



Increasing Consumer Involvement in Medicaid Nursing Facility Reimbursement: Lessons from New York and Minnesotaⁱ

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ABSTRACT

Medicaid is the major purchaser of nursing home care in the United States. States design their methods of reimbursing nursing homes to achieve desired policy objectives related to facility cost and quality, access to care, payment equity, service capacity, and budgetary control. The incorporation of multiple, sometimes conflicting incentives into state reimbursement systems has resulted in enormously complex and demanding methodologies that inhibit consumer participation in state rating setting decisions. In turn, the lack of consumer involvement has the potential to result in the adoption of reimbursement systems 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 when reimbursement policy is being discussed.

Now is the time to be planning how to take advantage of several provisions within Patient Protection and Affordable Care Act (ACA) of 2010 related to provider reimbursement where implementation would benefit from consumer involvement. One example, the National Pilot Program on Payment Bundling, will combine payments for hospitals, physician, outpatient, and post-acute care into a unified payment for ten specific chronic conditions. Elsewhere in the ACA are a number of Medicare value-based purchasing/pay-for-performance provisions which require the development of plans to implement value-based purchasing for nursing homes and home health care providers as well as to pilot test pay-for-performance for other providers, including long-term care hospitals, rehabilitation hospitals and hospice. What strategies should consumers pursue to influence these and other similar endeavors?

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 payment policy, 24 in-depth interviews were conducted with 27 individuals in these states with known or demonstrable experience in this area. Subjects interviewed include: 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. The primary purpose of this report is to detail lessons learned from New York and Minnesota about how best to promote effective consumer involvement in the reimbursement of nursing homes and other long-term care providers.

Given their predominant focus on quality of care issues, consumers have historically focused on improving the survey and certification process. That is where the calls for greater government involvement and oversight tend to be focused. Part of the reluctance to wade into reimbursement issues stem from the belief that a focus on reimbursement may divert attention from quality. A larger part, however, seems to derive from the absence of the knowledge and expertise necessary to understand the complexities of reimbursement, in addition to the absence of the staff and other resources needed to participate actively in these discussions. Two very different types of advocacy groups that have minimized their

involvement in provider payment were identified. On the one hand, there were those groups with very narrow interests who are overwhelmed focusing on their own mission, let alone adding reimbursement to the mix. On the other hand, there were those groups that were much less involved in reimbursement because, while they may have had the resources to participate, doing so did not comport with their broader interests and goals.

For a number of the interviewees, it is important to have consumer advocates at the table, because they represent the residents of nursing homes, and the reimbursement system should, fundamentally, be focused on furthering resident wellbeing. Interviewees also felt that it was important to have consumer advocates at the table because they can serve as a counterpoint to other key stakeholders, including state agency officials and provider representatives. Perhaps most fundamentally interviewees felt it was important for consumer advocates to be at the table because how providers are reimbursed affects access, care quality, quality of life, and other potential outcomes.

Experience in New York and Minnesota suggests 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 involvement. These include:

- **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

Together the findings suggest the importance of developing, demonstrating, and volunteering expertise as a means of gaining credibility as a legitimate actor, which, once earned, will lead to an ongoing role in state reimbursement policy discussions. They also suggest strategies for using that knowledge and credibility to effectuate change. These include volunteering and/or insisting on participating on state work groups and taskforces targeting reimbursement. They also include developing and accessing relationships with key public officials in the legislative and executive branches, in addition to supplementing taskforce memberships and stakeholder meetings with grassroots activities—e.g., action alerts, legislative lobbying days—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 mass rallies, letter writing, email, and other broader-based endeavors.

EXECUTIVE SUMMARY

Medicaid is the major purchaser of nursing home care in the United States. States design their methods of reimbursing nursing homes to achieve desired policy objectives related to facility cost and quality, access to care, payment equity, service capacity, and budgetary control. The incorporation of multiple, sometimes conflicting incentives into state reimbursement systems has resulted in enormously complex and demanding methodologies that inhibit consumer participation in state rate setting decisions. In turn, the lack of consumer involvement has the potential to result in the adoption of reimbursement systems 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 when reimbursement policy is being discussed.

