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Patient Champions or Profit Chasers? The Rise of Profit-Driven Patient Advocacy and Legal Implications for Managed Care Organizations

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Summary

- While patient advocacy organizations have traditionally operated as non-profit entities in the healthcare space, private, for?profit patient advocacy is on the rise.
- While such advocates may still deliver real value to patients, the introduction of a profit motive undercuts the financial independence of the advocate and challenges the loyalty owed to patients. This new and growing model introduces significant risk into the relationship between patients, providers, and payors.
- This article looks at the origins of patient advocacy and the shift toward a profit-driven approach, explains the business models behind it, and highlights key risk areas that health plans should be prepared to navigate.

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Patient advocacy organizations have traditionally operated as non-profit entities in the healthcare space, supporting patients through the complexities of the healthcare system and serving as healthcare experts whose sole loyalty is to the patient. Such advocates were a central part of the early development of the patients' rights movement, and eventually that role grew into non profit organizations designed to help patients navigate care and coverage.

However, a different model is now on the rise: private, for?profit patient advocacy. While such advocates may still deliver real value to patients, the introduction of a profit motive undercuts the financial independence of the advocate and challenges the loyalty owed to patients. This new and growing model introduces significant risk into the relationship between patients, providers, and payors, carrying with it misaligned incentives, privacy vulnerabilities, potential conflicts of interest, and increased exposure to litigation and fraud.

For managed care organizations, the rise of for?profit advocacy can distort care decisions, increase out-of-network utilization, escalate disputes, and complicate compliance and cybersecurity. For patients, it can mean paying substantial fees to entities that are largely unregulated and not always transparent about their incentives. This article looks at the origins of patient advocacy and the shift toward a profit-driven approach, explains the business models behind it, and highlights key risk areas that health plans should be prepared to navigate.

From Patients’ Rights to Organized Advocacy

The concept of patient advocacy emerged prominently in the 1970s as part of the broader patients’ rights movement. Hospitals and physicians held significant informational and structural power over patients’ access to care and understanding of their options. Early proposals for such advocates envisioned a patient representative within the hospital or healthcare facility who would “assist the patient in learning about, protecting, and asserting his or her rights within the health care context.”

Such advocates would serve either as a representative, advocating on a patient’s behalf as to specific healthcare decisions, or as an “ombudsman” who would seek out broad problem areas and propose solutions, without participating in actual decision making. Over time, non-profit organizations developed this vision to provide broader case management and financial aid services to patients. As an example of this model, the non-profit Patient Advocate Foundation (PAF) was founded in 1996 and helps patients with chronic illness navigate denials, appeals, and coverage disputes, as well as offering co?pay relief and other financial aid. Other non-profits and foundations target specific diseases, populations, or forms of financial need.

These non-profit models often serve particular populations and are donor- or grant?funded. Their primary “customers” are patients and caregivers, not paying clients or investors. While such organizations are not immune from conflicts of interest or misalignment of goals or incentives, their non-profit status has generally allowed them to retain the traditional patient-centered loyalty that is the hallmark of the early patient rights movement.

The Rise of Private Professional Advocacy

Such non-profit advocacy organizations often cannot serve all patients due to mission or funding limitations, and it was perhaps inevitable that the desire for guidance navigating an increasingly complex healthcare system would outstrip the ability of such organizations to meet that demand. Beginning in the early 2000s, private, professional, for?profit advocates began to gain popularity. This growth occurred in response to several factors affecting the healthcare industry:

- **Increasing costs and complexity.** Prior authorization requirements, tiered networks, specialized coverage criteria, and member cost sharing rules have made navigating benefits and claims more complex. While payors offer customer service resources to assist members to understand their plans, patients may seek out an “independent” voice, especially when facing life-altering diagnoses or potentially costly services.
- **Growth of managed care and utilization review.** As plans emphasize utilization management to avoid runaway costs and ensure service availability, patients and providers encounter additional scrutiny of referrals, out-of-network authorizations, and the medical necessity of high-intensity or novel services. This friction supports a market for “experts” who promise to “fight the insurance company.”
- **Conflict of interest concerns.** Patients and providers may be skeptical of non-profit organizations that receive industry funding or of hospital-based patient-relations offices they see as aligned with institutional interests.
- **Demand for intensive, individualized support—for those who can pay.** In high-dollar, high-complexity situations, families are willing to pay significant sums for specialized advocacy, particularly where approval of a desired course of treatment is uncertain.

