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# Medicare Trends and Recommendations:

An Analysis of 2018-2019 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**

The Medicare Rights Center (Medicare Rights) is a national, nonprofit consumer service organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. In 2018-2019, Medicare Rights staff and volunteers addressed more than 37,000 questions and issues through the organization's national helpline. In addition, Medicare Rights' free and independent online reference tool Medicare Interactive, designed to help older adults and people with disabilities navigate the complex world of health insurance, answered 6.1 million questions for people with Medicare, their caregivers, and professionals. This report will feature select helpline trends and highlight the most commonly sought Medicare Interactive answers, providing a glimpse into the information and coverage needs of Medicare beneficiaries and their families.

Helpline callers and Medicare Interactive users are geographically and socioeconomically diverse and need assistance with a wide array of complex Medicare-related issues. In 2018-19, Medicare Rights served clients in all 50 states, Puerto Rico, and the U.S. Virgin Islands. Approximately 36% of helpline callers were living on incomes of less than \$19,000 per year. This number includes people dually eligible for Medicare and Medicaid, who represented 14% of all callers. Caregivers helping to resolve issues and asking questions for family members accounted for 20% of all helpline callers. Around 21% of helpline calls were by or for individuals under 65 who were eligible for Medicare due to disability. Medicare Interactive provides less robust demographic data on users, but such users represent both beneficiaries and the professionals serving them. The most popular sections in 2018-2019 included one on Medicare-covered services and one that introduces Medicare eligibility and coverage topics.

**Figure 1:**  
**List of Medicare Interactive Sections Sorted by Number of Page Views, 2018-2019**

Section Title	Page Views
1. Medicare-Covered Services	3,244,235
2. Medicare Basics	1,696,967
3. Medicare Health Coverage Options	1,233,004
4. Programs for People with Limited Income	1,030,411
5. Coordinating Medicare with Other Types of Insurance	685,731
6. Medicare Prescription Drug Coverage	520,867
7. Medicare Denials and Appeals	277,630
8. Introduction to Medicare	193,321
9. Types of Medicare Advantage Coverage	142,103

Source: Calendar year 2018-2019 Google Analytics data for [www.medicareinteractive.org](http://www.medicareinteractive.org).

People with Medicare and their families depend on the program for overall wellbeing and economic security. In 1963, two years prior to the advent of Medicare, an estimated 44% of Americans over 65 had no health insurance.<sup>i</sup> As one University of Pennsylvania historian notes, “In the early 1960s, the choices for uninsured elderly patients needing hospital service were to spend their savings, rely on funding from their children, seek welfare (and the social stigma this carried), hope for charity from the hospitals, or avoid care altogether.”<sup>ii</sup> Medicare fundamentally altered this reality, and today only around 1% of Americans over 65 have no health insurance.<sup>iii</sup> Further, since Medicare’s inception in 1965, the average life expectancy for adults 65+ has increased by five years.<sup>iv</sup> Statistics like these point to the twin need to protect Medicare and strengthen it for future generations.

Through client stories and data, this report seeks to put a face on the Medicare population today and the top issues facing people with Medicare and their families in Medicare’s 55th year. The report explores three top themes on Medicare Rights’ national helpline: 1) navigating Medicare Part B enrollment and overall health care affordability; 2) appealing Medicare Advantage (MA) denials of care; and 3) accessing and affording prescription drugs. The report also summarizes the most commonly searched for answers on Medicare Interactive.

Medicare Rights produces this report so that advocates, policymakers at the Centers for Medicare & Medicaid Services (CMS) and the Social Security Administration (SSA), elected officials, and other stakeholders can better understand the needs of beneficiaries and work toward greater accessibility and affordability in Original Medicare and Medicare Advantage.

## Helpline Trend

### Helping Clients Navigate Medicare Part B Enrollment and Health Care Affordability

**Case Story**— George turned 65 in 2014, and at the time was actively employed by a large employer. At age 67, he was laid off from his job and enrolled in COBRA, assuming that the coverage was adequate to meet his needs. George was never informed by his employer, the COBRA insurer, or his Social Security office that he needed to enroll in Medicare Part B.

