Medicare Trends and Recommendations:
An Analysis of 2016 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.

Introduction and Summary

In 2016, the Medicare Rights Center’s (Medicare Rights) staff and helpline volunteers fielded more than 16,758 questions and issues through the organization’s National Consumer Helpline. Clients included Medicare beneficiaries, families, and caregivers across the country. As in previous years, clients were geographically and socioeconomically diverse, and needed help with a wide array of complex Medicare-related issues.

Medicare provides guaranteed health benefits to more than 58 million older adults and people with disabilities. These individuals and their families rely on Medicare for basic health and economic security. In this report, we analyze our 2016 call data to re-examine the top three reoccurring trends on the Medicare Rights national helpline: 1) Medicare Part B enrollment rules and pitfalls; 2) difficulties with Medicare Advantage (MA) health service denials and coverage rules; and 3) financial hardship affording Medicare Part D cost-sharing.

While these problems persist, Medicare Rights has worked with partners, policymakers, and the Centers for Medicare & Medicaid Services (CMS) to address them. To help prevent Medicare enrollment mistakes, for example, Medicare Rights developed the Beneficiary Enrollment Notification and Eligibility Simplification (BENES) Act, federal bipartisan legislation (see text box on “The Benes Act”). Medicare Rights also led the advocacy effort for CMS to extend the Medicare Part B time-limited equitable relief opportunity for Medicare beneficiaries who are enrolled in federal Marketplace plans instead of Medicare. We applaud CMS for extending this relief opportunity. Although these are important successes resulting from ongoing advocacy on behalf of beneficiaries, Medicare Rights continues to field many calls from individuals seeking other forms of Part B enrollment relief.

In this report, we:

- Revisit Part B enrollment as a confusing process for people transitioning from other types of health insurance coverage.
- Identify Medicare Advantage plan coverage and network issues.
- Highlight Medicare affordability concerns due to escalating Medicare Part D drug costs.

As in previous years, our client stories appear throughout the report to illustrate the real life struggles for people with Medicare.
**Medicare Part B Enrollment Pitfalls**

**Case Story**: Ms. B was covered by COBRA and undergoing cancer treatment. She declined to enroll in Medicare Part B because her employer incorrectly told her COBRA would pay as a primary health insurance payer after she went out on disability. While receiving expensive life-sustaining cancer treatment, the COBRA plan stopped paying primary and recouped a year of payments. Ms. B was left without health insurance, charged for thousands of dollars in medical bills, and threatened by providers to cut off her cancer treatment because she lacked insurance coverage for outpatient services.

Every year, the Medicare Rights National Helpline hears from Medicare beneficiaries who failed to enroll in Medicare Part B on time. In 2016 alone, helpline counselors responded to over 1,000 questions about Medicare Part B enrollment issues. Many beneficiaries face punitive enrollment penalties and gaps in health insurance coverage because they failed to enroll in Part B on time and must enroll in Part B during the Medicare General Enrollment Period. For very sick people with Medicare like Ms. B, waiting for health insurance coverage to kick in is a life and death matter. The overwhelming majority of people simply cannot afford to pay for their care without Medicare. One quarter of Medicare beneficiaries have less than $11,900 in savings. In this section, we review some of the common pitfalls in Part B enrollment.

For many people, transitioning from other types of health insurance coverage to Medicare is not an automatic process. For people like Ms. B who worked and had employer health insurance coverage, knowing when to enroll in Medicare falls on the beneficiary without proper notification from the Social Security Administration or Medicare. We find that many employers’ benefits departments lack the Medicare knowledge to guide their employees and retirees on Medicare enrollment. Whether due to the misinformation provided by employers or lack of access to reliable information about Medicare enrollment, enrolling in Medicare Part B at the right time after employer coverage ends is a challenge that many people can get wrong. Contributing to the problem is the lack of a formal notice about enrolling in Part B or how to use the Part B Special Enrollment Period (SEP), as well as a misunderstanding of Medicare’s coordination of benefits rules when people have other types of health insurance coverage.