Out of these demands grew for?profit advocacy businesses, often marketing themselves as insiders who understand how to “work within the system.” And professional advocate network organizations grew up to support these businesses, providing marketing, training, templates, and legal support, and establishing national directories of professional advocates.

Given the realities of modern healthcare systems, the professional advocate is almost certainly a permanent part of the healthcare landscape and potentially an increasing presence in the relationship between patient, provider, and payor. The balance of this article discusses the current state of professional patient advocacy and the potential risks to healthcare payors.

Private Advocacy Cost Models

The key difference between traditional advocates and the professional advocate—and a key driver of risks associated with professional advocacy—is the compensation of the for-profit advocate. How patients compensate professional advocates shapes the pressures on the advocate's loyalty to the patient's interest and the risks created by the advocate's involvement. Common models include:

- **Hourly billing**. Advocates may charge $100–$500 per hour or more. In complex disputes, bills can reach thousands or tens of thousands of thousands of dollars. Patients may not fully understand that they are paying for effort, not a positive outcome.
- **Flat fees**. Fees are to a specific transaction—such as claims submission or assistance appealing a particular claim—or operate on a fee per service, monthly, or hybrid of these models. Fixed fees are often appealing for patients but may incentivize the advocate to cut corners to minimize time spent.
- **Value based.** These potentially troubling arrangements tie compensation to financial results, such as a percentage of reimbursement obtained for out-of-network claims or a fee based on cost savings as compared to billed charges. While these arrangements resemble contingency-fee arrangements, they can create a powerful incentive for the advocate to steer patients toward out-of-network providers and high-cost care where the "savings" and resulting fee for the advocate are larger.

Patients, especially those in crisis, may not be able to fully understand or evaluate these fee structures. This creates risk that financially vulnerable patients may end up paying thousands of dollars for services that do not materially change their outcomes or that expose them to additional risk.

For payors, these models often translate into aggressive, high-volume appeals, pressure campaigns, and litigation strategies potentially driven as much by the advocate's economic interests as by clinical needs.

Impacts on Healthcare Claims and Litigation

The fee models discussed above pose a risk of several negative impacts on the healthcare claims process.

Increased Out-of-Network Utilization

Advocates frequently market their ability to secure coverage for out-of-network providers or facilities. While there are circumstances where patients genuinely require services that are unavailable in-network, advocates may steer patients to out-of-network providers due to undisclosed referral relationships or financial ties, or simply greater reimbursements available through approved out-of-network coverage as compared to contracted rates, driving higher advocate fees.

Advocates may thus encourage patients to bypass adequate in?network options on the assurance that the advocate can obtain coverage or negotiate deep discounts, and then aggressively pursue “network gap exceptions” based on highly specialized criteria (which may or may not be genuinely required by the patient) and a narrow interpretation of the adequacy of in-network providers.

Advocates may also take advantage of urgent or emergency requests to compress the timeline in which an in-network provider must be located to increase the likelihood of an out-of-network referral or approval.

For payors, the effect is not just higher out-of-network spend. It can also disrupt network utilization and undermine efforts to manage quality and cost through contracted networks. Over time, this behavior erodes the predictability and integrity of the benefit structure for all members.

Increased Litigation and Settlement/Reimbursement

In high-cost or specialized clinical areas, these advocacy tactics often lead to a marked increase in litigation due to not only an increase in utilization, but also a focus by advocates on building a repeatable playbook. To that end, advocates will often portray denials of benefits in these areas as systemic failures by payors to recognize the efficacy or medical necessity of treatment rather than individualized medical-necessity decisions. These advocates may also have or seek to establish relationships with attorneys who specialize in coverage litigation, facilitating rapid escalation from internal appeal to external review and litigation. And their marketing may highlight “wins” against insurers and high-value reimbursements, reinforcing an adversarial posture from the outset and conditioning the member to expect prolonged litigation and a potential windfall, rather than simply reimbursement of costs incurred.

In addition, patients may seek recovery of advocate fees in addition to medical costs, effectively raising the baseline for any resolution. And depending on the advocate’s fee structure (especially contingency-like models), the advocate may push the patient to seek maximum recovery, even if a quicker or more limited resolution might better serve the patient. The result is a higher likelihood of disputes going to external review, arbitration, or court, even in cases where clinical evidence is uncertain or benefit language is clear. For plans, this can lead to more entrenched disputes, higher settlement amounts in some cases, and reputational risk if advocates publicly frame routine coverage determinations as unjust denials.