Now is the time to be planning how to take advantage of several provisions within the Patient Protection and Affordable Care Act of 2010 related to provider reimbursement where implementation would benefit from consumer involvement. What strategies should consumers pursue to influence these and other similar endeavors? New York and Minnesota are two states where consumers have been successful in influencing Medicaid nursing home reimbursement to better encourage access, quality of care, and quality of life. To understand how consumers can acquire a seat at the table and be effective in influencing payment policy, Medicaid nursing home reimbursement policymaking was studied in these two states. The primary purpose of this report is to detail lessons learned from New York and Minnesota about how best to promote effective consumer involvement in the reimbursement of nursing homes and other long-term care providers.

BACKGROUND & SIGNIFICANCE

Like other third-party payer situations, providers are likely to have interests that are at odds with other interested parties. States seek to align providers' interests with their own, in part, through controls and incentives built into state reimbursement systems. Indeed, state governments design their methods of reimbursing nursing homes to achieve desired policy objectives related to facility cost and quality, access to care, payment equity, service capacity, and budgetary control. Although resident advocates have been successful in influencing major changes in both nursing home rules and regulations and in encouraging culture change, few have been involved in the development or modification of state methods for reimbursing nursing homes. Simply put, many consumer advocates do not understand rate setting well enough to knowledgeably participate in state policy making discussions; few appreciate that the way payment systems are structured can directly affect quality and other outcomes (e.g., culture change).

Without doubt the interests of advocates may differ from those of state officials and nursing home industry representatives. In general, industry representatives prefer to maximize payment and flexibility under state methods for reimbursing nursing homes. This is in contrast to advocates who also tend to favor maintaining payment levels but prefer that systems be promulgated that incentivize quality by holding providers

accountable for performance and outcomes. Lack of consumer involvement has the potential to result in the promulgation of reimbursement methodologies more favorable to industry and government than residents and families.

METHODS

This study analyzed consumer participation in the design and implementation of Medicaid nursing home reimbursement in New York and Minnesota using archival resources and in-depth open-ended interviews with key stakeholders. New York and Minnesota were chosen for study because preliminary research indicated that consumer advocates had proven effective in influencing Medicaid nursing home reimbursement in these two states. Semi-structured interviews were undertaken with individuals with known or demonstrable experience with Medicaid nursing home reimbursement.

Through our interviews we sought to identify which consumer advocacy groups had been active and/or influential in Medicaid nursing home reimbursement policy and which had not. In doing so, we asked our interview subjects to provide concrete examples of consumer activity in this area. We also asked them why they felt some consumer groups have not typically been active or influential in this area. We further sought to understand what the basic prerequisites were for consumer involvement and what strategies consumers have undertaken to influence nursing home reimbursement. We sought to identify both the most and least effective strategies undertaken as well.

Twenty-four interviews were conducted with 27 individuals between February 2, 2011 and June 20, 2011, 12 each in New York and Minnesota. Interview subjects included state legislators/legislative staff, officials within the pertinent state administrative agencies, consumer advocates representing both citizen advocacy groups and the state ombudsmen program, union staff, and nursing home industry representatives. All interviews were recorded and transcribed. Transcripts were subsequently coded to identify recurring themes and patterns in responses. Archival information was collected as well.

CONSUMER PARTICIPATION & INFLUENCE

Consumer advocates in both New York and Minnesota played a role in the development of case-mix reimbursement. Whereas advocates in New York convinced policymakers to enact a number of rate setting components intended to improve access, quality and efficiency, including pay-for-performance (quality pools) and adds-ons for dementia and other high needs residents with accompanying requirements, those in Minnesota have successfully supported such reimbursement system attributes as rate equalization and wage encumbrance.

Consumer advocates in New York and Minnesota participate in nursing home reimbursement policy discussions differently. Elder advocacy groups in Minnesota sometimes work together on specific issues; for example, advocating with unions on behalf of nursing home residents and direct care staff through a coalition, Seniors & Workers for

Quality Care. Other times, the heads of several different consumer groups have taken the lead, with the big three including the AARP, Alzheimer’s Association, and ElderCare Rights Alliance. In New York, by contrast, consumer advocacy in the reimbursement arena is more concentrated, occurring primarily at the behest of a single organization, the Long Term Care Community Coalition or LTCCC. The LTCCC is a long standing coalition of consumers, civic groups, and professional associations that focus on long-term care. It is the Directors of the LTCCC that have taken the lead on nursing home reimbursement issues.