George missed his Part B Special Enrollment Period and enrolled in Medicare Part B during the General Enrollment Period. Unfortunately, George misunderstood the nature of COBRA coverage, and had a medically necessary surgery during the period of time between the end of his active employer coverage and before Part B took effect. COBRA denied paying claims as primary coverage, resulting in over \$10,000 in out-of-pocket costs for George.

Part B enrollment mistakes like George's are common and can result in lifetime consequences for Medicare beneficiaries, including permanent enrollment penalties, higher out-of-pocket health care costs, and gaps in coverage that can present barriers in accessing medically necessary services. In 2019, an estimated 764,000 people with Medicare were paying a Part B late enrollment penalty (LEP), with the average LEP amounting to a 28% increase in an individual's monthly premium.<sup>v</sup> LEPs are one way that health coverage and care can become unaffordable for beneficiaries, but there are many others. In order to understand the need for measures to increase health care affordability for older adults and people with disabilities, it is crucial to recognize that the majority of Medicare beneficiaries have fixed incomes, with half of all beneficiaries living on incomes less than \$26,600 annually and approximately one-quarter on incomes less than \$15,250.<sup>vi</sup>

The Medicare Rights Center answers many questions about Part B enrollment and, more generally, health care affordability. In 2018-19, enrollment questions accounted for 23% of all helpline questions and 7.04% of visits to Medicare Interactive. During this same period, affordability questions represented 20% of all helpline questions and 13.88% of visits to Medicare Interactive. Taken together, helpline questions about enrollment and affordability accounted for 43% of all questions.

Helpline calls regularly demonstrate that beneficiaries and their families may lack timely, consistent information about Medicare enrollment and benefits—including how and when to enroll in Medicare, how Medicare works with other insurance, and costs that Medicare does and does not cover. Many people fail to enroll in a timely manner, due in part to incorrect advice from employers, benefits administrators, and/or health insurance companies. Currently there is little or no recourse for individuals to correct errors or reverse consequences such as late

#### Medicare Trends and Recommendations:

An Analysis of 2018-2019 Call Data from the Medicare Rights Center's National Helpline

enrollment penalties, coordination of benefits problems, and coverage gaps. Many people, too, are unaware of benefits that can help pay for Medicare costs, such as Medicare Savings Programs (MSPs) and the Part D Extra Help subsidy.

The majority of Americans are automatically enrolled into Medicare Parts A and B when they turn 65. However, as an increasing number of individuals continue to work past the traditional retirement age of 65, many are delaying Medicare enrollment. For those who are not receiving Social Security benefits, transitioning to Medicare is not an automatic process. Many people, like George, innocently assume they can continue to rely on the coverage they had prior to turning 65, including retiree benefits, Marketplace coverage, or COBRA. Lack of a universal written notice regarding the need for people to actively enroll in Part B when necessary, or the availability of information about the Part B Special Enrollment Period available to individuals in specific circumstances, compounds the problem.

At the same time, Medicare Rights' experience demonstrates how vital it is that those with limited incomes are screened for cost-assistance programs like MSPs and Extra Help. MSP enrollment can eliminate late enrollment penalties for those who made enrollment mistakes—and they also do much more. Through its helpline, Medicare Rights annually helps around 1,000 beneficiaries enroll in MSPs and related benefits. In 2019, this enrollment work was valued at \$8.8 million and helped ensure access to needed care and medicines. But more can be done to help increase the visibility of and access to Medicare cost-assistance programs.

## Policy Recommendation

### **BENES Act and Other Enrollment and Affordability Improvements**

Today, as in 1965 when the rules were written, most people are automatically enrolled in Medicare Part B at age 65 because they are receiving Social Security benefits. But a growing number of Americans are working later in life and deferring Social Security.<sup>vii</sup> In 2016, only 60% of Medicare-eligible 65-year-olds were taking Social Security, compared to 92% who were in 2002.<sup>viii</sup> Unlike those who are automatically enrolled, this growing cohort of employed older adults must actively sign up for Medicare, taking into consideration complex rules and timelines.

