their insurance premiums, medical bills and prescription drug costs. These include Medicare Savings Programs and Extra Help, also known as the Medicare Part D Low-Income Subsidy (LIS).<sup>13</sup> Yet many people who are eligible are not receiving this assistance.<sup>14</sup> Some who may be eligible do not realize that aid is available, or do not know how to find out if they might qualify. Others who would qualify for aid find the application and recertification processes so onerous that they fail to enroll or they lose coverage.<sup>15</sup> As a result, millions of eligible Americans are not enrolled in programs for which they are eligible, a loss that may force older adults and people with disabilities to forego needed health care or other necessities, such as food and housing.

Further, years of declining home values, job losses, and inadequate retirement savings and pensions mean that many Baby Boomers—half of whom are expected to have incomes below \$27,000—will need help affording Medicare.<sup>16</sup> In fact, a growing number of Americans are reporting economic insecurity, with a recent study finding that four out of five U.S. adults struggle with “near-poverty” at some point in their lives—a sign that social programs like Medicare are more crucial now than ever before.<sup>17</sup> Sadly, these near-poor individuals frequently have incomes or assets just barely too high to qualify for benefits, leaving them in sight of aid but unable to reach it without encountering greater hardship.

## Helpline Data:

As previously noted, nearly all callers to the Medicare Rights Center’s national helpline—poor, near-poor and even middle class—are grappling with affording costs associated with Medicare. The lowest-income subset of these individuals requires assistance specifically in enrolling in Medicare low-income benefits, including Medicare Savings Programs and Extra Help. In 2012, 21 percent of all questions fielded by the helpline related to low-income program enrollment. Among New Yorkers, particularly those in New York City, this was the top issue, likely because Medicare Rights is authorized by the city to help residents apply for aid. (Counselors direct callers from other states to the appropriate state and local agencies.) More than half of low-income calls were related to MSPs, and one-quarter of calls involved the Extra Help program. Remaining call issues (15 percent) concerned Medicaid, which helps the lowest income beneficiaries pay for costs not covered by Medicare, and state pharmaceutical assistance programs (SPAPs). For all issues, callers

almost always sought help determining eligibility and then enrolling, a process many found confusing.

Fortunately, enrollment in an MSP in many states results in “deeming for”—or automatic enrollment into—Extra Help.<sup>18</sup> At the same time, thanks to data-sharing rules under the Medicare Improvements for Patient and Providers Act (MIPPA), individuals enrolled in Extra Help by the Social Security Administration should have their data shared with their state for automatic processing as an MSP. But deeming and data-sharing are imperfect processes and used to varying degrees by different states. It remains an unfortunate fact that MSPs are severely under-utilized, with only about one-third of seniors eligible for the Qualified Medicare Beneficiary (QMB) MSP enrolled in the benefit, and only about 13 percent of eligible seniors enrolled in the Specified Low-Income Medicare Beneficiary (SLMB) MSP.<sup>19</sup> Additionally, an estimated two million Americans are not receiving Extra Help.<sup>20</sup> Thus Medicare Rights and other advocates continue to pursue advocacy strategies, further discussed in Section VII, to increase awareness of these programs and streamline eligibility and enrollment systems.

Further, as indicated above, Medicare Rights cannot resolve all callers’ affordability issues by enrolling them into public benefits. These factors include the sad reality that eligibility limits for “low-income programs” are still often too low for near-poor seniors and people with disabilities: they fall just on the other side of eligibility, ineligible for benefits but unable to access affordable care. Callers in this predicament present a strong argument for reforms to improve education around and expand access to low-income programs.

## HELPLINE VOICES

Mrs. G had not been to the doctor in 16 years—until she suffered a stroke and was rushed to the hospital. After two weeks, blind in her right eye and weak on her right side, the New York woman was being discharged to the care of her daughter and son-in-law. The couple both work and feared having to leave Mrs. G alone for many hours a day, trying to maneuver with a walker around their apartment’s steps and narrow halls. To their knowledge, Mrs. G had never enrolled in Medicare, and on her small Social Security income she had no way to pay her bills. The hospital suggested that it might file liens against Mrs. G and her family. Worried and upset, Mrs. G’s son-in-law called the Medicare Rights Center. The counselor explained how to appeal the hospital’s discharge decision and to find out for certain whether Mrs. G had any Medicare coverage. If not, the counselor explained, Mrs. G likely would qualify for special programs that would allow her to enroll in Medicare at an affordable cost, with no penalty. Medicare Rights recently followed up with Mrs. G’s son-in-law and learned that Mrs. G had successfully been enrolled in Medicare and is now receiving care for the consequences of her stroke and other conditions that had previously gone untreated.

Mrs. G (see box above) represents the low-income callers to Medicare Rights’ helpline who are eligible for Medicare low-income programs such as Medicare Savings Programs and Extra Help. Because of the widespread need for help affording Medicare, Medicare Rights screens all callers to its helpline for low-income programs. Thus, while many callers—like Mrs. G’s family—present a different issue when they call, it often emerges during counseling that they are also eligible for low-income programs and can receive assistance enrolling from Medicare Rights or a local agency. One such caller was Mrs. B, a Virginia retiree who sought help when the drug she had been taking for years was suddenly denied by her provider. During the call, the Medicare Rights counselor discovered that Mrs. B’s Social Security benefit is less than \$800 a month, yet she does not receive assistance paying her Part B or Part D premiums. Mrs. B not only found out how to appeal the medication denial, she also learned about assistance that could put more than \$100 per month back into her Social Security check and also provide a drug subsidy.

Some callers have gone without health coverage for years, believing they could not afford it. Mr. H called the Medicare Rights Center from his home in Oregon

when, at age 71, he no longer could postpone certain medical care. A helpline counselor asked him about his income and learned that not only could Mr. H receive Medicare at little or no monthly cost, thanks to enrollment in a low-income benefit, he would also be exempt from any late enrollment penalty.

The examples of Mrs. B and Mr. H illustrate a widespread lack of awareness of Medicare Savings Programs and related assistance, pointing to a need for greater government outreach related to these programs and—especially—greater automation of enrollment functions so that eligible individuals automatically receive benefits without having to find out about them, navigate the often-complicated application process, and wait to hear whether they are enrolled. Many callers to Medicare Rights’ helpline underscore this need, as they are eligible for programs such as Extra Help but do not know that these programs exist:

Ms. O lives on the Lower East Side of Manhattan and has a total monthly income of \$961.90. Despite her low income, Ms. O pays Part B and Part D premiums out of pocket, spending more than 10 percent of her monthly

income on these costs. A social worker learned of her situation after Ms. O faced eviction and called Medicare Rights to help Ms. O apply for an MSP and Extra Help. With this assistance, Ms. O should be able to pay rent.

