

Congress Should Appropriate Funds for Consumer Assistance Programs in Every State



KEY POINTS

- » Consumer assistance programs (CAPs) need a 2022 appropriation and ongoing permanent funding.
- » CAPs play a crucial role in helping consumers with health insurance and billing issues.
- » The need for CAPs will increase as the health care landscape changes.

Among consumers across the country, there is a tremendous need for assistance with health insurance and health care billing issues.

Congress recognized this need when it permanently authorized grants to offices of health insurance consumer assistance and health care ombudsman programs in 2010 and appropriated first-year funding for them. These programs are collectively known as “consumer assistance programs” or “CAPS.” However, Congress has not appropriated funds for these programs since 2010, leaving many states without this important resource. In 2022, as the No Surprises Act goes into effect and the nation faces a health care landscape altered by the pandemic, Congress should appropriate \$400 million for health consumer assistance programs, to remain available without fiscal year limitation, and establish a permanent appropriation for them.

Consumer Assistance Programs Play a Critical, Expert Role in Ensuring That Consumers Can Access Insurance Benefits and Health Care

The U.S. health care system is exceedingly complex. And health care consumers regularly need expert assistance to understand how to use their health insurance; resolve medical bills that are often confusing and conflicting; appeal health plan decisions; understand their insurance rights and responsibilities; and secure a specific service, treatment or medication. Resolving health care problems often requires technical knowledge that is beyond the skills of even highly educated consumers.

Congress recognized this and established an innovative grant program to create and support state “consumer assistance programs” (CAPs) as part of the Affordable Care Act in 2010.¹ These programs assist people no matter what kind of coverage they have: job-based, union-sponsored, public, or individually purchased.² In fact, insurance notices, including explanations of benefits and notices of adverse determinations, are legally required to inform enrollees about the availability of consumer assistance

programs.³ The initial federal seed money of \$30 million funded CAPs in 40 states, but Congress has not appropriated any additional funds since. Some states did not apply when federal funds were available due to the limited funding offered, and some others have since closed their programs. Currently, 19 states do not provide consumer assistance programs at all.

Some states use their own funds to continue to provide some assistance, but most of these programs lack adequate resources and face a variety of challenges. For example, there will be new demands with implementation of the new federal No Surprises Act. The vast majority of consumers who are eligible for CAP assistance are enrolled in employer-sponsored plans (about 150 million enrollees), and the majority of these plans are federally regulated. However, CAPs that operate with no federal funding cannot manage this large scope of work.⁴ Furthermore, CAPs should but often cannot provide outreach and develop expertise in evolving areas, including parity in treatment for mental health and substance use disorders under the Mental Health Parity and Addiction Equity Act, public health in the wake of the coronavirus pandemic and health equity.

For patients, addressing their health care problems can be emotionally intense, often involving life and death circumstances. Many consumers struggle to understand how their insurance works and how to resolve problems when they arise. Surveys show that about one out of four consumers avoids or forgoes care because they do not know what their plan covers.⁵ When people do get or seek care, if an insurer denies payment, getting a denial reversed may be a matter of providing additional medical evidence — a feat that is beyond many consumers’ abilities. And data reported by some insurers indicate that consumers appeal less than two-tenths of 1% (0.002) of denied insurance claims, indicating that many consumers do not even know whether or how to appeal a denied claim.⁶

Federal law requires CAPs to “collect, track and quantify problems and inquiries encountered by consumers.”⁷ This data is then reported back to regulators to identify areas where enforcement activities may be required. The New York State experience illustrates this important sentinel and consumer advocacy function that CAPs can serve.⁸ In 2014, the FDA approved an important but expensive drug that cured patients with Hepatitis C. Initially, health insurance companies put in place barriers to accessing this cure, such as requiring patients to get sicker — or to have symptoms of kidney failure



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— before they would approve medication. The [New York CAP](#) successfully appealed a number of these cases and then brought their data to state regulators and the state attorney general, who secured a settlement with the insurance industry to ensure medically appropriate access to life-saving treatment for patients with Hepatitis C.⁹

Remaining CAPs throughout the country have developed deep expertise to help with consumer issues. For example, staff of the Connecticut Office of the Health Care Advocate includes nurse consultants who are skilled in behavioral health treatment and long-term care, as well as lawyers and paralegals.¹⁰ New York’s Community Health Advocates program is a network of nonprofit organizations with a centralized hotline. The network includes legal services programs that specialize in Medicaid, Medicare and private coverage; community organizations with reach into various ethnic and linguistic communities; groups that assist small businesses; and organizations that focus on services ranging from independent living for people with disabilities to maternal and infant care.¹¹ Other state consumer assistance programs are located in nonprofit organizations under contract with their state, in independent state offices, in attorneys general offices and in insurance departments, and these locations bring different types of expertise.

