Engaging Consumers in Medicaid Nursing Home Reimbursement Policy: Lessons From New York and Minnesota

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Received May 29, 2012; Accepted October 1, 2012
Decision Editor: Nancy Schoenberg, PhD

Purpose of the Study: This study draws lessons for successful consumer engagement in Medicaid nursing home (NH) reimbursement policy from New York and Minnesota. In these two states, resident advocates have influenced reimbursement policy to better encourage access, care quality, and quality of life. Design and Methods: Twenty-four semi-structured interviews were conducted, including consumer advocates, state agency officials, legislators/legislative staff, and NH industry representatives. Transcripts were coded to identify recurring themes and patterns in responses. Related documents were reviewed as well. Findings: Interviewees report that consumer advocates should participate in NH reimbursement policy making to provide a unique perspective distinct from other stakeholder groups. Skills necessary for successful participation include developing, demonstrating, and sharing expertise to gain credibility as a legitimate actor. Effective strategies include participating on state workgroups and taskforces and developing and accessing relationships with key legislative and executive branch officials. A division of labor may be useful with those consumer advocates possessing expertise in NH reimbursement policy partnering with other organizations with the experience and resources necessary to marshal grassroots support. Implications: State and federal reimbursement reform provide opportunities for consumer advocacy influence during the design and implementation process. The experience of consumer groups in New York and Minnesota provide lessons for advocates looking to influence these and other reimbursement initiatives. Key Words: Consumer advocates, Lobbying, Medicaid, Nursing homes, Reimbursement

Medicaid is the major purchaser of nursing home (NH) care in the United States. Extant evidence suggests that the manner in which NHs are reimbursed—the amount of money received each day to care for a resident and the way in which those payments are determined (i.e., the methodology)—have ramifications for NH quality (Feng, Grabowski, Intrator, Zinn, & Mor, 2008; Mor et al., 2011). Although consumer advocates have successfully influenced NH rules and regulations to residents’ benefit, few have participated in the development or modification of state methods for reimbursing NHs (Miller, 2008; Rudder, Mollot, Holt, & Mathuria, 2009). The lack of consumer involvement has the potential to result in reimbursement systems that favor industry and government interests at the expense of residents. State officials have primarily been concerned with restraining spending (Smith, Gifford, Ellis, Rudowitz, & Snyder, 2011); industry representatives have primarily been concerned with...
maximizing reimbursement (Edelman, 1997/1998; Miller, 2008). Consumer advocates tend to favor maintaining payment levels but prefer systems that incentivize and hold NHs accountable for quality (Edelman 1997/1998; Rudder et al., 2009). Continuing problems plague NH quality, and the way it is overseen by the federal and state governments (Harrington, Mullan, & Carrillo, 2004; Harrington, Carrillo, Dowdell, Tang, & Blank, 2011). Reimbursement provides advocates another avenue with which to spur improvements in this area.

States often employ taskforces when making major changes to NH reimbursement policy (Freeman, 1997/1998; Miller, 2008). Consumers/residents’ advocates are rarely asked to participate on these bodies. When serving on state taskforces, advocates’ participation tends to be less consequential than the participation of state officials and NH industry representatives (Miller, 2008; Miller & Wang, 2009). All stakeholders must participate if truly informed reimbursement reform is to take place. The primary purpose of this study is to draw lessons for successful consumer advocacy engagement in Medicaid NH reimbursement policy from the experience of New York and Minnesota. In these two states, advocates have been effective in influencing the development and implementation of NH reimbursement methods and rates.

**Elders, Consumer Advocacy, and Lobbying**

Older Americans are active participants in the political process (Binstock, 2010). Political engagement, however, is challenging for NH residents, many of whom who face debilitating functional and cognitive limitations that limit opportunities to participate in the political process. Lack of political participation may be due to isolation, transportation issues, personal care requirements, stereotyping, bias, and/or discrimination (Anderson & Dabelko-Schoeny, 2010).

The social worker profession plays a prominent role advocating for the interests of individual NH residents (Anderson & Dabelko-Schoeny, 2010; Kane 2004), so too does the National Long-Term Care Ombudsmen Program (LTCOP) established to advocate for the health, safety, welfare, and rights of persons in long-term care facilities (Harris-Whehling, Feasley, & Estes, 1995). Presently, the LTCOP consists of 1,167 paid staff and more than 11,000 volunteers and operates in every state and 578 localities as per statutorily mandated responsibilities under Title VII of the Older Americans Act (OAA; Administration on Aging, 2012). Identifying, investigating, and resolving complaints made by or on behalf of residents is foremost among the program’s charges. The program is also charged with conducting systems advocacy, including representing the interests of residents before governmental agencies; pursuing administrative and legal remedies to protect residents’ rights; and monitoring, commenting on, and recommending changes to laws and regulations affecting residents.

In addition to the LTCOP, the policy interests of NH residents are represented by old-age interest groups, including 66 that have joined together under the banner of the Leadership Council of Aging Organizations. Membership includes the more than 40 million strong AARP, which devotes tens of millions of dollars toward legislative lobbying and public policy research annually (Binstock, 2010). Membership also includes the National Consumer Voice for Quality Long-Term Care (formerly the National Citizens Coalition for NH Reform) formed to represent the interests of NH residents by championing federal reform (Edelman, 1997/1998). NH-specific advocacies have arisen among old-age interest groups at the state and local levels as well (Freeman, 1997/1998).