An Ohio woman, Ms. T, called Medicare Rights to find out about appealing her plan's refusal to pay for an x-ray ordered by her physician. In the course of the session, the counselor determined that Ms. T's income appears to qualify her for at least partial Extra Help for her drug costs.

After incurring copayments of nearly \$2,400 and receiving collection notices related to surgery needed to correct an improperly performed colonoscopy, Ms. P called Medicare Rights from her home in Florida. In tears, Ms. P told her counselor that she is trying to get the hospital to agree to a payment plan. The counselor recognized that Ms. G is likely eligible for the Extra Help program and completed an application on her behalf.

Even if a Medicare beneficiary successfully enrolls in a subsidy program, there can still be problems accessing the benefits. For example, Ms. L qualified for Extra Help and EPIC, New York State's SPAP, but a Medicare Rights counselor found that the premium for Ms. L's drug plan was still being erroneously deducted from her Social Security check. Ms. L had already contacted EPIC and Medicare about the problem, but the counselor explained that it actually is Social Security that is responsible for Extra Help, and directed her to call that agency. Unfortunately, successful enrollment into benefits like Extra Help does not always mean that people will receive the benefit, and speaks again to the need for greater enrollment automation to ensure that eligible individuals are enrolled in benefits without having to face uncertainty and financial and health consequences.

While the above examples explore the problems encountered by Medicare beneficiaries who are eligible for MSPs and Extra Help, many callers to Medicare Rights' helpline face high medical costs but are not eligible for such programs. The following stories suggest the need for an expansion of low-income program eligibility limits so that near-poor individuals can avoid slipping into poverty and, in many cases, seeing their health deteriorate further.

Mr. C, a disabled New York man, has required multiple amputations. His income is too high to qualify him for an MSP, yet it is not enough for him to afford a Medigap plan or a Part D drug plan. He called Medicare Rights' helpline to learn how to "spend down" his income by paying out-of-pocket for health care costs and thereby become eligible for an MSP or Medicaid.

Mrs. R called from Pennsylvania because her husband was in the hospital, his care resulting in bills they could not afford. For instance, a one-day visit as an outpatient cost \$300. A staph infection contracted in the hospital necessitated a return trip—and a \$700 copay. An apparatus to treat the infection cost \$500. The couple's income was too high for a low-income program, and the only option that the Medicare Rights counselor could suggest was a \$378 per month Medicare Advantage plan that did not offer drug coverage, so the costs would not be as high if Mr. R needs to access similar care in the future.

Ms. V, a Delaware woman, had been enrolled in an MSP for three years, but a small cost-of-living adjustment (COLA) increase raised her income to \$1,286 per month. This increase made her ineligible for an MSP and imposed new premium costs that outweighed her COLA increase.



## IV. TRANSITIONING TO MEDICARE

**PROBLEM:** Navigating Medicare eligibility, enrollment and benefits coordination can be a confusing process, with significant health and financial consequences for individuals who make decisions based on insufficient or inaccurate information. People who do not realize when they should sign up for Medicare benefits may face lifelong financial penalties for late enrollment—penalties that many beneficiaries cannot afford. Further, missing the appropriate enrollment period can mean going months without health insurance coverage until the next opportunity to enroll arrives. And coordinating Medicare with other types of insurance—including coverage through an employer or spouse, retiree coverage and COBRA—raises questions for many beneficiaries and must be handled properly to avoid penalties and gaps that can strain family finances and result in declines in health if treatment is delayed.

The implementation of new health insurance Marketplaces under the Affordable Care Act in 2014, and a new set of enrollment periods for individuals seeking Marketplace coverage, makes it particularly imperative that people with Medicare and their families understand Medicare enrollment periods and how Medicare coordinates not only with employer, retiree and related coverage, but also with

Marketplace products. Examining the current experiences of Medicare beneficiaries, such as those who call the Medicare Rights Center, can provide valuable insights into how the system works now and how to improve it for future enrollees.

### Helpline Data:

Whether an individual is about to become eligible for Medicare, did not realize they could have enrolled years ago, or is already enrolled in the program but has seen their health and life circumstances change, thousands of callers to the Medicare Rights Center's helpline report challenges, misunderstandings and misinformation related to Medicare enrollment and benefits coordination. Too often such confusion leads to beneficiaries facing gaps in coverage and premium penalties that many have difficulty affording.

As indicated previously, 23 percent of callers to Medicare Rights' helpline in 2012 had questions about transitioning to Medicare. Nearly all of these callers needed help enrolling in or disenrolling from Medicare Part B, choosing between traditional Medicare and a Medicare Advantage plan, or determining how Medicare works with other types of insurance, such as employer insurance, a spouse's insurance or COBRA.

### HELPLINE VOICES

Mr. S, a New York senior, enjoyed comprehensive health insurance benefits through his employer, a major pharmaceutical manufacturer. The benefits continued for a year after Mr. S retired, at age 70. A few months before his employer benefits were to end, Mr. S contacted the Social Security Administration to enroll in Part B and received some difficult news: though he had signed up for Part A at his 65<sup>th</sup> birthday, he had declined Part B because he was covered by his employer's policy—and had now missed his special enrollment period. Mr. S did not realize that once his status changed from employee to retiree, he should have signed up for Part B, as Medicare becomes the primary insurance for most retired individuals. Mr. S learned that he would have to wait until January 1 to sign up for coverage that would not begin until July 1. This meant that he faced nearly half a year without health insurance, and a late enrollment penalty as well.

Clients confronting these transitions issues are diverse—geographically, economically, and culturally. The helpline fields calls from professionals astonished at the complexity of Medicare, including corporate benefits managers, retired bankers, teachers and attorneys. Callers with coordination questions also include individuals with chronic illnesses and those in the early stages of dementia, who cannot make sense of the many options they must navigate in order to successfully enroll. Caretakers seeking affordable help for family members too sick or impaired to help themselves also call Medicare Rights for assistance, as do immigrants who lack the English-language skills to navigate the system.

By far the greatest number of transitions-related calls to the Medicare Rights Center’s helpline, from patients, benefits managers and care providers, concerned transitioning from employer-based health insurance to Medicare. As Mr. S’s story reflects, many people require more education around employer-based insurance and the different ways in which this insurance works with Medicare. Specifically, Medicare Rights fields many questions from beneficiaries and professionals who need help understanding enrollment-related rules for small and large employers. Even company benefits managers have called Medicare Rights seeking clarity on the fact that when a Medicare-eligible employee keeps working, large-employer coverage is primary to Medicare, and small-employer coverage is secondary to Medicare.<sup>21</sup> Such calls spotlight the need for improved education of consumers and professionals by government agencies and simplified enrollment processes where possible. Please find these and other recommendations elaborated in Section VII.