When the Federal Government Implements the No Surprises Act, Consumer Assistance Programs Will Have Additional Responsibilities

The No Surprises Act provides consumers with extensive protections against surprise medical billing. Consumers can no longer be billed more than the in-network cost-sharing rate for emergency services, nor can they be billed for certain out-of-network services performed at in-network facilities, unless the consumer has consented to the higher charges in advance. Disputes will still arise, for example, about whether a health plan accurately identified claims as surprise medical bills that are subject to federal protections, whether a provider overcharged a patient for cost-sharing, whether services were emergent, whether a patient was adequately notified of an out-of-network service and consented, and whether a patient has additional rights to continuity of care because the plan network has changed. But now consumers can appeal if they do not think their health plan correctly applied protections against surprise medical billing, and CAPs will thus have new duties to help them with this process.

The No Surprises Act provides consumers with extensive protections against surprise medical billing. CAPs will help them exercise their new rights.

Consumer Assistance Programs Save Consumers Millions of Dollars Each Year

A sampling of CAPS' annual reports illustrates the considerable help they provide:

- » In fiscal year 2020, the Maryland Health Education and Advocacy Unit recovered or saved consumers \$4.3 million. Among its cases was an **infant with a rare spinal muscular disorder who received a life-saving medication** – the only known treatment to cure the disease – which the health plan had previously denied.¹²
- » Community Health Advocates (CHA), administered by the [Community Service Society in New York](#), served consumers in over 32,000 cases, saving New Yorkers \$37 million in health care and insurance costs in fiscal year 2020. For example, CHA **saved one patient \$65,000 (more than her annual salary) when she was billed for out-of-network charges for a COVID-19 hospitalization.**¹³
- » The **Connecticut Office of the Healthcare Advocate** saved consumers \$6.2 million in calendar year 2019. For example, **when an adolescent boy was in crisis, the Advocate helped him get psychiatric residential treatment services that his plan had initially denied,** followed by outpatient services.¹⁴
- » The **Rhode Island Parent Information Network**, which **includes a peer-run hotline**, is a consumer assistance program that takes referrals from the Rhode Island Office of the Health Insurance Commissioner. It saved consumers \$3.9 million in 2018-2020.¹⁵
- » The **Mississippi Health Advocacy Program**, listed as a resource by the Mississippi Department of Insurance, received private grant funding to continue its work in three cities when federal funding for statewide work ended. The program helps families – many of whom are insured for the first time in their lives - understand how to retain and use their insurance. **It also tackles balance-billing issues, which are illegal under a Mississippi law**, saving consumers in the three cities \$778,400 in calendar year 2019.¹⁶

The Federal Government Should Provide Permanent Appropriations for Consumer Assistance Programs and Clarify Their Administrative Independence

In 2010, Congress appropriated \$30 million for consumer assistance programs and authorized further funding – but has not since appropriated

it. Some CAPs closed entirely when federal funding disappeared, and those that remain are severely underfunded relative to the level of consumer need. These programs also need the assurance of ongoing federal funding in order to hire the staff that they need and to make basic investments in outreach, training and data systems.

Congress should appropriate \$400 million for CAPS in 2022 so they can adequately provide services to hundreds of millions of U.S. residents who struggle with health insurance, to help resolve problems with surprise medical bills under the No Surprises Act, and to help people access services that are required under behavioral health parity laws.¹⁷ Further, Congress should establish permanent, ongoing funding for consumer assistance. For example, to establish an ongoing funding mechanism, the government could assess all health plans – including the self-funded employer-based plans that are beyond the reach of state regulators – a small fee that would support consumer assistance. An assessment of 0.0005 (5% of 1%) applied to gross premium revenue from private health insurance, including grandfathered and non-grandfathered group and nongroup policies, would raise about \$400 million the first year.

Federal law and/or administrative action should clarify that states and territories can do either of the following:

- » Directly establish an independent office of health insurance consumer assistance or contract with a nonprofit to do so.
- » Allow nonprofit organizations to directly apply to the federal funding agency (CMS) to become consumer assistance programs in cases where state governments do not designate a program.

Conclusion

The American health care system is daunting to navigate for even the most sophisticated patient. Few consumers understand the nuances of insurance, including cost-sharing rules; drug formularies; clinical criteria; claims processing; and when and how to appeal a denied benefit, treatment, or payment of a claim. CAPs play an essential role in helping consumers navigate our complicated health care system. Laws enacted in recent years, such as the federal No Surprises Act, the Mental Health Parity and Addiction Equity Act, and the Affordable Care Act, provide enhanced consumer protections. A well-funded infrastructure of CAPs can make these legal promises a reality for millions of consumers.