If this transition is mismanaged, individuals new to Medicare may face lifelong financial penalties, higher health care costs, gaps in coverage, and disruptions in care continuity. Unfortunately, as Medicare Rights' helpline data show, many people do make mistakes and, through no fault of their own, fail to enroll in Part B on time.

To help prevent such errors, Medicare Rights continues to support the bipartisan Beneficiary Enrollment Notification and Eligibility Simplification (BENES) Act (116<sup>th</sup> Congress, S. 1280/H.R. 2477), which would empower beneficiary decision-making and simplify the Part B enrollment process. The legislation was introduced in Congress in 2017 and reintroduced in 2019.

Despite the significant consequences of inadvertently delaying Part B enrollment, federal assistance for those who experience this misstep is quite limited. One pathway, known as equitable relief, allows some individuals to request immediate or retroactive enrollment into Part B and the elimination of their late enrollment penalties. However, equitable relief is only available to those who delayed Part B due to their reliance on misinformation from a federal employee, such as a Social Security or 1-800-MEDICARE representative. This leaves individuals who rely on misinformation from other sources, like an employer or a health plan, with no recourse.

The other opportunity—enrollment in a Medicare Savings Program (MSP)—is also highly restricted, available only to individuals with minimal income and assets.<sup>ix</sup> While those who qualify are able to avoid or eliminate lengthy waits for coverage and late enrollment penalties, this is not a retroactive fix; enrolling in an MSP does not undo the majority of health costs an individual incurred when they were without Part B coverage. Further, because MSP eligibility standards are so narrow, these programs are not viable solutions for most people.<sup>x</sup>

Medicare Rights supports strengthening these avenues for relief. Congress should expand the Social Security Administration's authority to grant equitable relief to individuals who receive and rely on incorrect information from non-federal sources, such as employers, health plans, and insurance brokers. Additionally, Congress should ease MSP access and eligibility rules so more people can enroll in the programs.

## Helpline Trend

### Helping Clients Appeal Medicare Advantage Denials

**Case Story**— Martin was in the hospital for two days and received a denial from his Medicare Advantage Plan for emergency care he received at an out-of-network hospital. His denial notice stated that coverage was denied because the plan had not received medical records from the hospital to document medical necessity. A Medicare Rights counselor helped Martin appeal the denial and communicate with the hospital, his primary care provider, and his plan, as he was being billed \$19,000 for the emergency services that his plan should have covered. After Medicare Rights' intervention and assistance with the appeal, Martin received a call from his Medicare Advantage plan stating that the denial was overturned. The outstanding bills were paid for by the plan, and Martin's only out-of-pocket cost was the standard \$50 copay for emergency care.

In 2018-19, 35% of Medicare Rights Center helpline callers had questions about Medicare Advantage coverage. Of these, 28% of callers were inquiring about a denial in coverage. A recent Office of Inspector General report stated that only 1% of Medicare Advantage enrollees appeal their denied claims. Yet for those who do appeal, the report found that plans reverse an estimated 75% of their own decisions, strongly suggesting that many of those denials are inappropriate.<sup>xi</sup> Plans have two opportunities to either approve or deny care for their members:

#### Medicare Trends and Recommendations:

An Analysis of 2018-2019 Call Data from the Medicare Rights Center's National Helpline

at the coverage determination, which can be appealed, and at the reconsideration of the coverage determination, which can also be appealed. Medicare Rights advises beneficiaries to appeal and ask for help from their doctors.

In situations such as Martin's, navigating a denial in the middle of a health crisis can be overwhelming. Often, helpline callers report confusion as to the reason for denials, uncertainty as to next steps, and a feeling of exhaustion regarding the complexity of resolving a denial of coverage. As the popularity of Medicare Advantage Plans continues to grow, a clear and straightforward appeals process, as well as increased oversight to make sure that denials are appropriate, is imperative to ensuring that Medicare beneficiaries are receiving adequate access to medically necessary services and care.<sup>xii</sup> Beneficiaries who forgo appeals run the risk of losing access to care or being burdened with large medical bills for uncovered services. Too often, they do not appeal because they are confused by the rules, deadlines, or the need to appeal at all.