The need for effective communication, education and assistance is particularly important for individuals who are new to Medicare, facing confusion about when and how to enroll in Part B. Some callers who are turning 65 report feeling pressured to take a Medicare Advantage plan from a private insurer, even if they do not want managed care, or travel

frequently and cannot find a managed care network that meets their needs. Others fear losing access to trusted health professionals because they hear rumors that doctors increasingly will not accept Medicare, despite the fact that 96 percent of people with Medicare have regular access to care at a doctor’s office.<sup>22</sup> In addition to these issues, many clients must also be assured that although some decisions will have long-lasting ramifications, the Medicare program also offers flexibility, for instance in offering beneficiaries the option to switch between Original Medicare and Medicare Advantage at specific times each year.

Ms. K, a 51-year-old Massachusetts woman, became eligible for Medicare several years ago owing to a disability. However, her health care providers advised her not to enroll, because her COBRA plan offered better coverage for her needs. After 36 months of COBRA, she enrolled in a private insurance plan on the advice of a physician who told her not to enroll in Medicare since he expected her to recover sufficiently to return to work soon. Instead, her condition deteriorated. Ultimately, she enrolled in Medicare—six years after she was eligible—incurring a 60 percent late-enrollment penalty, or nearly \$60 added to her monthly Part B premium in 2012.

As Ms. K’s story demonstrates, transitions problems often become all the more pronounced when a beneficiary is facing a medical crisis. As another example, consider the story of a New York couple, Mr. and Mrs. P, who declined Part B coverage, thinking that retiree health insurance was all they needed. But when Mrs. P was diagnosed with Stage 3 breast cancer and faced significant medical costs, they realized that the retiree plan was secondary to Medicare. Unfortunately, they had just missed their Part B enrollment period. Mrs. P required chemotherapy, and it would be months before they could secure Medicare coverage for it.

**Other reasons for callers to the Medicare Rights helpline requiring help enrolling in or disenrolling from Medicare Part B include the following:**

- ✓ Some move abroad for a time, and think that they do not need to pay for Medicare since they will be unable to use it outside the U.S.
- ✓ Some are getting divorced and do not know whether to enroll or disenroll in Part B and how their action might affect their health coverage.
- ✓ Immigrants with poor English skills must depend on family members to sort through their options, sometimes unsuccessfully. For instance, an Indian woman who speaks no English was eligible for Medicare but not enrolled because her son-in-law thought she did not need it.

As these examples suggest, the consequences of failing to properly enroll in Medicare Part B can lead to coverage gaps, late enrollment penalties and magnified health problems. Confusion is common when navigating Medicare transitions and Medicare Rights sees a persistent need for better information and streamlined Part B enrollment processes. The following stories further illustrate this need:

Mrs. R has been on medical leave from her job for years but was advised by her company that she was technically still an employee, and so could defer enrollment in Part B without penalty. Yet because Ms. R did not meet the Social Security Administration's definition of an active employee, by the time she tried to enroll she faced a 150 percent premium penalty, an additional \$149.85 per month in 2012.

Mrs. I became eligible for Medicare owing to End-Stage Renal Disease. Because she could not afford her Part B premium, she stopped paying it. After a kidney transplant, she needed costly anti-rejection medications and called Medicare Rights to find out how to re-enroll.

Mr. A, a 67-year-old man who spends more than he can afford on private insurance, called Medicare Rights at the urging of a social worker. He had declined Part B even though it would have been far more affordable than private insurance.

What is more, successful enrollment into Medicare Part B is not the end of a beneficiary's enrollment journey: many beneficiaries must also enroll into Part D drug coverage. Last year, Medicare Rights used Plan Finder, the federal drug plan selection tool, to assist 74 helpline callers in choosing a Part D plan that would meet their needs. The following stories demonstrate some of the complexity that beneficiaries confront:

Mr. Y's social worker called the Medicare Rights on Mr. Y's behalf to request assistance in helping Mr. Y choose a Part D prescription drug plan. Mr. Y has End-Stage Renal Disease, is on dialysis, and takes a number of extremely expensive medications. When Medicare Rights spoke directly with Mr. Y, it was discovered that he did not currently have any drug coverage because he had been unable to afford his monthly premiums and had been disenrolled. He had been seeking the help of various charities to help with his prescription drug costs. Medicare Rights used the Plan Finder tool to help Mr. Y find a drug plan that would meet his needs, but only one plan offered in his area covered all of his prescriptions. This plan was going to cost him over \$5,000 in yearly expenses, and Mr. Y said that there was no way he would be able to afford the cost. He opted

for a less expensive plan even though it did not cover all of his medications.

Some of the most affecting calls to Medicare Rights' helpline involve individuals who have suffered cognitive declines or other issues that increase the challenges of navigating Medicare Parts B and D enrollment effectively. For instance, a 78-year-old caller, Mr. K, told a helpline counselor that he had had a stroke and his memory is poor. His Medicare card reflected Part A coverage only—not Part B or Part D—and medical bills of \$70,000 had accumulated over the past five years before being turned over to a collection agency. Earning only \$900 each month, largely through Social Security, Mr. K cannot pay these debts.

Mr. K's experience tracks with findings in a recent study published in *JAMA Internal Medicine*. Harvard researchers found that people with the lowest cognitive scores are far less likely to be enrolled in Medicare Part D, and even if they know about low-income subsidies, they are less likely than others to apply for them.<sup>23</sup> The researchers' conclusion: "Current educational and outreach efforts...may not be sufficient for beneficiaries with limited abilities to process and respond to information."<sup>24</sup>

## VI. APPEALING DENIALS OF COVERAGE

**PROBLEM:** Enrolling in Medicare is only the first step to accessing and affording health care. Many times, beneficiaries have not received sufficient education about how their benefits work and are subsequently confused when coverage for health services or medicines is denied. And Medicare Advantage and Part D drug plans can make changes to their formularies and related rules each year, necessitating that individuals review changes on an annual basis and switch plans if needed. Even beneficiaries who know their coverage rules and have worked with

their health care providers and insurers to research options can find that the treatments their doctors have prescribed are not covered.