Despite the proliferation of old-age interest groups, including those representing the interests of NH residents, the effectiveness of elder advocacy has languished in recent years (Binstock, 2010; Freeman, 1997/1998; Rother, 2004). Growing emphasis on individualism, personal responsibility, and market forces has placed elder advocacy groups on the defensive; so too has the portrayal of older Americans as a flourishing population cohort that consumes a disproportionate share of tax dollars (Binstock, 2010; Freeman, 1997/1998). At the federal level, challenges elder advocates experience in influencing policy have been exacerbated by ongoing debates over deficit reduction and entitlement reform. At the state and local level, challenges elder advocates have experienced in influencing policy have been exacerbated by the adverse fiscal implications of the protracted economic problems that have persisted since 2008.

Ombudsmen have struggled to fulfill their role as advocates for vulnerable long-term care residents as well. Both state and local ombudsmen tend to rate their effectiveness as policy monitors and advocates lower than their effectiveness performing other mandated activities (Estes, Zulman, Goldberg, &
Ogawa, 2004; Estes et al., 2010; Hollister & Estes, 2012). Explanations include lack of autonomy due to placement of most ombudsmen programs in another government agency, lack of ombudsmen understanding and training to perform the systems advocacy role, lack of resources and prioritization of complaint investigations over other functions, and lack of strong interorganizational relationships, including with citizen’s advocates (Estes et al., 2004, 2010; Harris-Whehling, Feasley, & Estes, 1995; Hollister & Estes, 2012; Hollister, 2008).

Like other consumers, elderly NH residents would benefit from increased and more effective representation in the policy process. According to Kingdon (1995), elder advocates, like other interest group representatives, can play a prominent policy-making role. Kingdon’s policy streams’ framework suggests that when potential policy solutions are joined to public problems and both are joined to favorable political forces, policy windows—or opportunities for placing issues on the policy agenda—may arise. Especially important in this process are champions willing to invest the time and resources necessary to promote a particular option and to take advantage of windows of opportunity for policy change. These “policy entrepreneurs” may reside among “visible” or “hidden” participants in the policy process. Visible participants, including the governor, prominent state legislators, and high-level appointees, play a prominent role making authoritative decisions that place items on the policy agenda. Hidden participants, including legislative staffers, career bureaucrats, and academicians, play a prominent role developing policy solutions. Interest groups play a key role connecting visible and hidden clusters of participants; for example, interest groups may serve directly as policy entrepreneurs or may provide information and expertise that supports policy entrepreneurs.

There is growing interest in developing strategies with which to promote greater consumer advocacy engagement in health and long-term care policy at the state level (Priester, Hewitt, & Kane, 2006; Rother, 2004). A noteworthy example is a Robert Wood Johnson Foundation initiative, Consumer Voices for Coverage, which is built around six capacities believed to impact the ability of consumer advocates to influence the policy process, including (a) acquiring the expertise and staff necessary to understand critical issues, monitor policy proposals/actions, and contribute as credible actors; (b) building a strong grassroots base to engage those directly affected by government policy while informing policy makers about potential political ramifications; (c) maintaining broad-based alliances that work jointly toward a common goal; (d) developing public and political support by implementing effective communication strategies; (e) generating the resources necessary to carry out one’s mission; and (f) accessing key decision makers (“champions”) and providing them with the information necessary to take advantage of windows of opportunity for policy change (Community Catalyst, 2006; Strong et al. 2011).

Political scientists who study interest group lobbying behavior make a basic distinction between direct lobbying techniques, which involve direct contact with state legislators and program administrators, and indirect lobbying techniques, which engage citizens rather than government through grassroots campaigns and media advocacy (Nownes & DeAlejandro, 2009; Nownes & Freeman, 1998; Nownes & Newmark, 2013; Schlozman & Tierney, 1983). The most commonly used strategies are direct techniques, though indirect techniques are used frequently as well (Nownes & DeAlejandro, 2009; Nownes & Freeman, 1998; Nownes & Newmark, 2013). Direct techniques include meeting personally with state legislators/legislative staff, helping to draft legislation and/or proposed regulations, testifying before legislative committee hearings, meeting personally with executive agency personnel, and serving on advisory boards. Indirect techniques include talking with people in the media, issuing press releases, running advertisements, and inspiring letter writing/telephone/e-mail campaigns. Lobbyists believe that personal meetings with government officials are the most effective way to influence statutory and regulatory decisions (Rosenthal, 2001; Nownes & DeAlejandro, 2009; Nownes & Newmark, 2013), possibly because direct contact enables them to learn about pending proposals, build close relationships, and, in turn, access their targets when needed (Nownes & DeAlejandro, 2009). Lobbyists believe entering into coalitions and inspiring communication is also effective.

**Methods**

New York and Minnesota were chosen for study because prior research indicates that these two states were among the few states where consumer advocates had been influential in Medicaid NH reimbursement policy (Freeman, 1997/1998; Miller, 2008). Data were derived from archival
resources and semistructured interviews. The interviews were undertaken with people chosen through a combination of purposive and snowball sampling (Patton, 2002). Thus, selection of participants was initially based on our own knowledge as experts in Medicaid NH reimbursement policy but later on information provided by our respondents regarding additional actors who should be interviewed about consumer involvement in Medicaid NH reimbursement policy in each state studied.

Twenty-four interviews were conducted with 27 individuals between February 2, 2011 and June 20, 2011, 12 interviews in each state. Three interviews included two participants each, a state legislator and a staff member, two consumer advocates, and two Medicaid reimbursement officials. Interviews were about 1 hour long. Interview participants included state legislators/legislative staff (six individuals), officials within the pertinent state administrative agencies (six), consumer advocates representing both citizen advocacy groups and state ombudsmen (eight), union staff (two), and NH industry representatives (five).

