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## A Primer for Consumer Involvement in Medicaid Nursing Facility Reimbursement: Lessons from New York and Minnesota<sup>1</sup>

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### INTRODUCTION

Medicaid is the major purchaser of nursing home care in the United States. To ensure that providers behave appropriately, the federal and state governments have established an extensive set of regulations that nursing homes must comply with if they are to be reimbursed for patients insured by Medicaid. Consumers exert considerable influence here by focusing on regulations and enforcement of non-compliance.

States also seek to align providers' interests with those of other interested parties through controls and incentives built into state reimbursement systems, including with respect to facility cost and quality, access to care, payment equity, service capacity, and budgetary control. Prevailing lack of consumer involvement in the development and implementation of state rate setting systems has the potential to result in the adoption of methodologies that favor industry and government interests at the expense of issues important to residents and their families. All stakeholders, including consumer advocates, must be at the table if truly informed reimbursement policy reform is to take place.

New York and Minnesota are two states where consumers have been successful in influencing the development and implementation of Medicaid nursing home reimbursement policy to better encourage access, care quality, and quality of life. To understand how consumers can acquire a seat at the table and be effective in influencing Medicaid nursing home reimbursement, 24 in-depth interviews were conducted with 27 individuals in these states, including state agency officials, state legislators and legislative staff, consumer advocates (including ombudsmen), union staff, and nursing home industry representatives. Pertinent documents were reviewed as well.

## PURPOSE OF THIS BRIEF

The purpose of this brief is to detail the lessons learned, to both encourage and assist you, as a consumer advocate, in your participation in developing and implementing state policy on Medicaid nursing home reimbursement. Several strategies are identified for successful advocacy in this area. We hope that you will find them useful as you advocate for reimbursement systems that favor the interests of current and future nursing home residents and their families.

### THE IMPORTANCE OF CONSUMER ADVOCATES BEING “AT THE TABLE”

It is important that you, as a consumer advocate, participate in reimbursement because:

- You represent the constituency that the system is all about;
- You can serve as a counterpoint to the nursing home industry;
- You can serve as a counterpoint to state government; and
- Reimbursement is critical to encouraging the outcomes consumers care about.

*“Instead of the discussion being just about cost and labor and that kind of stuff, [the advocates have] been able to keep the patient voice at the table...[They do so] whenever we kind of stray, and start talking more about the technical aspects or like the business of nursing homes instead of about the patients, or the client.”*

--State Official, New York

*“It’s really helpful that the consumers do get involved as much, and in the ways that they do, because it makes it real obvious to everybody that when an industry representative is telling us what’s obvious, that everybody knows that there are other opinions that exist out there and it isn’t just us bureaucrats who have to say that. They’re at the table, also, to say it. I find that to be a helpful thing.”*

--State Official, Minnesota

*“[What consumer advocates] have that to some extent [providers] don’t is they have a white hat that allows them to leverage relationships with legislators in different ways than the self-interest that we sometimes associate with a provider organization like our own. The white hat is that we’re [consumer advocates] here to make things better for the older person. We have no other agenda.”*

--Provider Representative, Minnesota

*“We did studies of New York State’s inspection system...It was very clear to me that how you make inspections systems better often related to Medicaid and money. I felt that you couldn’t just look at the inspection enforcement system. The reimbursement system also gave incentives to facilities to give better care, so it was kind of all wrapped up into one. You can’t look at one without the other.”*

--Consumer Advocate, New York

*“The key to this assuring that residents and consumers are well cared for is directly related to the dollars in the system, and how those dollars are allocated...[They have] been good about focusing on the connection between quality of care and the money. Form follows finance.”*

--State Official, New York

## TOWARD A MORE INFLUENTIAL CONSUMER ROLE IN REIMBURSEMENT

Experience in New York and Minnesota suggest certain prerequisites for consumer action. It also suggests effective strategies for successful consumer involvement and potentially useful supplements to further enhance the effectiveness of that action.