The Part B SEP applies to people who have had employer health insurance coverage through current employment. For people over the age of 65, employer coverage can be from either the beneficiary’s own active employment or their spouse’s. People with disabilities under the age of 65 with Medicare can also access the Part B SEP if they have access to reliable information about Medicare enrollment, enrolling in Medicare Part B at the right time after employer coverage ends is a challenge that many people can get wrong. Contributing to the problem is the lack of a formal notice about enrolling in Part B or how to use the Part B Special Enrollment Period (SEP), as well as a misunderstanding of Medicare’s coordination of benefits rules when people have other types of health insurance coverage.

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meet the criteria for the Part B SEP, and would most likely run into problems with Medicare Part B enrollment.

The uncertainty about when to enroll in Medicare is magnified in situations where people who are eligible for Medicare have other types of health insurance coverage. Medicare Rights frequently receives calls from people like Ms. B who did not understand Medicare’s coordination of benefits rules. Many beneficiaries do not know that retiree coverage with few exceptions is almost always secondary to Medicare. Health insurance coverage provided through the Consolidated Omnibus Budget Reconciliation Act or COBRA is also always secondary to Medicare coverage. Hence, people with retiree coverage or COBRA will need to enroll in Medicare in order to have primary health insurance coverage. People with retiree coverage or COBRA who fail to enroll in Medicare will end up without a primary health insurance payer. In some cases, people may slip through and go unnoticed while the secondary health insurance erroneously continues to pay primary. Some beneficiaries explain that they are informed of this employer error only after they have incurred high medical costs. When this happens, Medicare-eligible beneficiaries run the risk of the insurer recouping all payments made to providers. Unfortunately, Ms. B is not alone in experiencing this type of worst case scenario. Understanding “current” employment versus other types of inactive employer coverage is imperative to getting Medicare enrollment right and avoiding the Part B enrollment pitfalls.
**Helping Clients with Medicare Advantage Denials of Care**

**Case Story:** Ms. R received a denial letter from her Medicare Advantage Plan HMO for a visit to the emergency ward of her local Florida hospital. She had used the facility before and confirmed that this was a hospital in her plan’s network. The denial letter states that the doctor she saw in the emergency room was not a network doctor. The reason for her visit was that during the night, she had gastrointestinal bleeding. Prior to this incident, Ms. R's doctor had placed her on blood thinners to help reduce her blood pressure. At that time, the doctor told her that if she ever began to bleed she should go directly to the emergency room to be examined. When she did go, the attending physician examined her, ordered tests, and performed an EKG. She paid an outpatient fee directly to the hospital. The plan denied payment of services because she was seen by an out-of-network physician. She wanted to understand how using an in-network hospital could result in this coverage denial and subsequent bill, and why this in-network facility could have out-of-network doctors. Ms. R and her spouse have a limited income and are unable to afford additional medical bills.

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**BENES Act**

If a person is receiving Social Security benefits as they reach Medicare eligibility, they are automatically enrolled into Medicare Part B. But as many people work later in life and defer their Social Security benefits, they may not be aware that such a deferral means they must actively enroll in Part B. Medicare’s complex enrollment rules can lead to these individuals missing enrollment deadlines, and can cause both those who must actively enroll and those who automatically enroll to mistakenly decline Part B. These mistakes can lead to lifetime late-enrollment penalties, higher-out-of-pocket costs, and gaps in coverage.

To prevent Part B enrollment mistakes, Medicare Rights supports the bipartisan Beneficiary Enrollment Notification and Eligibility Simplification (BENES) Act. Reintroduced in Congress in 2017, the BENES Act would modernize and simplify the Part B enrollment process.

The BENES Act would make two changes. First, it would provide a clear notification to individuals approaching Medicare eligibility about enrollment rules and how other insurance works with Medicare. Second, it would ensure people with Medicare do not experience a break in critical coverage by eliminating coverage gaps during a person’s Initial Enrollment Period and the General Enrollment Period (GEP) and bringing the GEP into alignment with the enrollment periods of other health insurance systems.