 Stakeholders representing different backgrounds were recruited as interview participants to ensure representation of varying points of view about consumer engagement in Medicaid NH reimbursement policy making (Glaser & Strauss, 1967). Use of a diverse sample is important because the greater the degree to which the perceptions of people about a particular phenomenon converge, the more likely that they provide a reasonably accurate portrayal of the process studied (Jick, 1979). Use of a diverse sample also is important because employing multiple types of informants minimizes the threat of single-source information bias while maximizing the breadth of the information consulted (Potthas & de Wet, 2000).

 Through our interviews, we sought to identify which consumer representatives—citizen advocates, ombudsmen—have been active in Medicaid NH reimbursement policy, and why it is important that consumer representatives become involved in the design and implementation of state policy in this area. We also sought to understand why some consumer representatives have chosen not to become active participants in the Medicaid NH reimbursement policy-making arena. We further sought to understand the basic skills necessary for successful consumer advocacy involvement in Medicaid NH reimbursement policy, in addition to the major and supplemental strategies consumer representatives in New York and Minnesota have adopted to successfully influence the direction of state policy affecting how NHs are paid under Medicaid.

 All interviews were recorded and transcribed. Each transcript was subsequently coded by both authors to identify recurring themes and patterns in responses (Miles & Huberman, 1994). We employed an open-ended coding process, guided initially by concepts drawn from the broader literature on state lobbying, interest group activity, and consumer advocacy (Community Catalyst, 2006; Kingdon, 1995; Nownes & DeAlejandro, 2009). This initial set of concepts was refined through a process, whereby each of us read through the transcripts and independently generated suggestions for specific categories that we observed in the data. Once we had agreed upon a full, final set of codes, we went back and recoded all transcripts using the common set of themes developed. Thus, our study was deductive to the extent that preexisting constructs informed our thinking regarding the relationship between consumer advocacy and state policy making. However, our study was inductive to the extent that we used our data to understand consumer advocacy involvement in the unique context of Medicaid NH reimbursement policy, adapted pre-existing constructs to this unique context and developed new categories. Quotes illustrative of each theme were excerpted (Table 1).

 Pertinent statutes and regulations about Medicaid NH reimbursement were identified and collected; so too were relevant government reports and other documents. Information was collected from consumer advocacy groups and other non-governmental entities as well. Statutes, regulations, and other documents were used to cross-validate the descriptions and perspectives of key informants (Jick, 1979), corroborating accounts given by interviewees through independent verification in alternative sources. They also provided historical background on the Medicaid NH reimbursement policy changes that took place during the time period studied. Although the archival and interview data collected from Minnesota and New York were analyzed together, noteworthy differences across the two states were identified where they arose.

 Findings

 This section begins with an examination of consumer advocacy engagement in Medicaid NH reimbursement policy in Minnesota and New York. This discussion is followed by a review of the basic
Table 1. Major Themes Arising from Key Informant Interviews with Illustrative Quotes

<table>
<thead>
<tr>
<th>Theme 1: Varying Degrees of Consumer Engagement in Medicaid Nursing Home (NH) Reimbursement in Minnesota and New York</th>
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<tr>
<td><strong>1.a. Consumer Representatives Active in Influencing NH Reimbursement Policy</strong></td>
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<tr>
<td>“The big three have been the AARP, Alzheimer’s Association, and ElderCare Rights Alliance.” (Union Staff, MN)</td>
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<td>“The LTCCC has been more involved in discussions about NH reimbursement than any other consumer groups I can think of. I don’t know that there are other groups that have been much involved in those types of discussions.” (Provider Representative, NY)</td>
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<td>“Instead of the discussion being just about cost and labor and that kind of stuff … [they 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 NHs instead of about the patients, or the client.” (State Official, NY)</td>
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<td>“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 like all wrapped up into one. You can’t look at one without the other.” (Consumer Advocate, NY)</td>
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<td>“If there’s legislation that will give the NHs more money, [the consumers] would be there … to make sure that the money gets to the workers, because they feel that only when workers’ lives are improved are the residents going to see the difference in [quality].” (State Legislator, MN)</td>
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<td><strong>1.b. Consumer Representatives Not Active in Influencing NH Reimbursement Policy</strong></td>
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<td>“Knowledge level is one issue, because it is terribly complicated. And secondly, I think that people view the missions differently. Some groups don’t think they should have anything to do [with] reimbursement; their only interest is patient care issues.” (Provider Representative, NY)</td>
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<td>“Because of their limited funding and limited staff, they have really focused on abuse cases, both physical and sexual abuse of elders, and I do not believe that they have had the time or the staff to be able to get into the reimbursement issues.” (Consumer Advocate, MN)</td>
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<td>“I’m scared for the future … It’s kind of Maslow: They just have to keep their doors open and see clients [let alone adding reimbursement issues to the mix] … The movement isn’t as big as it was.” (Consumer Advocate, MN)</td>
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<td>“[The AARP’s] active members are not in NHs … so I would guess it may be difficult to get them activated on those issues … AARP is much more involved in things like home foreclosures and our elderly pharmaceutical program … property [taxes].” (State Legislator, NY)</td>
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<td>“[The ombudsmen] should become aware that in their focus on NH issues [that] reimbursement should be at the top of their list, just like inspection and quality care.” (Consumer Advocate, NY)</td>
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<th>Theme 2: Skills Necessary for Successful Consumer Engagement in Medicaid NH Reimbursement Policy</th>
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<td><strong>2.a. Consumer Advocates Prioritizing Engagement in NH Reimbursement Policy</strong></td>
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<td>“It seems like organizations sometimes reflect their founders, and their leadership and … consumers benefited, frankly, from a group of people that recognized that reimbursement and what it is and how it works is critical to the outcomes for consumers.” (State Official, NY)</td>
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<td>“The landscape has never been more fertile to hooking up quality with reimbursement. Now is like the ground floor for trying to understand where we are with … that … [With the] advocacies coming together, there’s a drive to make that happen.” (State Official, NY)</td>
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<td><strong>2.b. Consumer Advocates Developing, Demonstrating, and Sharing Expertise about NH Reimbursement Policy</strong></td>
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<td>“They really try to be well informed. It’s clear to everybody that it’s not just somebody spouting sort of a line that an association told them to spout but saying things that they truly believe and can provide you some evidence on.” (State Official, MN)</td>
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<td>“Policymakers [had] looked at consumer advocates as people who really didn’t 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 of research.” (Consumer Advocate, NY)</td>
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<td>“The largest role [they have] played was certainly with respect to the quality pools. They were very helpful in putting together a couple of reports that were effective in demonstrating the way [P4P] was done around the country, effective in really helping at least me understand and parse out some of the facts.” (Legislative Staff, NY)</td>
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<td>“Give and reach out, establish a relationship, get to understand other people’s point-of-view before you start asking people for anything … You can’t be there just demanding a voice at the table all the time before you established that you are a trustworthy partner.” (Union Staff, NY)</td>
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Theme 3: Major Strategies for Successful Consumer Engagement in Medicaid NH Reimbursement Policy—Interacting with State Legislators & Legislative Staff