- **Prerequisites for Consumer Action**
  - Develop a reputation; make reimbursement a priority
  - Develop, demonstrate, and volunteer knowledge
- **Effective Strategies for Influencing Reimbursement Policy**
  - Develop and access relationships with state legislators
  - Develop and access relationships with state bureaucrats
  - Participate in reimbursement work groups and taskforces
- **Supplemental Strategies for Consumer Action**
  - Grassroots strategies: action alerts, email, letters
  - Develop coalitions with other consumer-oriented groups
  - Develop coalitions with unions and provider groups

### The Key Prerequisites: Reputation, Information, Credibility

It is important to develop a reputation by making reimbursement a visible priority for your organization over time. It is also important to develop and demonstrate expertise in nursing home reimbursement and the policy process, and to further enhance one's credibility by sharing that knowledge with others. In other words:

- Instill reimbursement as an important issue in your organization;
- Be persistent, consistent, and assertive in pursuing policy change;
- Make sure you know your stuff; learn the basics, both in your state and other states;
- Produce knowledge through research and reports;
- Know the key pressure points in the policy process; and
- Generate good will and trust by sharing information with other constituency groups.

*"[Consumers were successful because]...they had persistence, I would say...to the degree that we got [the consumer points] in, it was because [they] were just persistent about it."*

--Union Representative, Minnesota

*"Policymakers looked at consumer advocates as people who didn't really know what they were talking about, but just being emotional...telling anecdotes...When we started I realized that you really had to know your stuff in order to be at the table and that was a big part of why we did a lot research...When things came up, whatever they were, we actually [did] research on it."*

--Consumer Advocate, New York

*"If you want something changed, you'd better have an idea of how it should get changed. You'd better have a methodology to suggest, because otherwise nothing's going to happen."*

--Legislator, Minnesota

***“What [they have] consistently done is...understand how the policy making works, meaning legislation, executive budget, the budget process, and how regulations and policies affect providers which obviously directly affect consumers...They have been very good at...understand[ing] all the pressure points.”***

--State Official, New York

***“They were very helpful in putting together a couple of reports that were effective in demonstrating the way [pay-for-performance] was done around the country. Really helping at least me understand and parse out some of the facts. One of the critical things is always fact versus rhetoric...Some of the reports that the advocates put together were helpful in saying this has been done in 32 other states, and the sky hasn’t fallen, so would New York be different?”***

--Legislative Staff, New York

## **Effective Strategies for Influencing Nursing Home Reimbursement Policy**

To be influential in influencing nursing home reimbursement policy, you must:

### ***Develop relationships with key legislators and their staffs***

- Meet with key legislators/staff; educate them about the consumer point-of-view;
- Share information with key legislators/staff;
- Testify before legislative hearings; and
- Make issues “real” and “local” for legislators by having constituents tell their stories.

***“It largely has been a matter of trying to cultivate champions at the legislature among people who had enough power in their committees to be champions.”***

--Consumer Advocate, Minnesota

***“Just the fact that [the consumer advocates are] at hearings, they’re always watching; they’re testifying a lot. They’re meeting with people. Everybody knows that there’s a presence there. That alters people’s behavior, I think, to some degree.”***

--State Official, Minnesota

***“Legislators are desensitized by our never-ending quest to balance the bottom line on a spreadsheet [which is] pretty impersonal. When somebody looks at you in the eye and can tell you that your potential decision will make a difference or have an impact on their lives, it personalizes the issue.”***

--Legislator, Minnesota

***“It’s incredibly valuable and important to...maintain a real grassroots consumer voice to the extent that you bring residents to the table, families to the table.”***

--Consumer Advocate, New York

### ***Develop relationships with key bureaucrats and other officials in state government***

- Meet with key officials in the pertinent state agencies;
- Bring otherwise non-communicating agencies together to the benefit of residents;
- Share information with key bureaucrats and other state staff; and
- Account for, and, perhaps, ameliorate the workload burdens of state officials.