## **Policy Recommendation**

### **Medicare Advantage Appeals Improvements**

The Medicare Advantage appeals process is unnecessarily complicated, often trapping beneficiaries in a burdensome struggle to access care. Medicare Rights urges the Centers for Medicare & Medicaid Services (CMS) to strengthen and streamline this system, working with Congress in any areas where the agency lacks the authority to make necessary changes.

Reforms are needed across the Medicare Advantage appeals process, including to how plans communicate with beneficiaries. Under current rules, when plans issue a denial, they are required to notify the affected enrollee in a timely manner. This notification should contain everything the enrollee needs to determine next steps, which may involve pursuing an appeal. Without such notice, beneficiaries may not understand their rights, how to appeal, or even that they have been denied coverage. Despite the importance of this obligation, a report from the U.S. Department of Health and Human Services Office of Inspector General (OIG) found that many plans fail to comply. In 2015, 45% of Medicare Advantage contracts sent denial letters with incomplete or incorrect information.<sup>xiii</sup>

Medicare Rights urges CMS to work with Congress to ensure plan compliance with notification requirements, and to strengthen oversight and enforcement authorities that may be needed to do so. This includes ensuring the notices are correct, promptly delivered, available in languages other than English, and accessible to people with varying levels of health literacy. Medicare Rights also supports invalidating and immediately escalating denials that were not accompanied by proper notice.

Concerningly, insufficient notice may be a factor in the low rate of filed appeals. As mentioned elsewhere, from 2014 to 2016, beneficiaries and providers appealed only 1% of service and

#### **Medicare Trends and Recommendations:**

An Analysis of 2018-2019 Call Data from the Medicare Rights Center's National Helpline

coverage denials. Of the decisions that were appealed, a stunningly high number—75%—were overturned by the plan, with independent reviewers at higher levels issuing additional reversals.<sup>xiv</sup> While overturned denials do not necessarily mean that plans acted inappropriately regarding the initial request, that same year a CMS audit found that 56% of Medicare Advantage contracts did indeed make inappropriate denials.<sup>xv</sup> Given increasing Medicare Advantage enrollment (more than 24 million people in 2020), even low rates of inappropriate denials can create and exacerbate significant access problems.<sup>xvi</sup> And as OIG notes, each overturned denial represents an instance in which beneficiaries and providers had to take an extra step to obtain needed payments and services.<sup>xvii</sup> For beneficiaries with urgent health conditions and those who face other barriers to care—such as language issues, a lack of cultural competency, transportation limitations, and structural or individual racism—the administrative burden may be too much to bear, causing them to abandon their appeal and forgo needed services.

At the very least, these findings suggest a pattern that warrants attention and correction. Medicare Rights is extremely concerned about inappropriate denials, which can impede care and lead to worse health and higher costs for beneficiaries. The consequences may be even more severe for those whose inappropriate denials are never remedied—a problem of unknown size, since 99% of initial plan decisions go unchallenged.<sup>xviii</sup>

To encourage accurate initial plan coverage decisions—and reduce the number of people who need to file an appeal—Medicare Rights urges CMS to increase its oversight of and penalties for Medicare Advantage Plans that inappropriately deny care.<sup>xix</sup> This includes tracking initial plan coverage decisions and making this data publicly available, as well as conducting program audits more frequently and incorporating those findings into Medicare Advantage Plan Star Ratings in more concrete and transparent ways. CMS must also notify beneficiaries about plan violations.

As part of this effort, Medicare Rights urges CMS to specifically monitor for high initial denial and overturn rates as well as for low appeal rates, and for patterns in the issuance of inappropriate denials, such as for specific services. Any trends that emerge should lead to a more comprehensive review to determine the underlying cause of the error and to obligate the plan to resolve it. Plans that regularly engage in such practices should lose the ability to enroll new members—or, if the violations are severe, to contract with CMS—until corrections are made and publicly documented. Offending plans should remain subject to higher levels of review going forward.

CMS should also work with Congress to make the appeals process more manageable and accessible. In particular, the first level of appeal should be handled by an independent entity, rather than the plan itself. This would simplify the system, help ensure that beneficiaries have more timely access to care, and, along with the changes outlined above, encourage plans to make accurate initial coverage determinations.