Appeals for denied medicines can lead to particularly compelling stories, as a denial often means that the beneficiary must go without the needed medication. Medicare Rights has found that these cases generate some of the greatest confusion, as denials typically occur at the pharmacy counter, but patients are not told why their medicine is denied or how to effectively navigate the appeals process. Further, numerous studies have demonstrated a clear link between medication adherence, cost sharing and health outcomes. For instance, a 2006 article in the *Journal of the American Medical Association* examined a program designed to improve seniors' adherence to a blood pressure medication regimen.<sup>25</sup> It found that participants who used their medications faithfully achieved "clinically meaningful reductions" in blood pressure.<sup>26</sup> And a 2012 study in a peer-reviewed pharmaceutical practice journal analyzed 160 studies dating back to the 1970s and found clear linkages between out-of-pocket costs and medication adherence: when patients must cover more of their medication costs out of pocket—for instance because a needed drug is denied—there is a significant association with a decline in using medications as directed.<sup>27</sup>

### Helpline Data:

The largest single category of problems handled by the Medicare Rights Center helpline in 2012—33 percent of all questions—involved insurance denials and appeals, reflecting the significant difficulties many people with Medicare face in obtaining coverage for needed medicines and care. The majority of these calls related to Medicare Advantage and Part D denials, discussed below.

## HELPLINE VOICES

During an appointment with her psychiatrist, Ms. E, a disabled Colorado woman, was suddenly unable to walk. The physician, not knowing whether his patient was having a stroke or reacting to a change in her medications, said Ms. E needed to go to the hospital immediately. He called Ms. E's primary care physician, and paramedics took Ms. E to the nearest emergency department. After three days of testing, doctors could not determine the cause of the problem, though they ruled out a stroke. Ms. E's mother was assured by the hospital and physicians that her daughter's Medicare Advantage plan would cover hospital costs, because Ms. E had been admitted on an emergency basis. However, the insurer determined that Ms. E's situation was not an emergency, and it would cover neither the cost of Ms. E's treatment at the out-of-network hospital, nor the skilled nursing care the hospital recommended. Fortunately, Ms. E's family contacted the Medicare Rights Center, which was able to help Ms. E pursue a successful appeal and secure Medicare coverage for her hospital costs. (267020)

As previously noted, by the time people call Medicare Rights' helpline, they frequently have done as much as they can to solve their own problems. When denied service or medication, a beneficiary's first resort can be to skip a needed appointment or drug, sometimes with serious health consequences. In other instances they pay out of pocket, even if it means forgoing other necessities such as heat and food. Undertaking an appeal is a daunting process for many beneficiaries. Some report difficulty in getting their physicians to write necessary letters. Others do not understand the importance of obtaining written documentation from insurers and providers. Still others attempt an appeal, but find the process arduous and lengthy.<sup>28</sup>

Since implementation of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, managed care plans in the Medicare Advantage program have enrolled an estimated one-third of the Medicare market in New York State, and more than one-fourth of the national market.<sup>29</sup> Privately administered MA plans offer the promise of lower out-of-pocket costs and more comprehensive benefits than Original Medicare. Further, if an individual enrolls in an MA plan with Part D drug coverage (an MAPD plan), there is no need for separate Part D coverage.

Most MA enrollees—85 percent according to a recent study—are happy with their coverage.<sup>30</sup> But the Medicare Rights Center's national helpline hears from beneficiaries who have learned that their MA or MAPD plan will not cover their care, for a variety of reasons. In counseling and educational materials, Medicare Rights underlines the importance of beneficiaries and their families knowing their plan provider network and formulary, and understanding how MA coverage differs from Original Medicare coverage, for instance, in the fact that individuals may need preauthorization before seeing specialists under Medicare Advantage, and that MA networks typically cover only a specific geographic area.<sup>31</sup>

Although individuals with Medicare are permitted to change their MA plan at least once per year, many beneficiaries choose a plan and keep it for years without assessing their health care needs and options annually. Some individuals like their plans and do not realize that networks and formularies can change. Others are overwhelmed by options, particularly if they have cognitive difficulties, low incomes and/or limited educations.<sup>32</sup> Each of these scenarios can lead to Medicare Advantage denials of care that cause some beneficiaries to pay out of pocket for needed care, or to forego care altogether. Medicare Rights'

counselors help callers navigate problems such as the following:

Mrs. J is a Florida woman who had extensive surgery on her jaw to repair damage resulting from osteoporosis and subsequently required significant dental work, both of which can be Medicare-covered services. Her MAPD plan denied the claim in 2009, and the appeals process was still in process and held up by plan questions at the time her husband contacted the Medicare Rights helpline in 2012. Mr. J says he has given up on recouping dental costs and is now only seeking compensation for the jaw surgery.

Mr. S, a diabetic, developed a serious foot infection requiring amputation of his lower leg. He called Medicare Rights' helpline because his MA plan denied preauthorization to fit him for a prosthesis.

Mrs. Y, a Florida resident, fell during a visit to Michigan and was taken to a hospital where an x-ray revealed that she had broken her ankle. The information was sent to her primary care provider in Florida, and a cast was put on in Michigan. The insurer denied the claim, saying it was not an emergency.

Mr. L is a 66-year-old man who fell and struck his head on a filing cabinet. He was able to call 911, but in the emergency room could not stand and was admitted to the hospital for testing. His insurer denied coverage for the out-of-network hospitalization.

Medicare Rights' counselors provide callers like those described above with information about Medicare Advantage rules and appeal procedures, helping clients pursue appeals where appropriate. As discussed in Section VII, Medicare Rights also works with federal policymakers to encourage greater

education and transparency around MA appeals and

At 91, Mrs. S lives independently in her small New York apartment, despite significant spinal pain owing to osteoporosis. She tried taking pills for the condition, but they upset her stomach so badly that she had to discontinue them. Last year, her physician began giving her injections of a brand-name pain medication every three months, and they proved helpful. This year, however, her Part D plan rejected the doctor's request for pre-approval of these costly injections. The doctor asked about a less expensive injectable, which was also denied by the plan. Instead, the plan advised the doctor to prescribe pills to Mrs. S, even though these have already been shown to have adverse effects on Mrs. S's health.

their outcomes, and simplified appeals processes. The second-largest category of denial/appeal-related calls on Medicare Rights' helpline in 2012 concerned the Part D prescription drug benefit, which almost 36 million beneficiaries rely upon for basic drug coverage.<sup>33</sup> Despite the access to needed medicines provided by Part D, many beneficiaries continue to struggle with affording their prescriptions—and denials of coverage only compound these problems. For instance, after paying \$8 per month for his angina drug for a few years, Mr. K, an older North Carolina resident, was startled to discover that its price had increased to \$112 per month because it had been moved to a higher cost drug tier.<sup>34</sup> With Medicare Rights' help, Mr. R pursued a successful appeal of the denial—specifically requesting a formulary tier exception—which all told required more than a dozen phone calls and an estimated 60 hours of work.