In comparison to citizen advocacy groups, ombudsmen were not nearly as active in influencing nursing home reimbursement as they could be. Reasons that ombudsmen have not participated 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. There was general consensus that the ombudsmen typically lack the expertise necessary to be knowledgeable participants as well. Still, interviewees felt that ombudsmen should become more actively involved in influencing policy in this area.

WHY DO CONSUMER GROUPS NOT BECOME INVOLVED?

Several reasons were identified for why some consumer groups do not become actively involved in Medicaid nursing home reimbursement. Given their predominant focus on quality of care issues, advocates have historically focused on improving the survey and certification process. Many have been reluctant to recognize the potential linkage between reimbursement and quality. Part of this reluctance stems from the belief that a focus on reimbursement may divert attention from quality. A larger part, however, seems to derive from the absence of the knowledge and expertise necessary to understand the complexities of nursing home reimbursement, in addition to the absence of the staff and other resources needed to participate actively in these discussions.

Two very different types of advocacy groups that minimize their involvement in nursing home reimbursement were identified. On the one hand, there were those groups with very narrow interests, whether in the way of nursing home quality or encouraging home- and community-based services, who are overwhelmed focusing on their own mission, let alone adding nursing home reimbursement to the mix. Furthermore, many advocacy groups struggle just to survive, something that has been exacerbated in the current fiscal climate. On the other hand, there were those groups that were much less involved in nursing home reimbursement because, while they may have had the resources to participate, doing so did not comport with their broader interests and goals.

THE IMPORTANCE OF BEING “AT THE TABLE”

For a number of the interviewees, it is important to have consumer advocates at the table, because they represent the residents of nursing homes, and the reimbursement system should, fundamentally, be focused on furthering resident wellbeing. Interviewees also felt that it was important to have consumer advocates at the table because they can serve as a

counterpoint to nursing home providers who generally want to increase their rates with as much flexibility as possible. Advocates can also serve as a useful complement to state bureaucrats whom legislators may view suspiciously, believing that they may just be making life difficult for providers and easier for themselves.

Perhaps most fundamentally, interviewees felt it was important for consumer advocates to be at the table because how providers are reimbursed affects access, care quality, quality of life, and other potential outcomes. The consumer role is particularly important when contemplating changes to the reimbursement system because it is often up to advocates to make the connection between reimbursement and quality explicit, directing attention to how the money paid to nursing homes can be used to benefit residents.

PREREQUISITES FOR SUCCESSFUL CONSUMER INVOLVEMENT

Experiences in New York and Minnesota suggest certain prerequisites for successful consumer participation in Medicaid nursing home reimbursement. First, it is important to develop a reputation in this area by making reimbursement a visible priority for the organization over a long period of time. Second, it is important to develop and demonstrate knowledge and expertise; how else can one's reputation be built? Third, it is important to further develop one's credibility by sharing information on Medicaid nursing home reimbursement with other constituency groups.

Prioritize Consumer Involvement in Nursing Home Reimbursement

Prioritizing reimbursement means instilling nursing home reimbursement policy as an important issue in the organization. Doing so begins with an organization's leadership. Many interviewees reported that the priorities of the LTCCC in New York were driven largely by the organization's founder and that such had become so ingrained in its culture that reimbursement as a priority would continue irrespective of that person's continued involvement. This is in contrast to Minnesota where the involvement of various consumer groups in this area has waxed and waned with the participation of a single, high profile individual. This, in part, reflects concern that the newer generation of advocates does not appreciate the details of nursing home reimbursement as much as the older generation.

Prioritizing reimbursement also means being a "persistent," "consistent," and "assertive" advocate. This is especially important for taking advantage of windows of opportunity that develop with which to influence reimbursement over time. In New York, proposed simplification of the reimbursement system through regional pricing has provided additional opportunities for advocates to pull quality into the discussion. In Minnesota, by contrast, opportunities to influence reimbursement to promote positive change have been relatively rare in recent years. Due to the state's fiscal crisis, implementation of a new, reimbursement system based on biennial cost reports has been suspended. As a consequence, the state's methodology for paying nursing homes has remained static, opening up few additional topics for negotiation other than the potential repeal of rate equalization under the new Republican majority in the State Legislature.

