



# Summary of Patient/ Consumer Advocate Programs

in New Hampshire and Other States

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**14**

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**Interviews**

**13**

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**Consumer  
Advocate Programs**

**11**

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**States**



## Introduction/Methodology

In late 2022, to inform planning for a healthcare consumer advocate program (HCAP) in New Hampshire, the Endowment for Health engaged a consultant to learn from consumer advocate programs across the country, including models, history and catalyst for program creation, services offered and audiences served, funding, staffing, key partnerships, and lessons learned. By recommending other states for inclusion, the first few key informants helped the Endowment achieve its aim of learning from diverse models in terms of size, longevity, location, and political climate. Ultimately, the assessment included 14 interviews with leaders in 13 consumer advocate programs in 11 states, including two in New Hampshire that are not focused on healthcare. The interviews, conducted by telephone or Zoom, utilized a semi-structured interview guide and lasted 60 minutes each. Thematic analysis was used to identify common and divergent themes.

## HCAP Histories, Models, and Services

The average age of the 11 HCAPs was 26.3 years with a range of 13 to 38 years. Five were formed in reaction to a crisis or identified need (e.g., concern about affordability and insurance denials; in reaction to managed care and need for prior authorizations), whereas the others were formed proactively (e.g., to ensure a dedicated voice for healthcare consumers). All advocate for healthcare policy and systems change (e.g., to improve availability, coverage, cost, or delivery) for the population at large. Nine (all but CA and KY) have helpline services and assist individual consumers; data about helpline requests are used to identify needs and argue for policy/systems improvements.

Among the HCAPs reviewed, two (NY and VT) are located within larger non-profits, a multi-service agency and a legal aid organization, respectively. One of these (NY) employs a “hub and spoke” model with a centralized lead organization and 27 community-based entities delivering services at the local level. Among the seven HCAPs that are stand-alone 501(c)(3) organizations (CA, CO, KY, ME, both in MA, PA), three (CA, ME, PA) also have 501(c)(4) status and four (CA, CO, KY, PA) are coalition models, with multiple stakeholder organizations involved in their development, decision-making, leadership, and in paying dues. Two HCAPs are public sector entities (CT and MD); one, defined in statute, is an independent state agency (CT) while the other is located within the State’s Office of the Attorney General, Consumer Protection Division (MD).

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## HCAPs Reviewed

CA	<a href="#">Health Access California</a>
CO	<a href="#">Colorado Consumer Health Initiative</a>
CT	<a href="#">Connecticut Office of the Healthcare Advocate</a>
KY	<a href="#">Kentucky Voice for Health</a>
ME	<a href="#">Maine Consumers for Affordable Healthcare</a>
MD	<a href="#">Maryland Office of the Attorney General, Health Education and Advocacy Unit</a>
MA	<a href="#">Health Care For All</a> and <a href="#">Health Law Advocates</a>
NY	<a href="#">Community Health Advocates</a> (a program of Community Service Society of New York)
PA	<a href="#">Pennsylvania Health Access Network</a>
VT	<a href="#">Office of the Healthcare Advocate/Vermont Legal Aid</a>

## Budgets

The annual budgets of the HCAPs range from \$800,000 to \$5.1 million. The non-profits rely heavily on grants, primarily from foundations, with some corporate support. Some have state contracts to supplement private funding. Events or trainings play a small role in generating revenue for some of the non-profits. Most coalition model programs have minimal member dues. The public sector programs rely fully or mostly on assessments levied on hospitals and/or insurers in their states. Some of the interviewees from non-profits indicated that their programs do not take direct industry funding (e.g., from hospitals, insurance companies, pharma companies) because they want to limit the influence industry has over their programs and agenda, and preserve their independence and the public's perception of it. Some have accepted direct funding from such organizations, but indicated that they are clear about their independence and stand on particular issues. Coalition organizations indicated that the coalition process, with multiple members involved in decision-making about the HCAP's agenda, can help preserve both the integrity and independence of the organization when accepting industry funding. Sometimes, some key informants argued, industry funding make sense. For example, in some states hospitals support a HCAP's consumer helpline because it aids consumers in gaining insurance coverage for health services.