Affordability also becomes an issue when a beneficiary is prescribed a drug not on their Part D plan's formulary.<sup>35</sup> For instance:

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14. Medicare Trends and Recommendations: An Analysis of 2012 Call Data from the Medicare Rights Center's National Helpline

Ms. D is a New York woman with metastatic cancer, who was prescribed a new chemotherapy drug that is not on her Part D plan formulary and costs \$319 per month—more than one-third of her monthly income.

Mrs. P, who told a Medicare Rights counselor that she has tried many drugs but has found that only one addresses her debilitating migraine pain—and it is not on her drug plan’s formulary. Mrs. P said that she has been so desperate at times that, despite her limited income, she will try to pay for the medication out of pocket, at \$40 per pill.

Mr. N had to leave his mother’s prescriptions behind when he was told he would have to produce \$400 out of pocket to pay for them.

To help callers avoid situations like the above wherever possible, Medicare Rights counsels callers to review their plan’s formulary each year, and to switch plans if their drugs are not listed. Unfortunately, too few beneficiaries take this advice: a recent Kaiser Family Foundation study found that among Medicare beneficiaries not enrolled in low-income assistance, 87 percent never switched prescription drug plans over four consecutive years, despite annual changes to premiums, covered drugs and cost sharing.<sup>36</sup> And reviewing drug plan policies annually is important not just to determine whether one’s drugs are still on the plan’s formulary but also to identify whether the plan employs utilization management tools to control spending. These tools include:

- ✓ Prior authorization by the plan before a prescription is filled
- ✓ Step therapy, which requires that a cheaper drug be tried first
- ✓ Quantity limits, which restrict the amount of medication a person receives.<sup>37</sup>

In 2012, 36 percent of medications were subject to these restrictions, an increase from 18 percent in 2007.<sup>38</sup> As helpline cases demonstrate, many beneficiaries find these limitations confusing—even if they have been careful to follow the rules as they understand them. For example, Mr. R, an MAPD plan enrollee who needs an expensive medication for depression, requested a tier exception, which, if granted, would lower his out-of-pocket cost for the drug. The plan granted the tier exception, but when Mr. R called his mail-order pharmacy to purchase a 90-day supply, he was told that the exception was in fact denied.

The above example spotlights another point of confusion for some beneficiaries: pharmacies. Beneficiaries frequently have questions about whether a pharmacy is in network, what it means for a pharmacy to be “preferred,” and when it is more advantageous to use a network mail-order pharmacy. These questions do not always have clear answers. Medicare Rights has even seen cases where a beneficiary is better off paying cash at an out-of-network pharmacy than using their MAPD plan at an in-network retailer.

## VII. LESSONS LEARNED AND POLICY RECOMMENDATIONS

Taken together, the leading case issues of 2012 on the Medicare Rights Center’s helpline underscore the basic health and financial difficulties facing many people with Medicare. Additionally, these cases illustrate how difficult it can be for beneficiaries, caregivers and professionals to navigate Medicare and related programs, and how important it is for beneficiaries and their families to have access to knowledgeable, impartial advocates and guides.

The pervasive challenges documented in this report provide a starting point from which policymakers can develop solutions to ease common beneficiary burdens. Most importantly, in spotlighting the stark

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15. Medicare Trends and Recommendations: An Analysis of 2012 Call Data from the Medicare Rights Center’s National Helpline

economic realities confronting many people with Medicare, the report powerfully conveys that older Americans and those with disabilities are ill-equipped to shoulder higher health care costs or to navigate added complexities within the health care system. In line with the top helpline trends, Medicare Rights makes the following recommendations to preserve and strengthen the Medicare program.

## AFFORDING MEDICARE

### 1. Do not shift added costs to people with Medicare.

While there is widespread agreement that members of Congress should seek solutions to extend the financial health of Medicare over the long term, policy proposals that would save federal costs at the expense of people with Medicare should be rejected.

As described in this report, many callers to the Medicare Rights helpline are living on low, fixed incomes. In many cases, these individuals are seeking relief from the expense of Medicare premiums, deductibles, coinsurances and copayments. While some of these callers can be screened for low-income assistance, including the Medicare Savings Programs and Extra Help, many others remain ineligible for these programs because their incomes are just over the eligibility threshold, and must pay out of pocket for needed care or forego care altogether. Proposals to cut Medicare benefits or shift higher health care costs to these individuals ignore the widespread economic insecurity experienced by older adults and people with disabilities. Given this, the following such proposals should not be adopted:

✓ **Further income-relating and increasing premiums:** Many policymakers suggest that “wealthier” beneficiaries are equipped to contribute more in Medicare costs, specifically through higher premiums, a practice known as means-testing or income-relating. Yet higher income beneficiaries are *already* means-tested, paying higher Medicare Part B and Part D

premiums, well above the standard Part B and Part D premiums.<sup>39</sup>

As proposed, added income-relating in Medicare premiums constitutes little more than a cost shift to middle class retirees and people with disabilities.<sup>40</sup> To achieve sizable savings, further income-relating of Medicare premiums requires that the middle class pay more, undermining a social insurance model with an historical, quantifiable record of success.<sup>41</sup>

✓ **Prohibiting or taxing Medigap “first dollar” coverage:** Some policymakers support increasing costs for beneficiaries who purchase Medigap plans, a widely used form of supplemental insurance to Medicare. Some proposals would add a surcharge, or tax, to Medigap premiums.<sup>42</sup> Other proposals would eliminate or discourage first dollar coverage under Medigap plans—meaning people would pay a larger share of health care costs through increased deductibles, coinsurance and copayments.<sup>43</sup>

Increasing Medigap cost sharing wrongly places the burden on beneficiaries to self-ration health care services. At the same time, increased cost sharing is shown to limit care indiscriminately, forcing patients to forgo both needed and unneeded care.<sup>44</sup> Prohibiting or discouraging Medigap first dollar coverage would cause the most harm to those beneficiaries who have the greatest need for coverage, the sickest individuals and people with low and modest incomes.<sup>45</sup>

✓ **Adding a home health copayment:** Introducing a Medicare home health copayment would be most damaging for the most vulnerable: the poorest, the oldest and the sickest. Among home health users, 30 percent are age 85 or older—compared to 13 percent among the general Medicare population—and 63 percent are women. What is more, home health users tend to have lower



incomes than the average Medicare beneficiary and already face higher health care costs.<sup>46</sup>

Some proposals attempt to mitigate the harm imposed by a home health copayment, ranging from \$100 to \$150 per episode of care, by limiting the charge to care not preceded by an inpatient stay. But this feature perversely imposes the most significant cost burden on the most vulnerable.<sup>47</sup> Specifically, beneficiaries who need ongoing home health services to remain in their homes and communities are most at risk of skipping needed care if forced to pay a copayment. In forgoing this care, they may end up being hospitalized more often or be ultimately forced to enter a more expensive long-term institutional setting, such as a custodial nursing home. In short, those who would be most harmed by a copayment are the very same beneficiaries who need this relatively cost-effective care the most.