#### **Medicare Trends and Recommendations:**

An Analysis of 2018-2019 Call Data from the Medicare Rights Center's National Helpline



## Helpline Trend

### Helping Clients Access and Afford Prescription Drugs

**Case Story**— Diana had been enrolled in a Part D plan with the same company for several years. When she received her Explanation of Coverage prior to Medicare’s Fall Open Enrollment, she learned that one of her drugs would not be on the formulary in the coming year. The drug was a brand name with no available generic, and to pay for the drug out of pocket would cost over \$80,000 per year. To avoid paying devastating out-of-pocket costs for her critical medications, Diana was faced with the challenge of either searching for a new plan with the drug on its formulary or navigating the Part D appeals process with her current plan to request a formulary exception. Medicare Rights assisted Diana in evaluating Part D plans during Fall Open Enrollment and counseled her on the appeals process.

Rising drug costs, difficulty accessing necessary medications, and trouble navigating the Part D landscape continue to be top issues for Medicare Rights Center callers. In 2018-19, 10% of callers contacted the helpline with questions about Part D coverage or denials.

As of 2019, the vast majority of Medicare beneficiaries are enrolled in a Part D plan, either through a stand-alone Part D Plan or a Medicare Advantage Plan.<sup>xx</sup> During Medicare’s Fall Open Enrollment, many beneficiaries, caregivers, and advocates turn to Medicare.gov’s Plan Finder tool for information about coverage options. During the 2018 and 2019 Fall Open Enrollment periods, Medicare Rights assisted hundreds of helpline callers in reviewing Part D and Medicare Advantage Plans with drug coverage using the Medicare Plan Finder tool. Beneficiaries and their caregivers frequently inquire as to which plan best fits their needs in terms of formulary, drug restrictions, preferred pharmacies, and overall costs.

In 2019, CMS debuted a new Medicare Plan Finder tool that made many improvements to the previous version. But the tool still has critical flaws, and many beneficiaries still struggle to use it without the assistance of an advocate. Informed by many sessions assisting Medicare beneficiaries with Plan Finder, Medicare Rights recommends changes to improve Plan Finder accuracy and personalization features, expand drug and pharmacy search options, increase plan filter options, and expand search options for dually eligible individuals.

Even in situations in which beneficiaries have utilized Plan Finder successfully and selected appropriate drug coverage, they may continue to face hurdles in accessing drugs. Like Diana, helpline callers often note that their drug is off-formulary in their current plan. Many plans place utilization management controls—such as prior authorization, quantity limits, or step therapy—on medications, making it that much harder for beneficiaries to access needed medicines.

#### Medicare Trends and Recommendations:

An Analysis of 2018-2019 Call Data from the Medicare Rights Center’s National Helpline

## Policy Recommendation

### Prescription Drug Access and Affordability Improvements

People with Medicare are often uniquely exposed to high and rising prescription drug prices. This is partly due to utilization and health status, as Medicare Part D enrollees take an average of four to five prescriptions per month, and more than two-thirds have multiple chronic conditions.<sup>xxi</sup> At the same time, many Medicare beneficiaries live on fixed or limited incomes that cannot keep pace with rapidly escalating drug prices. As noted elsewhere, half of all Medicare beneficiaries—nearly 30 million people—live on \$26,200 or less per year, and one in four individuals has less than \$14,550 in savings.<sup>xxii</sup> As a result, most people with Medicare cannot afford to pay more for care—yet drug prices continue to climb. Price hikes on brand name drugs have exceeded the rate of inflation every year since at least 2006,<sup>xxiii</sup> and new drugs are launching at ever-higher price points.<sup>xxiv</sup>

These trends have serious health and financial implications for older adults and people with disabilities. Bankruptcy is on the rise among people 65 and older, and medical debt is a big reason why, accounting for 60% of those filings.<sup>xxv</sup> And beneficiaries who cannot purchase their medications or pay for coverage may be forced to go without care—leading to worse health outcomes and quality of life. The cost to the Medicare program is also significant, as beneficiaries who forgo needed care and experience declining health as a result may need more costly interventions later, like emergency department or inpatient care.<sup>xxvi</sup>

Immediate congressional action is needed to transform the nation’s drug pricing system in ways that will lower prices, strengthen Medicare, and promote the wellbeing of those who rely on its coverage. Needed measures include authorizing Medicare to negotiate prices for certain drugs; improving transparency and accountability throughout the system; and restructuring the Part D benefit in ways that would cap beneficiary out-of-pocket costs at a maximum of \$2,000 per year, reduce the federal government’s liability, and better align pricing incentives.