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## Personnel

HCAP staffing ranged from seven to 50 positions. While some of the non-profits have a development person in their ranks, for most, fundraising responsibilities fall on senior staff. Several HCAPs have lawyers on staff. Some feel lawyers are essential (e.g., for complicated appeals and direct representation of individual patients), whereas others argued they are expensive and that most issues do not require legal expertise. While some HCAPs employ nurses and/or others with a healthcare background, others asserted that medical staff are not trained to build and argue a case. Some HCAPs contract with medical staff when such expertise is needed, although noted that treating doctors are often inclined to help in insurance disputes. One HCAP has found social workers to be essential for helping patients with mental health issues or substance use disorders. Some programs rely heavily on student interns or volunteers to perform critical program functions, but acknowledge that training, supervision, and turnover are challenges. Some informants indicated that public sector HCAPs and those with state contracts, even though outside of the administration's purview, can be affected by hiring freezes and understaffing of other state functions (e.g., Human Resources, Contracting).

## Partnerships

All HCAPs rely on partnerships of some sort. The non-profits, especially the coalition models, have broad alliances with other non-profits and advocacy groups. All interviewees reported that it is important to have the respect of and good relations with industry and noted that sometimes the HCAP and industry are on the same side of an issue and, at others, they are on opposing sides. Key informants from non-profits reported that it is important to build alliances with state agencies. They explained that, as non-profits, they can advocate for changes when state agencies generally cannot. Further, state agencies can provide information and guidance to support the HCAP

mission. Several interviewees noted the importance of engaging and educating legislators, ensuring that they understand how the HCAP benefits legislators' constituents. Some have cultivated champions within their state legislatures and are sure to credit them with important policy advances. Most explained that there are simple things HCAPs can do to engage legislators, such as having them advertise Marketplace or Medicaid enrollment dates to their constituents or share information about how the HCAP can help individual constituents.

## New Hampshire's existing consumer advocate programs

While, at the time of the assessment, NH did not have a HCAP, it did have two other consumer advocate programs. The first, the [Office of Consumer Advocate](#) (OCA), is an independent state agency created by statute with responsibility to represent residential customers of the state's regulated public utilities (i.e., electric, natural gas, water). The OCA was established in 1979 after a nuclear power plant failed and the company went bankrupt. The OCA focuses on policy and systems change, primarily participating in proceedings before the state's Public Utilities Commission where the OCA represents the collective interests of residential customers rather than those of individual consumers. The OCA has a staff of five, including a Director who, by law, must be an attorney; staff attorneys; a paralegal; and content experts. The OCA's annual budget of \$919,000 is funded through assessments on energy companies. While part of the state budget, ultimately the cost of assessments paid by the utility companies is passed on to rate payers.

### Office of Consumer Advocate

Est. 1979

### Office of Child Advocate

Est. 2018



The [Office of Child Advocate](#) is the state's other consumer advocate program. Established in 2018 following the death of children in state custody, the Office of Child Advocate oversees the state's child welfare, child protection, and juvenile justice agencies to ensure the best interests of children are protected. Its seven staff primarily focus on policy and systems change and include the Child Advocate, Associate Child Advocate, and Assistant Child Advocates (ombudsmen), data and support staff. The Office's annual budget of \$850,000 comes from the state's general fund although occasionally charitable grants fund special projects.

## Pros and cons of being a nonprofit vs. public sector program

Interviewees from the 13 consumer advocate programs involved in the assessment, including the two non-healthcare entities in NH, described pros and cons of being a non-profit versus a public sector entity (i.e., either an independent state agency or embedded within a state agency). For example, representatives of non-profit organizations indicated that they can be an independent advocacy voice. While acknowledging that government programs often face restrictions related to advocacy, three of the government entities involved in the assessment reported that they can advocate for changes in policy or the law, whereas one is able to influence policy by working closely with the state legislature, for example, advising on necessary changes. While those in non-profit programs indicated that they have more flexibility than public sector programs in terms of how they do their work, the public sector entities generally have subpoena or investigatory powers to collect data from health insurance plans whereas the non-profit organizations do not. Interviewees from public sector programs indicated that it is generally easier for them (versus non-profits) to access data and confidential information and that they generally have closer relations with the enforcement arm of government. Public sector HCAPs may, however, have less or no influence over public insurances (e.g., Medicaid, state employee plans) versus private insurances. Public

sector entities may find their funding more vulnerable to the political climate whereas non-profits indicated that fundraising is resource intensive, especially after a successful advocacy campaign because funders tend to move on to the next challenge.