***"We meet now on reimbursement with both the quality people and the Medicaid people in one meeting. One of the things we have been successful at is when we bring different parts of agencies or different agencies together, and connect them, because we found long ago that they don't speak to each other."***

***--Consumer Advocate, New York***

***"We're always confronted with limitations...to do extended long-term care projects that take a lot of staff, a lot of number crunching, a lot of time. That's where I think [she] is helpful, because she has had the ability to go out and do some of this work for us and do it on reports, and it's something that we can learn from without having to throw a lot of staff at it...I feel that if I needed to get [her] opinion on something or pull her into something, that she would be more than open to doing that."***

***--State Official, New York***

### ***Participate in nursing home reimbursement work groups and taskforces***

- Serve because they can be especially important conduits for consumer input; and
- Be assertive in promoting consumer representation on panels such as these.

***"Serving on a taskforce or work group is one of the most important forms of participation. It's crucial to be at the table as much as you can...We've been active as a member of the State Hospital Review and Planning Council during the years and then on the Nursing Home Reimbursement Taskforce...[Other advisory panels were appointed and we had to ask, 'why isn't there a consumer on [there]?'...We fought very hard to get consumer representatives on and had to actually show the Department where the law [required this to be the case]."***

***--Consumer Advocate, New York***

***"[They] participate in state advisory group[s]; they pretty actively follow along and participate in almost any opportunity that they have; they also provide testimony. Advocates are very well informed... Knowledge is power."***

***--State Official, Minnesota***

***"The important committees and meetings, and advisory groups that have been created by the state...to talk about reimbursement and other issues...the large number of people at the table are nursing home providers with, of course, a lot of state agency representatives, and usually the lone consumer voice has been [this one advocacy group], but they've been absolutely essential in winning a seat at the table, and nobly, under great odds, providing a consumer voice."***

***--Consumer Advocate, New York***

### **Supplemental Strategies to Higher-Level Participation in Reimbursement**

In addition to those activities deemed most effective, you should:

#### ***Undertake grassroots strategies to influence state policymakers***

- Promulgate newsletters and press releases; seek out press coverage;
- Issue action alerts; undertake email and letter writing campaigns;
- Let officials know you have people behind you; that they should pay attention;
- Focus on the big issues; keep the messages simple; and
- Recognize that some forms of communication are more effective than others.

***"The vast majority of legislative offices, numbers count a lot...So if advocates are going to be effective, they not only need a quality message...they also need to focus on having a large, popular base, as well, that can voice their message."***

--Legislator, New York

***"Each thing has varying weight established to it...I would say that the postcard is minimal; the form e-mail is minimal; the actual e-mail that's sent is stronger if someone takes the time to actually handwrite a letter. Who does that anymore? And if you make a phone call that's actually probably the strongest."***

--Legislative Staff, New York

***"They come and lobby, so they visit with members in their offices; they come and testify. Sometimes they participate in working groups. They will write letters that we can distribute on the floor of the Senate."***

--Legislator, Minnesota

***"It's very important to bring [people] together at least on a common issue [to] create a kind of summit of stakeholders that can fight, because if you don't have money, if you have numbers, you might effect change...That's the way we got quality pools into the Governor's Office. He got over 400 emails across the state from residents and people. It made a huge difference."***

--Consumer Advocate, New York

## **Develop Coalitions/Relationships with Other Key Constituency Groups**

### ***Consumer-oriented groups***

In New York, consumer advocates have gathered into a coalition—the Long Term Care Community Coalition—which, in addition to consumer groups representing the elderly and disabled, includes professional organizations and some civic associations as well as a number of local ombudsmen ([www.ltccc.org](http://www.ltccc.org)). Participation of these groups in the coalition has increased the coalition's impact in reimbursement and other discussions. It is known that the coalition's executive staff speaks for a large number of constituents. Other groups are, in turn, informed by the executive staff's expertise.

***"They've worked very hard to engage their membership...It's...understood and recognized that they're representing a broad array of consumer interests, and it's not just one or two voices using a platform of one organization to bring about a point of view, it's a real consumer position that's been developed."***

--Consumer Advocate, New York

***"Other groups come to us and ask questions, and so when [they go] visit a legislator they have the information they need on reimbursement, though they're focused on so many other issues."***

--Consumer Advocate, New York

### ***Unions***

In Minnesota, senior groups have formed a coalition with the unions: Seniors & Workers for Quality Care ([www.seniorsandworkers.org](http://www.seniorsandworkers.org)). Together they have accomplished quite a lot, including making sure that a large proportion of any new money put into the Medicaid nursing home reimbursement rate is directed towards workers' benefits and salaries.