Privacy, HIPAA, and Security Risks

One of the most significant—and underappreciated—risks is that for?profit advocates typically operate outside the Health Insurance Portability and Accountability Act’s (HIPAA) core regulatory framework. They are typically not “covered entities” (like health plans or providers) and, in most cases, they are not covered “business associates” because they are retained directly by the patient, not by the plan or provider. This creates several areas of potential risk:

- **Lack of HIPAA experience.** While advocates who offer to handle claims submission or appeals assistance will need access to sensitive private health information (PHI), they may have little to no training or experience in handling PHI. This may result in advocates sharing PHI with third parties—billing firms, marketing partners, attorneys, or other vendors—without appropriate safeguards.
- **Access through member credentials.** Advocates frequently obtain access to PHI via a member’s website or mobile application usernames and passwords, or broad authorizations. Plans may have difficulty distinguishing between the member and an advocate using the member’s credentials, complicating authentication and audit

trails.

- **Violations of patient privacy through advocacy.** Advocates may disclose more information than the patient fully appreciates or would freely choose under less vulnerable circumstances.

For payors, improper PHI handling by advocates creates risks stemming from potentially unauthorized or undisclosed access to patient information and subsequent disclosure of that information by the advocate, either intentionally or inadvertently. Even where the advocate discloses his or her involvement, ensuring proper authorization and compliance with HIPAA can present a significant challenge.

Cybersecurity risks exacerbate these concerns. Many advocates are small operations with limited technical resources. Yet they can accumulate extensive PHI across multiple plans and providers. For attackers, they are a high-value, poorly defended target. Advocates may also share this information with third-party vendors and subcontracts, increasing the potential attack surface for a bad actor. Even where the source of such a breach is a third party over whom a payor has no control, the compromise or exposure of member PHI can result in reputational harm, member complaints, increased operational costs to monitor the impact of breaches, and potentially regulatory investigation or litigation alleging non-compliance with the payor's obligations under HIPAA and other privacy requirements.

Additional Risks and Ethical Concerns

The unregulated nature of for-profit advocacy also creates risks of unethical or fraudulent conduct by advocates. Although advocates frequently lack any clinical expertise or licensure, advocates may recommend treatments or providers to patients. In some cases, the advocate may base these recommendations on their own experiences or review of the patient's medical records and history—creating concerns about the unauthorized practice of medicine—and in others the recommendation may be driven by the advocate's own financial incentives. In either case, the advocate may disrupt the physician/patient relationship and steer patients to more costly procedures or providers without the professional credentials necessary to evaluate the propriety of those recommendations for the patient's health. Additionally, advocate recommendations based on financial relationships with providers may violate state and federal anti-kickback statutes.

The combination of access to PHI, weak oversight, and financial incentives also create fertile ground for outright fraud. Potential fraudulent conduct by advocates in the healthcare context include: (1) misrepresenting clinical information to meet coverage criteria or to establish a need for out-of-network services, (2) submitting appeals or documents using member credentials without the member's authorization, or (3) encouraging patients to sign broad authorizations that are then used in ways the patient did not understand or anticipate.

While there is little doubt many advocates act in good faith, the structural incentives and lack of oversight create opportunities for bad actors to cause substantial disruption to payors and expose members to significant financial risks.

Managing Advocate Risks

For managed care organizations, for?profit advocates are not likely to disappear, and their influence on healthcare continues to grow. Payors must proactively manage the risks associated with such advocates to protect members and to preserve plan integrity. The following best practices help mitigate risks associated with patient advocacy involvement in member claims.

- Scrutinize out-of-network exceptions on the front end to identify potential trends;
- Educate patients and providers about (1) the risks of involving for-profit patient advocates in claims/appeals, and the impact of such involvement on the costs and complexity of litigation;
- Monitor clinical areas with high advocate presence, audit utilization management and billing trends;
- Develop strategies to address litigation risks and settlement challenges;
- Create ways to ensure transparency when advocates are acting on behalf of patients; Implement robust contracts that include HIPAA compliance requirements and security protocols;
- Maintain secure access for online claims submission (e.g., multi-factor authentication) to minimize security risks;
- Offer training for company employees, members, and special investigations units to spot problematic advocates; and
- Report suspected fraud to regulatory and law enforcement agencies, take legal action as needed.

Conclusion

For?profit patient advocates have emerged as powerful actors in the healthcare ecosystem, filling a need for patients who seek “independent” guidance navigating their benefits and claims. But unregulated, profit-driven advocacy creates substantial risks for members and payors. Collaboration between payors, providers, and patients is essential to mitigate those risks and ensure ethical advocacy practices. Payors must accordingly approach for-profit advocacy with an understanding of those risks and a plan to manage them.

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