See [here](#) for more information on the BENES Act.
Similar to previous years, coverage- and denials-related calls present with the most frequency and represent 34% of all Medicare Rights helpline calls in 2016. Within this subset, calls related to denials of coverage comprise the majority at 45%. These counseling sessions included people calling about denials related to Part A (9%); Part B (16%); Part D (35%); and Medicare Advantage (40%). Within the Medicare Advantage plan denials of coverage, calls about denials of physician services continued to persist as a trend. Calls about denials for physician services comprise 40% of the overall denials of coverage for Medicare Advantage plans.

We hear from hundreds of Medicare beneficiaries dealing with similar types of denials for medically necessary services received, often unknowingly, from out-of-network providers. Recently, the Kaiser Family Foundation reported that Medicare Advantage plan networks vary by plan and region, stating that networks include an average of 46% of physicians.\textsuperscript{vii} As in Ms. R’s case, people routinely use in-network facilities only to find that providers are not always in their plan’s network. Despite the protections for people with Medicare who use emergency services, plans continue to deny coverage due to out of network providers.\textsuperscript{viii}

We also hear from beneficiaries who are unable to access needed care in their plan’s network because the pool of network specialists is limited and may result in long waiting periods for appointments. A caller residing outside of Portland, Oregon, for example, had to wait up to four months to get an appointment with a dermatologist in her plan’s network to remove cancerous skin tissue. Callers from remote or rural communities outside of metropolitan centers were

\textbf{Figure 2:} Calls on the Medicare Rights helpline in 2016 about Medicare coverage and denials.
forced to travel miles from their home to reach in-network providers because there were no in-network specialists located within miles of their service area.

A caller from rural Indiana, for example, was denied coverage for services she received from an out-of-network provider. She went to this physician because otherwise she would have had to travel over 35 miles to see an in-network doctor. The out-of-network physician she saw, ordered medically necessary x-rays, which determined that she had an aneurysm in her stomach and needed treatment.

Though beneficiaries have the right to appeal denials of coverage, for many people, navigating the Medicare Advantage appeals process is a stressful and onerous task. This leaves countless beneficiaries unable to take the necessary steps to access needed health care services. Medicare Advantage plan network restrictions experienced by many of our helpline callers, pose real challenges and barriers to health care access for Medicare beneficiaries. Our callers’ experiences navigating their Medicare Advantage plan networks reflect the troubling effects of managed care network restrictions. As the most recent Kaiser Family Foundation report’s findings state, “The breadth and scope of provider networks has the potential to affect out-of-pocket costs and quality of care for Medicare enrollees.”

Medicare Advantage

Medicare Advantage beneficiaries don’t always understand how their MA plans function and may not have all the information they need to make good plan choices or appeal plan decisions successfully.

Medicare Rights urges CMS to improve consumer education and to make data on plan-level appeals and grievances publicly available so that beneficiaries can incorporate the information into their decision making. Health plans should have the burden of proving coverage is not warranted, instead of requiring beneficiaries to mount effective appeals on their own. In addition, CMS should protect beneficiaries by holding them harmless if plans fail to comply with notice rules and requirements.

Information is valuable, but it is not enough on its own. In addition to increasing the information available to people with Medicare, adequate funding and support for entities that help beneficiaries make coverage decisions and navigate the appeals process, including State Health Insurance Assistance Programs (SHIPs), is essential.