Meaningful access to prescription medications cannot be achieved without improvements to the Medicare Part D appeals process. Though intended to function as a safety valve that allows older adults and people with disabilities to obtain needed prescriptions, the system is overly onerous and deeply flawed. Its inefficiencies can lead to delays in access to medications, abandonment of therapies, reduced adherence to treatment protocols, worse health outcomes, and higher costs. Bipartisan legislation, the Streamlining Part D Appeals Process Act (116<sup>th</sup> Congress, S. 1861, H.R. 3924), offers a commonsense solution: allow a refusal at the pharmacy counter to serve as the plan’s initial coverage determination. This simple change would give people with Medicare more timely information about their plan’s coverage decision and eliminate unnecessary steps within the Part D appeals process—lessening burdens on beneficiaries, plans, providers, and pharmacists.

## 2020 Helpline Trends Preview

### Medicare and Coronavirus (COVID-19)

At the time this report was prepared, the Medicare Rights Center's helpline was beginning to see trends emerge related to the globally devastating COVID-19 pandemic, in addition to the 2018-19 trends outlined in this report. Older adults and people with disabilities are at higher risk of illness and hospitalization during the pandemic<sup>xxvii</sup>—with people of color facing additional risks and systemic disadvantages<sup>xxviii</sup>—and existing enrollment, affordability, and access challenges within the Medicare program have been exposed and worsened by the ongoing public health emergency and related economic struggles.

The U.S. workforce has experienced broad layoffs in many industries, leaving many Medicare-eligible individuals scrambling for coverage as they suddenly lose employment. These helpline callers often need immediate access to Medicare. While some may be able to use the Part B Special Enrollment Period and other special enrollment periods to select supplemental or drug coverage, others may have to wait until the next General Enrollment Period to sign up, and until July 2021 for coverage to begin. Additionally, because many individuals have experienced a loss of income, Medicare Rights' helpline has seen a spike in questions pertaining to programs that assist with Medicare costs, such as Medicare Savings Programs, Medicaid, and Extra Help.

The helpline has also seen increase in questions related to accessing care in skilled nursing facilities (SNFs), accessing telehealth, securing needed medications, and more. Many Medicare beneficiaries with complex conditions who are receiving skilled care or rehabilitation services in a SNF have needed assistance navigating several of the new or temporarily waived requirements related to SNF care and benefit periods. Others have sought guidance on accessing telehealth, including questions about payment, which providers are covered, and which technologies qualify for telehealth. Medicare Rights has been keeping abreast of CMS, SSA, and congressional modifications to Medicare during this time and updating beneficiaries and advocates through our existing communications channels and online here:

<https://www.medicarerights.org/medicare-watch/2020/05/12/what-you-need-to-know-about-coronavirus-and-medicare-coverage>.

## Conclusion

Medicare is a popular and vital program. The Medicare Rights Center's 2018-19 helpline data provides an overview of the recurring issues beneficiaries and their families encounter. This report provides actionable policy recommendations that would simplify the Medicare enrollment process and increase health care affordability, ease the burden of navigating complicated appeals processes, and make prescriptions more accessible and affordable for Medicare beneficiaries. Medicare Rights looks forward to continuing to work with CMS, SSA, fellow advocates, and beneficiaries to continually improve and protect the Medicare program.

### Medicare Trends and Recommendations:

An Analysis of 2018-2019 Call Data from the Medicare Rights Center's National Helpline

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### Medicare Trends and Recommendations:

An Analysis of 2018-2019 Call Data from the Medicare Rights Center’s National Helpline

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