## Lessons learned

The key informants were asked for lessons learned and to advise NH as it plans its HCAP. Most interviewees recommended that NH connect with Families USA's multi-state effort to restore Affordable Care Act funding for consumer assistance programs. Several suggested identifying a galvanizing issue as a springboard from which to launch the HCAP; one such issue might be the impending end of the public health emergency related to the pandemic when millions of people will lose their Medicaid and need to know how to refile and access coverage. Most interviewees advised NH to start small and focus the HCAP on a key mission. From there, they argued, the HCAP can share its successes and build its credibility. Several cautioned against "mission creep," explaining that a successful HCAP will be positioned (maybe even pressured) to take on more work. They emphasized the importance of securing additional resources before expanding the HCAP's mission. Some of the key informants suggested employing a broad definition of health (i.e., including the social determinants of health) to attract a range of partners and supporters and allow for flexibility in terms of the types of issues the HCAP will support or oppose. Some also recommended defining "good health care," building support and momentum for that vision, and then using it to hold systems accountable. Nearly all argued it is critical for the HCAP to have a strong leader who can command respect, build alliances, and hold firm when in opposition to others on a given issue.

With regard to resources, the key informants recommended being mindful of the funding landscape and recognizing that, for non-profits, allies and partners may often be competitors for grant funding. They suggested that those planning NH's HCAP think strategically from the outset

about the donor base and whether/how it will use volunteers to accomplish the HCAP's mission. If possible, they added, the HCAP should begin with two to three years of secure funding. The initial funder(s) should invite other funders to the table and the HCAP's leadership should use those early years to work on diversifying the program's funding streams. Some of interviewees queried whether it would be possible to build support for the HCAP into healthcare conversions (i.e., the sale of non-profit healthcare entities to for-profits). While noting the potential vulnerability of public sector HCAPs and those funded by government grants, some of the key informants suggested that any legislation related to NH's HCAP be specific enough to hinder the administrative branch's ability to constrain HCAP resources.

Most key informants recommended that NH's HCAP track data (e.g., people helped, issues addressed, money saved for consumers and/or the state) and share it to build support for the HCAP. They also advised using media judiciously; while some indicated that they are careful not to use media to shame industry, others see media as an important tool for educating and empowering consumers and that, sometimes, it is necessary to call out bad actors.

A few interviewees argued the importance of ensuring the program is recognized as NH's "official" HCAP or, at least, that the state's insurance commissioner or Medicaid Director mandate that the program be listed on all insurance notices (i.e., Explanation of Benefits, Medicaid Notices of Adverse Determinations) to inform patients about the availability of the HCAP. Some argued that the HCAP push for a highly visible location for its contact information on insurance claim denials.

Assuming NH's HCAP has a helpline and a limited scope (e.g., advocating only for those with commercial payers), interviewees said it is important for the helpline to assist all callers in getting what they need by connecting them to the right place and explaining relevant processes. Given the complexity of the healthcare landscape, the key informants explained,

simply providing callers with a phone number or transferring their call is insufficient to ensuring the public's interests are represented by the HCAP.

A few of the key informants reported that, while a 501(c)(4) designation may be attractive to funders who want to support lobbying, it comes with costs. They noted that, if going the non-profit route, the HCAP should be strategic and learn how it can advocate within the limits of a 501(c)(3) status.

One interviewee suggested NH consider the merits of a hub and spoke model given the geographic diversity and population distribution of the state. In such a model, the informant explained, a central office

provides a helpline and administrative oversight/coordination while partners with knowledge of local resources and community needs are responsive to cultural, linguistic, or other regional differences. The local offices are also positioned to build trust and health literacy in the communities they serve.

Finally, the key informants explained that a HCAP can appeal to both those with conservative and liberal political leanings. On the one hand, HCAPs can save the state money. On the other, HCAPs can hold industry accountable and be invaluable for building health literacy and empowering communities to advocate for their own needs.



## HCAPs can:



Save the  
state money



Hold industry  
accountable



Be invaluable for  
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Empower  
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