See here for more information on Medicare Advantage appeals.
Clients Struggle to Afford their Prescription Drugs

**Case Story:** Ms. M called the helpline because she is taking a very expensive Part D covered medication for her multiple sclerosis. The brand name drug is an injection that she purchases at the pharmacy and administers in the home. Ms. M has a Medicare Advantage PPO with drug coverage. This medically necessary drug was initially denied by her plan, but with her doctor's assistance, she appealed and won. The plan then placed the drug in a high cost specialty tier 5. With the $1,600 copay, the cost for the medication that she has been taking for many years since her diagnosis is too high for her to access the drug. Ms. M had a retiree plan that paid secondary to Medicare, but she no longer has secondary health insurance coverage because it is too costly for her household budget. Though Ms. M is married with two dependent children in college, her household income is above the limits of the federal Extra Help program that could help her lower the cost of her medication. Before ending the call, Ms. M asked why she can’t appeal the tier of the specialty drug.

The affordability of health care costs continues to present as a sustained trend on the Medicare Rights National Consumer Helpline. Given that half of all people with Medicare lived on annual incomes below $26,200 in 2016, it is not surprising that callers continue to express concern and frustration about the affordability of their health care and prescription drug costs. Medicare affordability calls represent 20% of the national call data. These types of calls comprised questions about how to afford Part B premium costs (53%), Part D drug costs (43%), and other types of assistance (4%).

![Figure 2: Calls on the Medicare Rights helpline in 2016 about Medicare affordability.](image-url)
Our call data shows that it is not just beneficiaries who have very low incomes that are affected by surges in their Medicare health and drug costs. In 2016, 44% of our helpline callers who we screened for assistance programs such as Extra Help did not qualify. Increasingly, we find that middle-income families and Medicare beneficiaries diagnosed with chronic conditions also struggle to pay for medically necessary health care and medications. People like Ms. M, who must take very expensive medications to maintain their quality of life, often do not qualify for programs that can alleviate drug costs, such as the federal Extra Help program, due to stringent income and asset limits. In addition, callers like Ms. M who need to take specialty tier drugs are unable to appeal to their drug plans to lower the tier and the cost of the medication. A caller from Florida, for example, called the helpline on behalf of her brother, a Medicare beneficiary scheduled to undergo a kidney transplant. She was looking for drug assistance programs for Valcyte, a specialty tier, antiviral medication that her brother must take for six months post-surgery. They were informed by his drug plan that the monthly copayment is 25% of the cost for the drug, or $2,500. The beneficiary was above the Extra Help income limits to qualify for assistance. Without access to the process to appeal expensive specialty medications or assistance programs that can mitigate exponentially increasing drug costs, beneficiaries are left scrambling to find a way to pay for their prescription drugs.

### Affordability and Tiering Exceptions

Medicare Rights supports efforts to improve the affordability of prescription drugs for people with Medicare, including allowing “tiering exceptions” for drugs on a Part D plan’s specialty tier.

Part D plans organize covered drugs onto a formulary, and many plans utilize a tiered formulary, where medications are grouped into different cost-sharing categories. Many of the most expensive drugs are on the plan’s specialty tier. A tiering exception allows a consumer to request that their Part D plan make a specific high-cost drug more affordable when a similar, lower-cost medicine is available on a lower tier of their plan’s formulary. Currently, if the drug is on the specialty tier, beneficiaries cannot request that the plan reduce the cost.

Medicare Rights urges a change to these rules that unfairly penalize people who need specialty drugs.

See [here](#) and [here](#) for more information on prescription affordability including tiering exceptions.
Conclusion

As shown in this report, Medicare Rights’ 2016 helpline data provides a view of the persistent issues that our clients face as well as reasonable and actionable policy solutions. Beneficiaries depend on Medicare for their health and financial security. There is growing concern amongst people with Medicare that Medicare Advantage and Part D plans are placing roadblocks to accessing care by denying coverage or making it unaffordable. Many of these challenges, including those related to Medicare Part B enrollment, can be resolved with the passage of federal legislation, such as the BENES Act, and improved education. Despite the challenges, the Medicare program remains a vital health insurance program not only to the older adults and people with disabilities who depend on coverage but also to their families. Through both Medicare Rights’ client and policy initiatives, we will continue to work with policymakers to build a stronger and improved Medicare program for generations to come.

References

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8 42 C.F.R. § 422.113(b)(2)