- ✓ **Increasing Extra Help copayments for brand-name drugs:** A proposal endorsed by the Medicare Payment Advisory Commission (MedPAC) and the Bipartisan Policy Center would adjust drug copayments for low-income Medicare beneficiaries enrolled in Extra Help, increasing brand name copayments while minimizing or eliminating copayments for generic drugs.<sup>48</sup> The plan is intended to promote generic drug use among low-income people with Medicare, but risks increasing cost burdens for those who can least afford it: individuals with Extra Help are among the most vulnerable people with Medicare, living on incomes lower than \$1,450 per month and retaining less than \$13,300 in lifetime savings.<sup>49</sup>

As stories in this report suggest, many older adults and people with disabilities must take a brand-name drug instead of a generic alternative out of medical necessity. Extra Help enrollees forced to pay a higher copayment for a brand-

name medication may be forced to self-ration needed prescriptions.

- ✓ **Restructuring Medicare cost sharing:** To produce cost savings, some policymakers propose restructuring Medicare cost sharing. While the details of each proposal vary, the most discussed plans would combine the Part A and Part B deductibles, implement a single coinsurance rate for health care services or a standardized set of outpatient copayments, and create an out-of-pocket spending cap for beneficiaries. In addition, as discussed above, some proposals would add copayments to home health services and limit first dollar coverage in Medigap plans.<sup>50</sup>

Streamlining coverage and simplifying Medicare cost sharing is a worthy goal, but not as a mechanism for securing federal cost savings by shifting costs to beneficiaries. The broad outlines of the most discussed proposals to restructure Medicare cost sharing would increase costs for most beneficiaries, and significantly so for those who can least afford it.<sup>51</sup>

- ✓ **Raising the Medicare age of eligibility:** Some policymakers suggest raising the Medicare age of eligibility from 65 to 67. Yet doing so would have devastating consequences for many people nearing Medicare eligibility, leading to higher costs and gaps in coverage. Older people of color with lower average lifetime wages, workers who perform physical labor unable to delay retirement and low-income older adults living in states without expanded Medicaid benefits would be among those hardest hit.<sup>52</sup>

In addition to these consequences for beneficiaries, raising the Medicare age of eligibility is *not* a prudent cost saver. While this proposal would create savings for the federal government, it would shift significant costs to private insurers, employers, state governments and 65- and 66-year olds. Estimates suggest that

such cost shifting would amount to nearly double the costs saved by the federal government.<sup>53</sup>

## 2. Strengthen low-income Medicare protections.

Streamlining access to low-income programs is proven to work. In New York State, Medicare Savings Program enrollment increased by more than 48 percent between 2003 and 2005 after the state—thanks to advocacy by Medicare Rights and others—implemented a series of measures to reduce financial barriers to enrollment like eliminating the asset test and simplifying the application process.<sup>54</sup> Arizona, Minnesota, Alabama, Delaware, Mississippi and Connecticut have experienced similar results as a result of eliminating or raising asset tests for one or more MSPs, in addition to diminished administrative burdens on the state.<sup>55</sup>

Just as the Affordable Care Act will expand coverage for the non-Medicare population, opportunities exist to improve the processes by which low- and middle-income Americans enter non-ACA Medicaid, MSPs and Extra Help. The following improvements will facilitate more affordable access to health care for people with Medicare living on low, fixed incomes, such as the clients Medicare Rights serves every day.

✓ **Make permanent a critical MSP, the Qualified Individual (QI) program.** Nearly half a million Medicare beneficiaries receive a fully subsidized Part B premium through the QI program, a critical benefit afforded to older adults and people with disabilities with very low incomes and few assets. Medicare Rights regularly helps New York clients apply for this program. Unlike other MSPs, the amount of federal funding available for the QI program does not automatically increase based on inflation and growing need, and Congress must act annually to ensure that federal funding for QI continues. States receive block grants based on need to provide QI benefits, meaning that once a state's funding is spent, no new eligible beneficiaries can enroll. The QI program should be made permanent to provide needed stability

to state governments and to low-income people with Medicare.

✓ **Increase and align eligibility standards, and align and simplify application and renewal processes:** States and the federal government can better align income and asset thresholds, as well as application and recertification processes, among Medicaid as expanded by the ACA, non-ACA Medicaid, MSPs and Extra Help. Such measures would help advocates and government agencies screen people for multiple benefits simultaneously, and maximize enrollment in programs that assist vulnerable populations with the cost of health care. In particular, policymakers should:

- **Align ACA and MSP income eligibility rules:** Ease and simplify transitions from ACA-expanded Medicaid to Medicare through income threshold alignment. Federal policymakers should increase the income test for MSPs to 138 percent FPL, or about \$15,850 for a single individual, to match the ACA income threshold for expanded Medicaid.
- **Increase income thresholds for MSPs and Extra Help:** Increasing unreasonably low income thresholds for MSPs and Extra Help would ease the burden of unaffordable out-of-pocket costs for vulnerable people with Medicare. Income thresholds should be adjusted to provide partial premium and cost sharing assistance through MSPs and Extra Help, up to 250 percent FPL, or about \$28,700 for an individual.
- **Eliminate asset tests for MSPs and Extra Help:** Asset tests, already eliminated from some jurisdictions, should be cut entirely in order to help states more efficiently process applications for MSPs and Extra Help and to streamline the beneficiary application

process. If asset tests remain intact, other standardization steps, such as an increased asset threshold, an automatic disregard for burial expenses aligned across programs, and streamlined documentation procedures would facilitate enrollment.