***"I would say that citizen advocacy groups that partner with labor organizations have a lot more clout than they would otherwise...I would say [they] are the sort of balance to the industry trade groups."***

***--Union Representative, Minnesota***

***"The consumers and the workers came together and said, 'We've got a common interest in making sure that the money going into nursing homes get to the front line caregivers, because that makes the biggest difference in their lives. The other big thing [they have worked on together is] rate equalization, which says that you can't charge private pay people more than your charge public Medicaid people."***

***--Union Representative, Minnesota***

## ***Providers***

Although working with nursing home providers to influence Medicaid nursing home reimbursement could be effective, it has been difficult to accomplish: The relationship between consumers and providers is generally adversarial. To develop a more productive working relationship with providers, you might want to:

- Distinguish among different types of providers; not all providers are created equal;
- Identify potential partners: find common ground around quality and spending;
- Incorporate provider input into your reform proposals if possible;
- Do not unduly antagonize providers; some might otherwise work with you; and
- Co-opt providers' positions; frame their arguments so they complement your own.

***"A good working relationship would be to have periodic discussions as groups, the nursing homes with the consumers, to list priorities for each group, and to agree to work on those we can agree to work on together. It would make sense to issue joint statements to do things like that, because I think a united front, especially when you're dealing with budget cutters is very important."***

***--Provider Representative, New York***

***"There are always people that are visionary, that you can work with, what we call 'leading change.' You can find those people, if you really seek them out...Don't indict an entire industry, because they are not all alike. There are some very good nursing homes in this state."***

***--Consumer Advocate, New York***

***"You want even your opponent's argument to work for your cause...In the nursing home realm, and I've seen [her] do this, where she will be in an argument with an operator over an issue, having to do with reimbursement...She can easily take their argument...turn it, and give it back to them on a plate that is the consumer interest plate with their interest as a complementary piece. And I've just seen her take the floor right out from under an operator in that type of situation in the taskforce setting."***

***--Legislative Staff, New York***

***"At the end of the day, my experience with advocacy generally is that so much is about relationships that you've built, about trust that you've built. I think working alongside one another is really the key to effective collaboration, and we believe pretty strongly as an organization in today's world that the kind of transformation that we're wanting to see in older adult services, really only happens through collaboration, so the bigger the stakeholder group, the better. I'd love to see something that seniors and workers and the [providers] did together, not just agreeing when you all have to sit down and find the compromise, but something we actually did together from the ground up."***

***--Provider Representative, Minnesota***

## PUTTING IT ALL TOGETHER

In conclusion, experience in New York and Minnesota suggests the importance of developing, demonstrating, and volunteering expertise in Medicaid nursing home reimbursement as a means of gaining legitimacy, which, once earned, will lead to an ongoing role in state reimbursement policy discussions. It also suggests supplementing higher-level participation in taskforce memberships and stakeholder meetings with legislators, bureaucrats, and other state officials with grassroots activities—e.g., action alerts, email, and letter writing campaigns—that draw more widespread attention to an issue. Here, a division of labor may be useful with those advocates becoming expert in reimbursement partnering with other organizations capable of marshaling the resources necessary to conduct broader-based grassroots endeavors.

***"[There needs to be a] core competency...such [that] an organization...has to first develop...content knowledge of what is the relationship between reimbursement and quality...That's...job number one...Number two is you need to develop relationships with the key influencers in the legislature and the executive branch; and then three, developing the ability to mobilize constituents to reach those people, so that they're hearing your message from the grassroots. And four, becoming proficient in the necessary skills to communicate effectively, and to advocate effectively, not just to have a relationship, but have a relationship that you leverage into persuasion by your ability to do advocacy, and kind of communicate the relationship between reimbursement policy and quality."***

--Provider Representative, New York

***"[Our success has] been a matter of finding our friends in public office, and in the state agencies, and doing [what] we can to understand what the issues are, and to understand how decisions will be made so that we can elbow our way into the decision making process."***

--Consumer Advocate, Minnesota

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