Knowledge about Nursing Home Reimbursement and the Policy Process

Perhaps the most important indicator that reimbursement has become a priority is to become knowledgeable about it. Indeed, the most effective advocates in Minnesota and New York made sure that they understood the nuts and bolts of nursing home reimbursement policy, not only in their states but around the country; expertise that they subsequently brought to the table to influence policy. Knowledgeable advocates commanded respect and were listened to; in both New York and Minnesota there was at least one advocate that was seen as always being there and having the answers. In New York, for example, the LTCCC developed policy papers, conducted research, and made presentations, thereby increasing their reputation for understanding the issue. It is also important for consumer advocates to become knowledgeable about the location of key pressure points for influencing the direction of state policy making in this issue area.

Share Information and Expertise about Nursing Home Reimbursement

Not only is it important to be knowledgeable but it is important to share resulting information and expertise as doing so can generate good will and trust among other constituency groups, which may pay off in the long run. Key to influencing how legislators and their staff think about reimbursement is information sharing. In New York, this is reflected in the dissemination and use by state legislative staff of LTCCC reports on pay-for-performance. The provision of information has also helped improve consumer advocates' relationships with the state bureaucracy.

MAJOR STRATEGIES FOR INFLUENCING REIMBURSEMENT

Establishing a reputation as credible and knowledgeable players in the world of nursing home reimbursement policy is a necessary but not sufficient condition for exerting influence. Doing so opens the door. Strategies must be put into place to walk through it to effectuate change. Advocates have pursued a variety of effective strategies. This includes participating on state work groups and taskforces targeted at revising the way nursing homes are paid under Medicaid. It also includes developing and accessing relationships with key public officials in the legislative and executive branches.

STATE LEGISLATORS & LEGISLATIVE STAFF

Relationships can be built and access with state legislators and their staff obtained through one-on-one meetings, legislative testimony, and making issues "local" and "real" by having constituents, residents, family, and direct care workers tell their stories.

Targeting key legislatures but not forgetting the “back benchers”

Meeting with key legislators and their staffs is seen as effective in both New York and Minnesota. Here, the focus tends to be on key legislators rather than the Legislature as a whole. This includes the Chairs of the Health and Aging Committees, sometimes the Appropriations and Budget Committees and Assembly/House and Senate leadership. It was generally felt that advocates tend to have more sway with Democratic legislators than their Republican counterparts or the governor’s office, irrespective of party affiliation.

Although most interviewees emphasized the importance of targeting key legislators, others highlighted the importance of lobbying and educating those who are not currently in a key decision making position but could be one day, or ultimately, will have to cast a vote one way or the other. It was recognized that the resources available for doing so were, admittedly, limited, however, particularly among consumer groups who are increasingly struggling to survive in the current fiscal environment

Educating legislators about the consumer point-of-view

Meetings with legislators are important because they provide advocates with opportunities to educate key decision makers about the consumer vantage point. Many legislators feel that nursing homes providers in their district are their constituents. Thus, they need to hear from the other side to better understand that nursing home residents are their constituents as well. Interviewees from both New York and Minnesota felt that the advocates had impacted the way key legislators thought and acted with respect to nursing home reimbursement. They also felt that although much less well-resourced, one advantage advocates have over providers when trying to influence legislators is that unlike providers, they are not seen as having a self-interested agenda other than helping the nursing home residents for whom they advocate. Largely for this reason ensuring a consumer voice has been a priority for some legislators.

Testifying at legislative hearings

Deemed crucial for influencing legislators in Minnesota was face-to-face, in person testimony at legislative hearings. Testimony is particularly useful because it helps to make otherwise dry and antiseptic issues real. On the one hand, testimony provides professional advocates an opportunity to explain the potential implications of a policy change. On the other hand, it enables advocacy groups to draw on the experiences of spokespeople whose integrity and caring for residents is beyond question. This includes families members, direct caregivers, and, occasionally, residents themselves. Legislative testimony is also important because it helps to make issues “local” by having constituents of particular legislators tell their stories. Bringing in sympathetic spokespeople can be difficult to implement in practice, however, due to the frailty of the population served and the lack of engagement in this issue by some better-resourced advocacy organizations.