3.a. Consumer Advocates Targeting Key Legislators about NH Reimbursement Policy

“[The LTCCC] is a bit more focused on ... sympathetic legislators who are in positions of influence ... rather than my perception being that it's a lot of diffuse broad-based messaging to every single person in the Legislature.” (Provider Representative, NY)

“We have 201 legislators, [advocates have] focused on the members of the Health and Human Service Committees and leadership, Speaker of the House, Majority Leader.” (State Legislator, MN)

“[The advocates] primarily ... focus almost exclusively on the Chairs of their respective committees [who have] a tremendous amount of weight in what goes through ...” (Legislative Staff, NY)

3.b. Consumer Advocates Educating Legislators about the Consumer Position on NH Reimbursement Policy

“It's sitting down with the legislators and talking one-on-one and helping them understand and it's not just one of my lobbyists or me ... [it's] one of our volunteers who's had a loved one in a NH ... who's been in a NH.” (Consumer Advocate, MN)

“[Advocacy organizations] 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.” (Provider Representative, MN)

3.c. Consumer Advocates Testifying at Legislative Hearings about NH Reimbursement Policy

“Legislators [such as myself] are desensitized by our never-ending quest to balance the bottom line on a spreadsheet, and those bottom lines on those spreadsheets are pretty impersonal, and 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.” (State Legislator, MN)

“Bringing people down that are local and that understand the community that Legislators come from is very important. I think that's their most effective way to do it.” (State Legislator, MN)

Theme 4: Major Strategies for Successful Consumer Engagement in Medicaid NH Reimbursement Policy—Interacting with State Agencies & Agency Personnel

4.a. Consumer Advocates Meeting One-on-One with State Administrators about NH Reimbursement Policy

“The Health Department was so much behind us,” reported one advocate, “that not only did we get stuff in the budget, but they opened up discussions for improving the criteria in the future...Identifying valid and reliable measures.” (Consumer Advocate, NY)

“There’s mutual respect, a very respectful exchange of opinions.” (State Official, MN)

4.b. Consumer Advocates Serving as a Conduit Bringing State Agencies Together about NH Reimbursement Policy

“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, NY)

4.c. Consumer Advocates Easing State Administrative Workloads in the NH Reimbursement Policy Area

“We try not to recommend things that they can’t do because they don’t have the people...They appreciate that.” (Consumer Advocate, NY)

“We’re always confronted with limitations, 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...It's something that we can learn from without having to throw a lot of staff at it...There's an open dialogue.” (State Official, NY)

Theme 5: Major Strategies for Successful Consumer Engagement in Medicaid NH Reimbursement Policy—Interacting with Taskforces & Workgroups

5.a. Consumer Advocates Being Assertive in Promoting Consumer Advocacy Representation in Taskforces/Workgroups on NH Reimbursement

“If there is a group convened around...reimbursement, invariably there is one or more consumer advocates present for those meetings.” (Provider Representative, MN)

“Serving on a taskforce or workgroup is one of the most important forms of participation. There were some...where we had to [fight] very hard to get other consumer representatives on and had to actually show the Department where the law [required this].” (Consumer Advocate, NY)

5.b. Consumer Advocates Finding Representation on NH Reimbursement Policy Taskforces/Workgroups Valuable

“Usually the lone consumer voice has been [the LTCCC] but they've been absolutely essential in winning a seat at the table, and nobly, under great odds, providing a consumer voice.” (Consumer Advocate, NY)

“[There was] extensive involvement of consumer advocacy” [in efforts to use] “the payment system to create incentives for improving quality...and staffing through [pay-for-performance].” (State Official, MN)

(Table continues on next page)
prerequisites for consumer action in the Medicaid NH reimbursement policy area, in addition to those strategies deemed most effective in influencing the way NHs are paid. Potential supplemental strategies to enhance the effectiveness of consumer engagement in this area are identified as well.

Varying Degrees of Consumer Engagement in Medicaid NH Reimbursement Policy in New York and Minnesota (Theme 1)

Consumer Representatives Active in Influencing NH Reimbursement Policy (Theme 1.a.)