Consumer assistance programs play an essential role in helping consumers navigate our complicated health care system.

Endnotes

¹ R. Grob, M.Schlesinger, S. Davis, D. Cohen, and J. Lapps, “The Affordable Care Act’s Plan for Consumer Assistance with Insurance Moves States Forward But Remains a Work in Progress,” *Health Affairs* 32, no. 2 (2013), <https://www.healthaffairs.org/doi/10.1377/hlthaff.2012.1090>.

² Under the ACA, these programs were to assist people in filing complaints and appeals with their group or individual health insurers, collect data to track problems arising for consumers, educate consumers about their rights, assist with enrollment questions or problems in group and individual coverage, and help resolve any problems with receipt of premium tax credits. Public Health Services Act, 2793 (42 USC 300 gg-93). A number of ACA-established consumer assistance programs operate as “all payer” programs, which also help people with problems and questions related to public health coverage.

³ Public Health Services Act, 2719 (42 U.S. Code § 300gg–19).

⁴ G. Claxton et al., *2020 Employer Health Benefits Survey* (Kaiser Family Foundation, October 8, 2020), <https://www.kff.org/report-section/ehbs-2020-summary-of-findings/>.

⁵ Hannah Horvath, “Health Insurance Literacy Survey 2020: Widespread confusion continues in an election year,” *Policygenius* (November 16, 2018), <https://www.policygenius.com/blog/health-insurance-literacy-survey-2020/>; R.Tipirneni, M. Politi, and J. Kullgren, “Association Between Health Insurance Literacy and Avoidance of Health Care Services Owing to Cost,” *JAMA Network Open* 1, no. 7:e184796 (November 16, 2018), <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2714507>.

⁶ K. Pollitz and D. McDermott, *Claims Denials and Appeals in ACA Marketplace Plan* (Kaiser Family Foundation, January 20, 2021), <https://www.kff.org/private-insurance/issue-brief/claims-denials-and-appeals-in-aca-marketplace-plans/>.

⁷ Public Health Services Act, 2793 (42 USC 300gg-93(c)(2)).

⁸ C. Tracy, E. Ryder Benjamin, and C. Barber, *Making Health*

Reform Work: State Consumer Assistance Programs (Community Service Society, September 2010), <https://www.cssny.org/publications/entry/making-health-reform-workSept2010>.

⁹ New York State Office of the Attorney General, “A.G. Schneiderman Announces Major Agreement With Seven Insurers To Expand Coverage Of Chronic Hepatitis C Treatment For Nearly All Commercial Health Insurance Plans Across New York State,” Press Release, April 26, 2016, <https://ag.ny.gov/press-release/2016/ag-schneiderman-announces-major-agreement-seven-insurers-expand-coverage-chronic>.

¹⁰ State of Connecticut Office of the Health Care Advocate, Facebook Page, <https://www.facebook.com/State-of-Connecticut-Office-of-the-Healthcare-Advocate-301102456997/>, see posts May 25-May 28, 2021.

¹¹ Community Health Advocates web page, “Who We Are,” <https://communityhealthadvocates.org/who-we-are/>, accessed on June 15, 2021.

¹² Health Education and Advocacy Unit, Consumer Protection Division, Office of the Attorney General, Maryland, *Annual Report on the Health Insurance Carrier Appeals and Grievances Process, FY 2020*, <https://www.marylandattorneygeneral.gov/CPD%20Documents/HEAU/Anual%20Reports/HEAUannrpt20.pdf>.

¹³ Community Health Advocates, *2020 Annual Report*, https://smhttp-ssl-58547.nexcesscdn.net/nycss/images/uploads/pubs/CHA_Report_2020_V61.pdf.

¹⁴ Office of the Healthcare Advocate, State of Connecticut, *2019 Annual Report*, <https://portal.ct.gov/-/media/OHA/OHA2019AnnualReport.pdf>.

¹⁵ Rhode Island Parent Information Network, *2020 RIPIN Annual Report*, <https://ripin.org/ripin/wp-content/uploads/2021/04/2020-RIPIN-Annual-Report-Final-web.pdf>.

¹⁶ Health Help Mississippi, Get Covered Stay Covered, *Final Narrative Report to Kellogg Foundation, #P3034616*. November 25, 2019.

¹⁷ Funds should remain available without fiscal year limitation.

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