STATE AGENCIES & AGENCY PERSONNEL

Developing and accessing relationships with officials in key state agencies is believed important for influencing Medicaid nursing home reimbursement. Specific activities that advocates engaged in include one-on-one meetings with state Medicaid, survey and certification, and/or other state staff, not to mention bringing otherwise non-communicating agencies together and helping frequently overwhelmed officials do their jobs through the provision of timely information and expertise.

One-on-one meetings with state administrative personnel

In New York, meeting with a broad array of state officials is viewed as an effective strategy. This includes officials in the Medicaid and quality sections of the Department of Health, in addition the Division of the Budget and Governor's Office, and, potentially, the Offices' of the Attorney and Inspector Generals. It was reported that moving forward in New York the executive branch would be the more productive venue at which to influence policy. This is because while the Legislature authorized development of the state's payment methodology, it has been left up to state administrative personnel to develop the details.

At the time of the study, the Office of Long-Term Care in New York was charged with survey and certification and monitoring of all long-term care providers; the Division of Health Care Financing with promulgating provider payment rates. Both Offices inform nursing home reimbursement policy. In addition to having quarterly, sometimes monthly communication with the LTCCC, the work of the Long-Term Care Office is informed through communication with actual residents and their families. Like New York, most interviewees believed that advocates in Minnesota have had a good, long term relationship with technical personnel within the Department of Human Services, though not with higher-level appointees. Unlike New York, most interaction with the Department has been through general stakeholder advisory groups and forums rather than one-on-one meetings with Departmental staff. In both Minnesota and New York, Department technical staff has often been willing to help educate consumers on reimbursement issues by presenting at consumer meetings.

Serving as a conduit to bring state agencies together

One of the useful roles that the Office of Long-Term Care serves in New York is to translate what they find in the field about facilities, from a surveillance and quality perspective, in their dialogue with other offices within the Health Department as well as with advocates, including with respect to reimbursement. Interviewees also felt that advocates have served as bridge for state agencies who might not otherwise communicate as frequently as would be optimal. This has been to the benefit of the issues advocates care about.

Account for and perhaps ameliorate the workload burden of state officials

When interacting with state agencies it is important to account for and, perhaps, help ameliorate the workload burdens that agency personnel face. This may help influence the

way state bureaucrats think about reimbursement and how it affects residents while generating a certain amount of good will and trust in the process. In light of prevailing shortages in critical personnel, the provision of assistance can serve a useful role; it is clearly appreciated. Sometimes the flow of information and expertise flows the other way, from state officials to consumer advocates. This is true in both New York and Minnesota.

TASKFORCES & WORKGROUPS

States typically employ taskforces when making major changes to the way nursing homes are reimbursed under Medicaid. Typically included are state Medicaid personnel, provider representatives, and their consultants. Often included are union representatives and state legislative staff. Included less frequently are nursing home residents and/or their advocates. In New York and Minnesota, however, taskforces and work groups have served as especially important conduits for consumer advocacy participation and influence.

Being assertive in promoting consumer advocacy representation

Advocacy groups have been particularly assertive in promoting consumer advocacy representation on reimbursement-related panels. Up until the last few years the Minnesota Department of Human Services routinely convened advisory committees on nursing home reimbursement which included consumer advocates and other key stakeholders groups. New York State is very interested in advocacy participation on state taskforces and workgroups as well. Due, in part, to the assertiveness of certain advocates in seeking to obtain a seat at the table, there is increasing sensitivity among state officials to ensuring consumer representation in those policy group meetings. Indeed, advocates worked with legislators in New York to make sure that any legislatively mandated state committee on Medicaid nursing home reimbursement include consumer representation.