Elder advocacy groups in Minnesota have sometimes worked together on specific Medicaid NH reimbursement issues; for example, advocating with unions on behalf of NH residents and direct care staff through a coalition, Seniors & Workers for Quality Care. At other times, the heads of several different consumer groups have taken the lead in Medicaid NH reimbursement policy, with the three major groups including AARP, Alzheimer’s Association, and ElderCare Rights Alliance. In New York, consumer advocacy has occurred primarily at the behest of a single organization, the Long-Term Care Community Coalition (LTCCC). The LTCCC is a long-standing coalition of consumers, civic groups, and professional associations that focus on long-term care. The Directors of the LTCCC have taken the lead on reimbursement policy.

Consumer advocacy groups in both states have played a role in the development of case-mix reimbursement, which adjusts Medicaid NH payments...
for patient acuity, thereby improving access for more resource intensive Medicaid beneficiaries. Advocates in New York have also convinced policy makers to include extra payments for dementia and other high needs residents with accompanying requirements, and to consider pay for performance (known as “quality pools” in New York), whereby the amount of reimbursement a provider receives is determined in part on how well they do on one or more measures of quality or other outcomes. Advocates in Minnesota have successfully supported rate equalization and wage encumbrance. Equalization stipulates that facilities cannot charge private pay residents more than the Medicaid rate. Encumbrance earmarks increases in reimbursement for wages and benefits for direct care workers.

A number of interviewees highlight the importance of consumer advocacy involvement because the reimbursement system should, fundamentally, be focused on furthering resident well-being. Interviewees also report that the advocacy role in Medicaid NH reimbursement policy is important because they have served as a counterpoint to NH operators who generally want to increase their rates with as much flexibility as possible. Perhaps most fundamentally, interviewees report that consumer involvement in Medicaid NH reimbursement policy was important because how providers are reimbursed affects access, care quality, and quality of life. Advocates have often been the ones to make the connection between reimbursement and quality explicit, directing attention to how the money paid to NHs can be used to benefit residents.

Consumer Representatives not Active in Influencing NH Reimbursement Policy (Theme 1.b.)

Interviewees report that consumer advocates have historically focused on improving the survey/certification process given their predominant focus on quality-of-care issues. Consequently, some advocates in New York and Minnesota have been reluctant to recognize the potential linkage between reimbursement and quality. Part of this reluctance has stemmed from the belief that a focus on reimbursement may divert attention from quality. A larger part of this reluctance, however, has derived from the absence of the requisite knowledge and expertise about NH reimbursement policy, in addition to the absence of the staff and other resources needed to participate actively in this area.

Two very different types of advocacy groups that minimize their involvement in Medicaid NH reimbursement policy were identified. There are those groups with very narrow interests (e.g., residents’ rights or NH quality) that do not have the financial means to expand their missions to include reimbursement issues. There are also those groups that are less involved in reimbursement policy than they could be because, whereas they may have the financial and personnel resources to advocate more in this area, they are focused on the interests of their broader membership, including healthy seniors living in the community.

In addition to some citizen’s advocacy groups, ombudsmen have not been active in influencing NH reimbursement policy. Reasons interviewees suggest for the absence of ombudsmen participation include lack of independence due to placement of the ombudsman program within a government agency and a focus on individual complaints rather than systematic impediments to quality and access. Because the ombudsman program is a quasi-governmental agency, interviewees report that ombudsmen are concerned about alienating state officials on whom the program is dependent for their budget and funding. There is also consensus among interviewees that ombudsmen typically lack the expertise necessary to be knowledgeable participants in NH reimbursement policy making.

Skills Necessary for Successful Consumer Engagement in Medicaid NH Reimbursement Policy (Theme 2)

Consumer Advocates Prioritizing Engagement in NH Reimbursement Policy (Theme 2.a.)

Prioritizing involvement means instilling NH reimbursement policy as an important issue in the organization. Making reimbursement policy a priority begins with the leadership of the organization. Many interviewees report that the priorities of the LTCCC around NH reimbursement policy have been driven largely by the organization’s founder. Indeed, the importance of NH reimbursement policy has become so ingrained in the culture of the LTCCC that reimbursement policy as a priority is expected to continue irrespective of the founder’s continued affiliation with the LTCCC. The continuous involvement of the LTCCC in New York is in contrast to Minnesota, where the involvement of various consumer groups in NH reimbursement policy has waxed and waned with the participation of a single, high profile individual.
Prioritizing reimbursement policy also means taking advantage of windows of opportunity that develop with which to influence NH payment policy over time. In New York, proposed simplification of the reimbursement system has provided additional opportunities for consumer advocates to pull quality into the discussion. In Minnesota, by contrast, opportunities to promote positive change have been relatively rare in recent years. Due to the state’s fiscal crisis, implementation of a new reimbursement system has been suspended. As a consequence, the state’s payment methodology has remained static, opening few additional topics for negotiation.

Consumer Advocates Developing, Demonstrating, and Sharing Expertise about NH Reimbursement Policy (Theme 2.b.)

The most effective consumer advocates in New York and Minnesota made sure that they understand the nuts and bolts of NH reimbursement policy. In New York, for example, the LTCCC developed policy papers, conducted research, and made presentations about NH reimbursement policy, thereby increasing their reputation in this area. Not only should consumer advocates become knowledgeable about reimbursement but they also should share resulting information and expertise about NH payment policy, as doing so can generate good will and trust among other constituency groups, which may pay off in the long run. Information sharing is key to influencing the thinking of legislators and their staff about NH reimbursement policy.

Major Strategies for Successful Consumer Engagement in Medicaid NH Reimbursement Policy—Interacting With State Legislators & Legislative Staff (Theme 3)

Consumer Advocates Targeting Key Legislators About NH Reimbursement Policy (Theme 3.a.)