- Facilitate cross-deeming between MSPs and Extra Help: Allowing full cross-deeming, both from MSPs to Extra Help *and* Extra Help to MSPs, would alleviate application burdens and increase enrollment among eligible beneficiaries.
  - Align and simplify application and renewal rules: States and the federal governments should also align application rules among ACA-related coverage, non-ACA Medicaid, MSPs and Extra Help to ease application hurdles for beneficiaries. Additionally, a completely electronic application process should be adopted.
- ✓ **Ensure that health care providers are paid cost sharing for people with MSPs:** The Qualified Medicare Beneficiary program is intended to facilitate access to needed medical care for the lowest income people with Medicare, helping pay for Medicare premiums and cost sharing, including deductibles, coinsurance and copayments. Unfortunately, providers who treat QMB enrollees often do not receive copayments or coinsurance owed to them. Fortunately, providers are prohibited from “balance billing” QMB beneficiaries for these charges. Yet as calls to Medicare Rights’ helpline evidence, many physicians unfamiliar with these rules inappropriately bill Medicare beneficiaries with QMB. Federal lawmakers should ensure that health care providers are paid the full amount owed for treating Medicare beneficiaries enrolled in QMB by requiring the federal government to pay full cost sharing for QMBs. Alternatively, state governments should be prohibited from reducing

or limiting cost sharing payments to providers for QMB enrollees.

**3. Prioritize funding for consumer outreach and counseling.** Unbiased information and assistance is essential to avoid higher costs for Medicare beneficiaries and for the federal government. Based on Medicare Rights’ experiences serving people with Medicare, the scope of assistance required reaches well beyond screening and enrolling beneficiaries into MSPs and Extra Help. Helping people with Medicare manage out-of-pocket health care costs also requires counseling related to pre-eligibility information gathering, enrollment into Parts A and B, and Medigap, Medicare Advantage and Part D plan selection.

To that end, federal policy makers should ensure that adequate funding is made available for Older Americans Act programs and networks, including robust support for the on-the-ground counseling and support provided by State Health Insurance Information and Assistance Programs (SHIPs). Funding for these resources should be enhanced to reflect a growing need, as the American population steadily ages and 10,000 Baby Boomers become Medicare-eligible daily.<sup>56</sup>

Further, the “no wrong door” philosophy advanced by the ACA must extend to people who seek information about Medicare. In addition to adequately funding Area Agencies on Aging (AAAs), Aging and Disability Resource Centers (ADRCs) and SHIPs, it is crucial that Navigators, Marketplaces and other community-based assistors are well-equipped and well-resourced to respond to the needs of people with Medicare.

## TRANSITIONING TO MEDICARE

**1. Alleviate late enrollment penalties.** Calls to the Medicare Rights helpline make clear that people newly eligible for Medicare often struggle to understand the rules associated with enrollment. This

struggle is most pronounced for people not yet receiving Social Security benefits, as enrollment into Medicare Parts B and D does *not* occur automatically. Increasingly, people newly eligible to Medicare are often confused about the need to enroll into all parts of Medicare, how Medicare benefits coordinate with existing coverage, and the consequences of failing to enroll when first eligible. A multi-pronged approach is needed to ensure that these consequences are avoided wherever possible:

- ✓ **Actively involve employers:** Particularly for individuals aged 65 and still working, employers are often the first, and sometimes the only, resource that individuals turn to in deciding whether or not to enroll in Medicare Part B. It is therefore critical that the information provided by employers to employees is accurate and comprehensive. Where possible, federal policymakers and administrators should seek opportunities to formally train and educate employers about critical messages and existing resources. For instance, they might contract with independent educators to ensure that clear and accurate guidance is provided to human resources departments and others.
- ✓ **Strengthen education on late enrollment penalties:** The consequences of delaying enrollment in Medicare Part B are significant, resulting in lifetime premium penalties that may be unaffordable for many older adults, as Medicare Rights has learned. Federal communications to beneficiaries should be strengthened, including information on the availability of Special Enrollment Periods (SEPs), the full scope of consequences associated with delayed enrollment, and how Medicare benefits coordinate with existing sources of coverage.
- ✓ **Expand equitable relief:** Even with improved information and outreach, mistakes will still be made, and the process for rectifying these errors—equitable relief—should be made faster,

easier and more transparent. Additionally, equitable relief should be expanded to include remedy for mistakes made in relation to incorrect information provided by an employer or insurer. Individuals should be able to request such relief online, in writing or in person at their local Social Security office. Decisions concerning equitable relief should explain the reasoning and should be reviewable on appeal.

- ✓ **Restructure the Part B Initial Enrollment Period (IEP):** Older adults newly eligible to Medicare are able to enroll in Medicare during the seven-month period surrounding their 65<sup>th</sup> birthday, known as the IEP. The start of Medicare coverage depends on when during the IEP a person enrolls and is delayed the longer a beneficiary waits to enroll around his or her 65<sup>th</sup> birthday. The current framework can result in coverage gaps for people newly eligible to Medicare who inadvertently delay enrollment. Federal policymakers should streamline the IEP, allowing the start of coverage to begin the month preceding enrollment.

**2. Improve consumer information on Medicare Advantage.** Payment adjustments under the ACA that critics feared might limit access to private Medicare Advantage plans have not had this impact; in fact, enrollment in MA products is increasing, a trend that is expected to continue well into the next decade.<sup>57</sup> Yet Medicare Rights’ helpline callers with MA plans repeatedly voice confusion over their coverage, and are reluctant to seek out plans that could better meet their needs. To address this need, we recommend the following:

- ✓ **Encourage meaningful variation among plans:** MA plan options can be dizzying for consumers. To encourage efficient plan selection, distinctions among plans must be meaningful and well understood. At the same time, increased standardization of benefit packages and cost sharing structures would facilitate “apples to apples” comparisons.<sup>58</sup>

- ✓ **Improve star ratings:** The star rating program for private Medicare plans, including both MA and Part D plans, shows considerable promise, already improving access to information about the merits of a given health plan. As it evolves further, the star rating system should be enhanced to provide consumer-directed information relevant to individual choices. Ongoing efforts to improve the star rating system for MA plans must be done in a way that keeps beneficiaries—many of whom are not aware of the system—informed and engaged. Clear, regular explanations of the rationale, meaning and importance of the star rating system is needed. In addition, this system should reflect timely quality measures so consumers make their choices based on the most recent data available.<sup>59</sup> In the future, people with Medicare should be able to “self-weight” various factors to create individualized quality ratings—sorting plans by the metrics most relevant to their individual needs.
- ✓ **Support consumer counseling services:** As previously noted, callers to the Medicare Rights helpline are routinely confused about how their Medicare Advantage plan works and how to choose a plan that is best for them. Federal policy makers should demand increased use of standardized, plain language information by MA plans. In addition, plan marketing materials and websites should refer prominently to unbiased sources for assistance, including SHIPs and 1-800-MEDICARE, and should be more thoroughly reviewed for misleading information. In particular, plans should be prohibited from asserting or implying that standard benefits, like an out-of-pocket cap or free preventive services, are unique to the plan. Similarly, plans should not be permitted to suggest that income-based benefits, like MSPs or Extra Help, are dependent on enrolling in a particular plan.
- ✓ **Strengthen Plan Finder.** Many Medicare beneficiaries turn to Plan Finder, the online tool

created and maintained by CMS, for help navigating their MA and Part D plan options. Over the years, Plan Finder has been continuously updated and it is a valued resource for people with Medicare, family caregivers and beneficiary advocates like the Medicare Rights Center. Medicare Rights annually conducts Plan Finder sessions for a sampling of callers to identify positive elements of the resource and problems—and to make recommendations for improvement. For instance, a 2010 survey of 91 Medicare Rights helpline callers who sought new stand-alone prescription drug plans revealed that less than half chose the plan recommended by Plan Finder.<sup>60</sup> The 2012 helpline data demonstrates a continued lack of knowledge about choosing a plan. Drawing from these data, Medicare Rights recommends the following improvements to Plan Finder:

- Improve initial search results based on past claims data, including noting whether doctors seen in the last 2-5 years are in network and drugs taken in the past year are on plan formularies.
- Establish searchable, up-to-date information about plan networks for MA comparisons.
- Create a decision tree to better guide users through the process.
- Ensure “Medicare & You” points to Plan Finder as the most comprehensive resource.
- Further consolidate drug plans that lack meaningful differences.

## APPEALING DENIALS OF COVERAGE

### 1. Reform Medicare Part D appeals.

As demonstrated by the health and financial hardships faced by callers to Medicare Rights’ helpline, substantial improvements are needed to the Medicare Part D appeals process.

Federal policymakers and administrators should consider the following:

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21. Medicare Trends and Recommendations: An Analysis of 2012 Call Data from the Medicare Rights Center’s National Helpline

- ✓ **Require that clearer information be provided at the pharmacy counter:** A Medicare beneficiary first learns that a drug is denied when a prescription is refused at the pharmacy counter. This represents a critical moment for educating beneficiaries about how to pursue the appropriate path forward—to appeal the plan decision or to pursue other avenues for obtaining a needed medication with the aid of their pharmacist or prescribing physician. Individually tailored language should be added to the existing standardized notice at the pharmacy. In addition to the plan contact information, including phone and online access, and clear guidance on the next steps in the appeals process, the denial notice should include a clear explanation of the reason the drug is refused.
- ✓ **Streamline the appeals process:** If an appeal is the appropriate course of action, Medicare beneficiaries must navigate several needless, burdensome steps before an appeal is officially filed—as Medicare Rights’ helpline callers too frequently find. Under the current process, plans are allowed three opportunities to refuse payment for a prescribed medication: at the pharmacy counter, through the coverage determination and again through redetermination. This three-step process is distinct from Medicare Advantage, Original Medicare and Medicaid appeals frameworks. In these health programs, a beneficiary receives a notice of non-coverage after a service is received or prior to the service because it is not authorized. Unlike Part D, beneficiaries are not expected to formally request notice of non-payment after refusal of a service.

Medicare beneficiaries would be best served by initiating the coverage determination request at the pharmacy counter when the prescription is presented. Combining the point-of-sale refusal with the formal request for a coverage

determination would be an ideal path forward for beneficiaries. In the absence of this change, other options to simplify the appeals process include: eliminating the redetermination step in the Part D appeals process; requiring a pharmacy counter refusal to trigger a plan inquiry with the prescribing provider; and allowing and encouraging pharmacists, with plan technical support, to counsel their patients regarding denial reasons and appeal rights.

- ✓ **Mandate that plan-level data on appeals is publicly available:** Limited data is made publicly available on the beneficiary experience and plan performance related to Part D appeals. Available data capture trends only after the appeal reaches review by the Independent Review Entity—the third formal tier of the appeals process, and the first time that a beneficiary appeal is reviewed by an entity other than the drug plan.<sup>61</sup> Given this reality, questions remain about how many beneficiaries are able to successfully process an appeal and how beneficiaries cope with delayed or limited access to prescribed medications. Plan performance should be measured at all levels of the appeal, beginning with the prescription refusal at point-of-sale, and these plan-level data should be released to the public.

**2. Improve the Medicare Advantage appeals process.** Specifically, Medicare Rights recommends improving the delivery of good information to beneficiaries about their appeal rights, and offering timely resolution of appeals requests. In addition, it is recommended that CMS and insurers make publicly available, through star ratings and elsewhere, information on plan denial rates and the frequency of decision reversals—meaning that a plan’s denial is subsequently overturned by the Independent Review Entity or Administrative Law Judge, suggesting blanket denials, rubber-stamped redeterminations, and/or overly restrictive medical review practices.

## APPENDIX: METHODOLOGY

The Medicare Rights Center’s independent National Consumer Helpline provides more than 50 callers each day with unbiased answers to their Medicare questions. Counselors are trained to provide service that is accurate, thorough, courteous and sensitive, and data collection is an essential part of this training. All calls are documented in a customized Salesforce database, using carefully developed protocols designed with two aims:

- 1) To better track and serve clients who call multiple times; and
- 2) To identify and track trends as they emerge regionally and nationally.

### *How Call Data is Gathered and Categorized: Understanding Data Collection Terms*

After speaking with a client, counselors enter information about the call into Medicare Rights’ database. Each client is assigned a Contact ID within the database, and each subsequent call from this client is assigned a unique Case Number. Further, because a single call may include discussion of several problems, counselors also identify each call’s Case Issues within the database.

Medicare Rights Helpline Terms	Salesforce Data Field Identifiers
Helpline Caller	Contact ID
Call	Counseling Session with a Case Number
Caller Issue(s)	Case Issue(s)

During each helpline call, counselors record the client’s city and state, the date and time of the call, the caller’s primary and secondary types of Medicare or other insurance, and the call’s general content. Counselors also tag calls with the relevant Case Issues, making it possible to effectively sort and analyze large amounts of data for multiple purposes. Case Issue categories, which drill down in detail to multiple “tiers,” were developed by Medicare Rights staff over years of counseling callers and recognizing themes. This qualitative classification system enables ready identification of the most frequent types of problems that callers face.

Calls to Medicare Rights’ helpline are not audio-recorded. However, in addition to tagging the call’s Case Issues, counselors input narrative counseling notes, which offer valuable information about the call related to the assessment of the problem, its impact on the client, and the strategy employed to address the problem. Counselors are trained on writing case notes that are clear and accurate, and these notes help supervisors and future counselors understand the fuller context of calls and the counseling provided.

### *Data Set*

The data set used for this analysis is an aggregate of all helpline calls for 2012. It represents 11,286 individual calls, some of whom presented more than one issue. From these calls, 14,102 distinct Case Issues were identified, and serve as the raw material of this report.

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