Consumer representation is valuable but limited

Advocates in Minnesota have successfully used participation on the Department's advisory panels to participate in the development of nursing home reimbursement, with consumer representatives being drawn from Seniors & Workers for Quality Care, AARP, and the ElderCare Rights Alliance. Topics have included transition from a Minnesota-specific to case-mix system to one based on Resource Utilization Groups in 2002 and the development and implementation of pay-for-performance (P4P) in 2006. Largely as a result of advocacy input, staffing was disproportionately weighted in the State's P4P system. In other areas, advocates influence has been much more limited; for example, the now suspended revision to the state's reimbursement system was developed primarily through negotiations between the Department and trade associations.

Because the number of knowledgeable advocates is limited, the LTCCC is typically the only advocacy group represented on reimbursement-related taskforces in New York. But although invariably outnumbered by provider and state interests, the Coalition has, in the views of most interviewees, nonetheless, provided valuable input to the benefit of resident

interests. The State Hospital Review and Planning Council (SHRPC), though now defunct, included providers, lawyers, business leaders, and consumer representatives. It was charged with adopting and amending rules and regulations, subject to the approval of the Health Commissioner. Most interviewees believed participation on the Council provided one leading advocate with an excellent opportunity with which to influence the development of the state's nursing home reimbursement system, largely by continually raising the relationship between proposed changes and quality.

The Nursing Home Reimbursement Workgroup, which operated from June 2007 through October 2010, was established by the New York State Legislature to inform Health Department implementation of a new regional pricing system for paying nursing homes. The LTCCC was the only consumer advocacy group to serve, given the absence of other available options. A number of interviewees expressed disappointment with the Nursing Home Reimbursement Workgroup. However, several believed it served several useful purposes, including informing subsequent legislation codifying regional pricing and the quality pools. The Workgroup also served as the primary place where key stakeholders could join together to discuss and analyze the issues. Furthermore, most believed the dialogue around regional pricing and quality pools, and other factors were more on the table than they were at the beginning of the conversation due to the LTCCC's participation. Quality pools, for example, will be implemented over the next two years, with facilities being paid to report quality data during the program's first year and rewarded, in part, on the basis of that data in subsequent years.

SUPPLEMENTS TO HIGHER LEVEL PARTICIPATION

Our findings suggest that consumer advocacy groups sometimes supplement higher level interactions in the way of stakeholder meetings and taskforce memberships with more grassroots approaches to influencing government policy. The most frequently used grassroots strategies include action alerts, email and letter writing campaigns, and legislative lobbying days. It was suggested that developing coalitions with other consumer-oriented groups, unions, and, potentially, provider organizations, could enhance advocates' grassroots presence and effectiveness as well.

GRASSROOTS STRATEGIES

The general purpose of the grassroots strategies identified is to complement higher level participation by letting key decision makers know that advocates have large numbers of people behind them. The idea is that although demonstrating knowledge will get you a seat at the table and allow you to contribute productively, the more traditional grassroots tools may be necessary to bring political pressure to bear should direct negotiations stall.

Newspaper coverage, advertisements

While advocates have been successful in obtaining press coverage of survey enforcement and elder abuse issues, it is little used in the context of reimbursement. The one exception

noted in the Minnesota interviews was AARP-driven coverage of rate equalization. This included advertisements in the State's most widely circulated newspapers. It also included letting legislators know that their constituents would be informed about how they voted.

Action alerts, letters, emails

Action alerts, which reach out to people about specific issues, were found useful in activating broader networks of individuals and organizations to generate letters and emails with the aim of moving policy by getting policymakers to take notice. The AARP in Minnesota has used "robo call" technology to stimulate communication on the part of its membership. The LTCCC in New York has promulgated action alerts through postings on the Coalition's newsletter and web-site. Some interviewees felt that the action alerts have been more effective at opening doors than influencing policy. Others felt that they had indeed been used to successfully shape reimbursement policy.

Mass rallies, legislative lobbying days

Advocates in Minnesota have occasionally been effective at stimulating large numbers to lobby state legislators and their staffs directly on behalf of nursing home reimbursement issues. This has occurred primarily under the auspices of the AARP who make their members visible by having them wear buttons and red shirts on designated lobbying days and, during the last legislative session, were successful in having volunteer leaders make personal visits to lobby against the repeal of rate equalization. Due to insufficient resources, the LTCCC has not engaged in this activity in New York.