Both Minnesota and New York respondents report that meeting with key legislators and their staff has been an effective strategy to influence NH reimbursement policy. Key legislators include the Chairs of the Health and Aging Committees, sometimes the Appropriations and Budget Committees, and Assembly/House and Senate leadership. Consumer advocates report that the resources available for targeting a broader array of legislators has typically been limited. Most interviewees report that consumer advocates have had more sway with democratic legislators than their republican counterparts.

Consumer Advocates Educating Legislators About the Consumer Position on NH Reimbursement Policy (Theme 3.b.)

Legislative visits have provided consumer advocates with opportunities to educate legislators from the consumer vantage point regarding NH reimbursement policy. Respondents report that legislators need to hear from consumer advocates because they often behave as if the NH operators in their districts are their constituents to the exclusion of NH residents and their families. Interviewees from both case study states report that the advocates had affected the way key legislators thought and acted with respect to NH reimbursement policy. Although not as well-resourced as NH operators, one advantage consumer advocates have had in influencing legislators is that they are viewed as being motivated purely by a desire to help residents. The ability to tap into a true network of consumers—people who reside in NHs and their families—is deemed critical for influencing payment.

Consumer Advocates Testifying at Legislative Hearings About NH Reimbursement Policy (Theme 3.c.)

Consumer advocates in Minnesota report that in-person testimony at legislative hearings has been crucial to influencing legislators about NH reimbursement policy. Testimony has helped to make otherwise dry and antiseptic issues “real” and has provided advocates with an opportunity to address the potential personal implications of a policy. Particularly important has been drawing on the experiences of spokespeople whose integrity and caring is beyond question (e.g., family members, residents themselves). Also important has been making issues “local” by having constituents of particular legislators tell their stories. Having sympathetic spokespeople testify has been difficult to implement in practice, however, due to the frailty of the population served by NHs.

Major Strategies for Successful Consumer Engagement in Medicaid NH Reimbursement Policy—Interacting With State Agencies and Agency Personnel (Theme 4)

Consumer Advocates Meeting One-on-One With State Administrators About NH Reimbursement Policy (Theme 4.a.)

In New York, meeting with a broad array of state officials is viewed as an effective strategy for influencing NH reimbursement policy. The LTCCC
has had quarterly or monthly meetings with the Medicaid and quality sections of the Department of Health and less frequent communication with the Division of the Budget and Governor’s Office. Interviewees report that recent legislative changes will make the executive branch a particularly productive venue for influencing NH reimbursement policy. This is because while the State Legislature authorized development of a new payment methodology, state administrators have been delegated the task of developing the details of the reimbursement system that will ultimately be put into place. An noteworthy example where administrative discretion may play a key role is in the potential incorporation of quality pools into the state’s new reimbursement system. Like New York, most interviewees report that advocates in Minnesota have had a good, long-term relationship with technical personnel within the Department of Human Services. Unlike New York, however, most interaction has been through general stakeholder advisory groups and forums about NH reimbursement policy rather than one-on-one meetings.

Consumer Advocates Serving as a Conduit Bringing State Agencies Together About NH Reimbursement policy (Theme 4.b.)

One of the useful roles that the survey/certification agency has assumed in New York is to translate what they find in the field about facilities, from a surveillance/quality perspective, in their dialogue with consumer advocates, and other offices within the Health Department. One of the useful roles that consumer advocates have assumed is to meet and share ideas with different state agencies; meetings that have served as a bridge, permitting knowledge from the survey/certification agency to influence Medicaid agency deliberations about the incorporation of quality incentives into the state’s NH reimbursement system.

Consumer Advocates Easing State Administrative Workloads in the NH Reimbursement Policy Area (Theme 4.c.)

Interviewees highlight the importance of consumer advocates accounting for and, perhaps, ameliorating the workload burdens agency personnel have faced when implementing Medicaid NH reimbursement policy both by fighting for more resources and by sharing information. This assistance has, in turn, helped influence the way state bureaucrats think about how reimbursement affects residents while generating good will and trust in the process. The provision of information and other assistance in the reimbursement area has served a useful role, particularly in light of prevailing shortages in critical state personnel.

Major Strategies for Successful Consumer Engagement in Medicaid NH Reimbursement—Interacting With Taskforces and Workgroups (Theme 5)

Consumer Advocates Being Assertive in Promoting Consumer Advocacy Representation in Taskforces/Workgroups on NH Reimbursement Policy (Theme 5.a.)

Advocacy groups have been particularly assertive in promoting consumer representation on NH reimbursement policy-related panels. Up until the last few years, the Minnesota Department of Human Services has routinely convened advisory committees on NH reimbursement policy that included consumer advocates and other stakeholders groups. New York State has been very interested in advocacy participation as well. Due, in part, to the assertiveness of certain advocates, there has been increasing sensitivity among state officials to ensuring consumer representation on these panels. Indeed, advocates have worked with legislators to make sure that any legislatively mandated state reimbursement committee include consumer representation.

Consumer Advocates Finding Representation on NH Reimbursement Policy Taskforces/Workgroups Valuable (Theme 5.b.)

Consumer advocates in Minnesota have successfully used participation on Department of Human Services’ advisory panels to participate in the development of NH reimbursement policy. Topics have included the 2002 transition to a new case-mix system and the 2006 development of pay-for-performance. Largely as a result of advocacy input, staffing was disproportionately weighted as a performance measure worthy of additional reimbursement in the pay-for-performance system adopted.

Because the number of knowledgeable consumer advocates has been limited, the LTCCC has often been the only advocacy group represented on New York’s NH reimbursement policy taskforces. Although outnumbered by NH operators and state
interests, the coalition has, in the views of most informants, nonetheless provided valuable input to the benefit of residents. Interviewees report participation enabled the LTCCC to influence the development of the state’s NH reimbursement system, largely by encouraging dialogue around pay-for-performance or quality pools, and how reimbursement affects quality of care.

Supplemental Strategies for Successful Consumer Engagement in Medicaid NH Reimbursement Policy—Developing Grassroots Approaches (Theme 6)

Consumer Advocates Promoting Newspaper Coverage About NH Reimbursement Policy (Theme 6.a.)

Although consumer advocates have been successful in obtaining press coverage of survey enforcement and elder abuse, they have rarely used this technique in the context of reimbursement policy. The one exception noted in the Minnesota interviews was AARP-driven coverage of rate equalization, including advertisements in the State’s most widely circulated newspapers.

Consumer Advocates Conducting Action Alerts, Letter Writing, E-mail, and Phone Call Campaigns About NH Reimbursement Policy (Theme 6.b.)

Action alerts, which reach out to people about specific issues, have been useful for activating broader networks of individuals to generate letters, e-mails, and phone calls with the aim of moving NH reimbursement policy by getting policy makers to take notice. AARP in Minnesota has used “robo-call” technology to stimulate communication about NH reimbursement policy on the part of AARP’s membership. Thus, during the last legislative session, AARP generated approximately 6,000 phone calls and e-mails advocating against the repeal of rate equalization.

The LTCCC in New York has promulgated reimbursement-related action alerts through postings on the coalition’s newsletter and website. The LTCCC has also forwarded their action alerts to stimulate e-mails and letters by other organizations’ memberships. Some interviewees report that the action alerts have been more effective at opening doors than influencing NH reimbursement policy. Others report that the LTCCC had indeed been successful in using action alerts to shape reimbursement. Currently, the LTCCC has 3,000 individuals across the state on its action alert list.

Consumer Advocates Conducting Legislative Lobbying Days About NH Reimbursement Policy (Theme 6.c.)

Consumer advocacy groups in Minnesota have occasionally been effective at stimulating large numbers to lobby legislators and their staffs directly on behalf of NH reimbursement policy. These events have occurred primarily under the auspices of AARP, which makes their members visible by having them wear buttons and red shirts on designated lobbying days. During the last legislative session, AARP was successful in having volunteer leaders make personal visits to lobby against the repeal of rate equalization. AARP in New York employs this tactic as well, although they have been much less active on reimbursement policy.

Supplemental Strategies for Influencing Consumer Engagement in Medicaid NH Reimbursement Policy—Developing Coalitions with Other Groups (Theme 7)

Consumer Advocates Forming NH Reimbursement Policy Coalitions with Other Consumer Groups (Theme 7.a.)

As noted, consumer advocates in New York have gathered into a coalition—the LTCCC—which, in addition to consumer groups, includes professional and civic organizations as well as local ombudsmen. Participation of these groups has increased the LTCCC’s impact in the NH reimbursement policy arena. Government officials know that the coalition’s executive staff speaks for large numbers of constituents. Thus, although LTCCC staff has taken the lead on reimbursement policy, the organization has drawn strength and support from its membership. This support has been manifested in a number of ways, including informing and providing feedback on LTCCC strategy, expanding the LTCCC’s lobbying strength, and enhancing the perceived legitimacy of the LTCCC’s efforts.

Consumer Advocates Forming NH Reimbursement Policy Coalitions with Unions (Theme 7.b.)

In Minnesota, Seniors & Workers for Quality Care includes most senior-oriented groups and
unions representing direct care workers. The unions and advocacy groups that constitute Seniors & Workers have assumed complementary roles. Whereas the unions have strong electoral and political arms, the consumer advocates have compelling individual members and more experience lobbying state legislators and administrators directly. The combination of these core competencies has helped Seniors & Workers serve as an effective countervailing weight to the NH industry and to successfully influence aspects of the state’s payment methodology.

Consumer Advocates Forming NH Reimbursement Policy Coalitions With NH Operators (Theme 7.a.)

Interviewees generally agreed that working with NH operators would be an effective strategy for consumers wishing to influence Medicaid NH reimbursement policy, though such collaborations have been difficult to accomplish due to the conflict between monetary and quality motivations sometimes held by providers and consumers. Suggestions made to improve this relationship include (a) distinguishing among NH operators—some may be more productive and natural coalition partners in the reimbursement area than others; (b) finding common ground around reimbursement issues related to quality, spending levels, and mission; (c) incorporating NH operator input into consumer advocates’ reimbursement policy proposals; (d) not unduly antagonizing NH operators—that is, being more empathetic to the realities of running a NH; and (e) co-opting NH operators’ positions about NH reimbursement policy in such a way that they complement your own.

Discussion

This study identified strategies pursued by consumer advocacy groups in Minnesota and New York to influence Medicaid NH reimbursement policy (Table 2). The findings are consistent with prior research highlighting the potential effectiveness of applying multiple lobbying techniques to different targets within state government (Nownes & DeAlejandro, 2009; Priester et al., 2006). They also are consistent with prior research suggesting that interest groups tend to engage in some lobbying techniques (e.g., direct contacts and legislative testimony) more than others (e.g., lawsuits and demonstrations, neither of which were mentioned in our study; Nownes & Freeman, 1998; Nownes & DeAlejandro, 2009; Schlozman & Tierney, 1983). Consistent with recent trends, consumer advocates in the two case study states have also joined coalitions and pursued grassroots and media strategies.