Focus on the big issues, keep the messages simple, make it personal

Interviewees generally agreed that grassroots strategies work better when the messaging is kept simple and the focus is on larger issues people more readily understand. The public is much more likely to connect to a message that says under-reimbursement of health care facilities may adversely impact quality than the specific details about how facilities are reimbursed. It was also noted that not all forms of communication with state officials are created equal; some have more credibility than others. In particular, the less effort devoted, the less effective the communication in influencing the behavior of those who were contacted. The form letter or email is least effective, followed by the personalized email or letter, and then phone call. The most effective is individual personal contact.

DEVELOPING COALITIONS WITH OTHER GROUPS

To increase the likelihood of policy impact, advocates could develop coalitions and relationships with other key constituency groups, whether additional consumer-oriented organizations, unions, or provider associations. Consumer-oriented coalitions have been especially important in New York. By contrast, coalitions with unions have been particularly important in Minnesota. Neither state has seen much in the way of provider-

consumer coalitions, though collaboration between the two groups could prove effective in influencing the direction of nursing home reimbursement to the benefit of both parties.

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, includes professional organizations and some civic associations as well as local ombudsmen (www.ltccc.org). Participation of these groups in the LTCCC has increased the Coalition’s impact. It is known that the Coalition’s executive staff speaks for large numbers of constituents. Thus, although LTCCC staff takes the lead on nursing home reimbursement, the LTCCC draws strength and support from its membership. This is manifested in a number of ways, including informing and providing feedback on LTCCC strategy, expanding the lobbying strength of the LTCCC, and enhancing the perceived legitimacy of the efforts made.

Unions

In Minnesota, senior groups have formed a coalition with the unions: Seniors & Workers for Quality Care (www.seniorsandworkers.org). This Coalition includes most senior-oriented groups in Minnesota. It also includes most 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 advocates have compelling individual members and more experience lobbying legislators and state administrative personnel. This has helped Seniors & Workers to serve as an effective countervailing weight to the nursing home industry and to successfully influence aspects of the State’s payment methodology to the benefit of residents and workers.

Providers

Interviewees generally agreed that having consumer advocates work with providers would be effective; that there would be strength in numbers. This has been difficult to accomplish due to the adversarial relationship that exists between consumer advocacy groups and industry associations. A number of suggestions were made to improve this relationship. This includes distinguishing among different types of providers—some may be more productive and natural coalition partners than others. It also includes finding common ground around issues related to quality, spending levels, and mission; incorporating provider input into advocates’ proposals for reforming reimbursement; not unduly antagonizing providers—that is, being more empathetic to the realities of running a nursing home, particularly in an increasingly difficult funding environment; and, where possible, co-opting providers’ positions in such a way that they complement your own.

TOWARD INCREASED CONSUMER INVOLVEMENT

Experience in New York and Minnesota suggests 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 involvement. These include:

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Together the findings suggest the importance of developing, demonstrating, and volunteering expertise as a means of gaining credibility as a legitimate actor, which, once earned, will lead to an ongoing role in state reimbursement policy discussions. They also suggest strategies for using that knowledge and credibility to effectuate change. These include volunteering and/or insisting on participating on state work groups and taskforces targeting reimbursement. They also include developing and accessing relationships with key public officials in the legislative and executive branches, in addition to supplementing taskforce memberships and stakeholder meetings with grassroots activities—e.g., action alerts, legislative lobbying days—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 mass rallies, letter writing, email, and other broader-based endeavors.

INTRODUCTION

Medicaid is the major purchaser of nursing home care in the United States. States design their methods of reimbursing nursing homes to achieve desired policy objectives related to facility cost and quality, access to care, payment equity, service capacity, and budgetary control. The incorporation of multiple, sometimes conflicting incentives into state reimbursement systems has resulted in enormously complex and demanding methodologies that inhibit consumer participation in state rating setting decisions. In turn, the lack of consumer involvement has the potential to result in the adoption of reimbursement systems 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 when reimbursement policy is being discussed.