Findings suggest that identifying, recruiting, and informing champions for the consumer point-of-view in the state legislature are especially important for influencing Medicaid NH reimbursement policy. Indeed, extant evidence suggests that lobbying is targeted not as much on persuading legislators to change their positions or to vote for one’s cause but to assist those legislators who already support your cause to achieve goals that correspond with your own (Hall & Deardorff, 2006). This explains why legislators listen to, seek out, and take advice from public interest groups even though they may not have the resources necessary to help them out with their electoral campaigns (Hall & Deardorff, 2006; Hinrichsen et al., 2010). What legislators gain instead is assistance from those willing to devote the time, experience, and issue-relevant expertise necessary to bolster their chances of legislative success. Not all legislative allies are as well positioned for achieving progress toward policy-making goals, however. Of particular interest are those with greater institutional endowments—formal positions, staff, procedural prerogatives—that enhance their impact in the legislative process (Hall, 1996). This explains why consumer advocates tend to focus on those sitting on the relevant committees and subcommittees, especially chairs, as well as the leadership in each legislative chamber.

Table 2. Engaging Consumer Advocates in Medicaid NH Reimbursement Policy

| Prerequisites for influencing NH reimbursement policy | Develop a reputation; make reimbursement a priority | Develop, demonstrate, and volunteer knowledge |
| Major strategies for influencing NH 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 influencing NH reimbursement policy | Conduct action alerts, e-mail, letters writing, and/or phone call campaigns | |
| | Develop strategic alliances with other consumer-oriented groups | |
| | Develop strategic alliances with unions | |
| | Develop strategic alliances with provider groups | |
There are two basic types of data that consumer advocates and other lobbyists provide state officials: information on substantive policy content and political impact. One-on-one meetings and reimbursement taskforces/workgroups are especially fruitful avenues through which those groups interested in Medicaid NH reimbursement policy can inform state officials about their positions, preferences, and concerns and thereby help shape the content of legislation and regulation. Grassroots organizing and legislative testimony by local constituents can play a critical role in highlighting the political ramifications of particular legislative and regulatory decisions. By demonstrating the presence of broader public support, these latter activities can help build an advocacy’s supportive coalition, not only among likely allies in the state legislature but also among undecided legislators and, perhaps, even some legislative opponents (Hinrichsen et al., 2010; Hojnacki & Kimball, 1999; McConnell, 2004). Although both grassroots and direct lobbying activities require monetary and organizational support, grassroots strategies tend to require more time and resources to implement (Hojnacki & Kimball, 1999; Nownes & DeAlejandro, 2009; Schlozman & Tierney, 1983). Consequently, advocates in our study used grassroots strategies to supplement direct contact with government officials rather than as the primary means with which to influence policy.

Extant research suggests that one reason why consumer advocacy groups in our study develop strategic alliances for purposes of influencing NH reimbursement policy is to increase the strength of their advocacy (Hojnacki, 1997). These alliances both enhance the resources available—financial, informational, and skill—and demonstrate greater legitimacy and visibility for membership concerns. As our study suggests, a division of labor among consumer groups and their alliance partners can be critical. The importance of such a division is also reflected in other areas, where some groups focus on network building, others on community organizing, still others on policy analysis and campaign strategy (Binstock, 2010; Freeman, 1997/1998; Nownes & DeAlejandro, 2009; Strong et al., 2011).

**Limitations**

We note several potential study limitations. First, we studied consumer advocacy involvement in Medicaid NH reimbursement policy in just two states. Consequently, our findings may not apply to other states that face substantially different circumstances. For example, ombudsmen in other states may play a greater role in NH reimbursement policy because their programs are located outside of a government agency instead of within one as is the case in New York and Minnesota. In general, however, we believe that our findings are transferable. The general contours of other states’ policy communities within which Medicaid NH reimbursement policy is developed and implemented is similar to that which exists in New York and Minnesota.

Second, there may have been bias inherent in the particular interview participants selected. Because there was no sampling frame, and we relied on a combination of purposive and snowball sampling, potentially knowledgeable individuals may have been excluded. Although we are confident that we spoke with most, if not all of the key stakeholders in the two states studied, our impressions may have been dependent, in part, on the specific individuals interviewed.

Finally, the study was designed to acquire detailed information on the particular topic addressed, strategies that enhance consumer advocacy engagement in Medicaid NH reimbursement policy. Although providing a rich source of data, doing so sacrificed breadth for depth in two respects. We studied one policy only and spent more time exploring strategies for successful consumer engagement than why they chose to do so or not. Future research could build on the results reported by further exploring the determinants of involvement; for example, applying insights from social movement and organization theory to better understand the impediments to ombudsmen engagement in this area (Hollister 2008). Future research could also build on the results reported by exploring additional issue areas that may benefit from more effective advocacy.

**Conclusion**

The way in which Medicare and Medicaid reimburse NHs and other providers is in flux. Several provisions within the Patient Protection and Affordable Care Act of 2010 relate to provider reimbursement policy. At the state level, there has been significant retrenchment across the board, including an increase in the number of states reducing/freezing NH reimbursement from 6 in FY 2007 to 30 in FY 2011 (Smith et al., 2011). In addition, a growing number of state Medicaid programs are adopting novel NH Medicaid reimbursement
systems. These changes should provide opportunities for consumer advocacy influence during the design and implementation process.

**Funding**

This research was supported by a grant (#20110033) from The Commonwealth Fund.

**Acknowledgment**

The authors would also like to thank the following individuals: Sara Rosenberg, Richard Mollot, Iris Freeman, Corina Oala, Jane Taveras, and Mary Jane Koren. An early version of this research was included in a report provided to the Commonwealth Fund. The views expressed are those of the authors and not necessarily those of Commonwealth Fund staff or anyone else.

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