Now is the time to be planning how to take advantage of several provisions within the Patient Protection and Affordable Care Act (ACA) of 2010 related to provider reimbursement where implementation would benefit from consumer involvement. One example, the National Pilot Program on Payment Bundling, will combine payments for hospitals, physician, outpatient, and post-acute care into a unified payment for ten specific chronic conditions. Elsewhere in the Act are a number of Medicare value-based purchasing/pay-for-performance provisions which require the development of plans to implement value-based purchasing for nursing homes and home health care providers as well as to pilot test pay-for-performance for other providers, including long-term care hospitals, rehabilitation hospitals and hospice. What strategies should consumers pursue to influence these and other similar endeavors?

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 payment policy, 24 in-depth interviews were conducted with 27 individuals in these states with known or demonstrable experience in this area. Subjects interviewed include: 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. The primary purpose of this report is to detail lessons learned from New York and Minnesota about how best to promote effective consumer involvement in the reimbursement of nursing homes and other long-term care providers.

We begin by setting the context for the study. This involves discussing the significance of Medicaid nursing facility reimbursement, not only for consumers but for state and federal officials and nursing home providers. It also involves discussing why it is important to educate consumer advocates about the need to learn about and become active participants in state policy making in this area. Next, we describe our methods, followed by discussion of our results. In this section we examine why some consumer advocates do not become involved in Medicaid nursing home reimbursement but why it is important that they do. We identify the prerequisites for consumer action; that is, what does it take to gain a seat at

the table? We discuss what strategies have proven most effective in influencing the way nursing homes are paid under Medicaid in the two case study states. Potential supplemental strategies to enhance the effectiveness of consumer action in this area are identified also. We conclude with a summary of our key findings.

BACKGROUND & SIGNIFICANCE

Medicaid provides health and long-term care coverage for poor, elderly and disabled individuals in the United States. It is jointly funded by the federal and state governments but administered by the states. Although the federal government matches state Medicaid spending at a rate of 50 to 83%, depending on per capita income, states have considerable discretion over Medicaid program characteristics. Not surprisingly, Medicaid is highly salient to both state and federal officials. At \$373.9 billion in total expenditures in 2009, Medicaid is the largest federal grant-in-aid program (Centers for Medicare and Medicaid Services (CMS) 2011). It also is the largest fiscal item in state budgets, accounting for 21.8% of total state spending in 2009, higher than any other area, including elementary and secondary education (20.8%), higher education (10.1%), public assistance (1.7%), corrections (3.1%), and transportation (8.1%) (National Association of State Budget Officers 2010). Long-term care is particularly salient as it constitutes approximately one-third of total Medicaid expenditures, with 67.0% being directed toward institutional care for the aged and disabled (Eiken, et al. 2011).

Medicaid is the main purchaser of nursing home care in the U.S., accounting for 32.8% of total nursing home spending in 2009, followed by out-of-pocket payments (29.1%), Medicare (20.4%), private insurance (7.7%), and other sources (10.0%) (CMS 2011). By 2020, total Medicaid nursing home spending is expected to reach \$65.6 billion, more than one and a half times what was spent by the program in 2005. Not surprisingly, since the government spends so much on nursing homes, it is a significant area of concern for state and federal officials. Indeed, to address Medicaid program growth and to help balance their budgets, states have adopted a variety of cost control measures. Particularly salient is the fact that freezes or reductions in nursing home reimbursement have become increasingly common, rising from just 6 states in Fiscal Year 2008 to 15 states in Fiscal Year 2009, 26 states in Fiscal Year 2010, and 30 states in Fiscal Year 2011; 31 states planned to freeze or reduce nursing home reimbursement in Fiscal Year 2012 as well (Smith, et al. 2010, 2011).

Medicaid reimbursement is also a significant area of concern for nursing home residents and providers. According to the National Nursing Home Survey, nearly all nursing home beds—98.5%—are Medicaid certified (Jones 2009). Furthermore, whereas Medicaid served as the primary source of payment for more than one-third of nursing home admissions (34.8%), it paid for all or part of the care received by nearly 60% of residents at the time the Survey was conducted (59.7%). Overall, two in three nursing home residents are paid for, all or in part, by Medicaid (67%) (U.S. Government Accountability Office 2003). Clearly, the methods used to determine how Medicaid dollars are spent should be of substantial interest to a diverse array of stakeholder groups.

Like other third-party payer situations, providers are likely to have interests that are at odds with other interested parties (Miller, et al. 2009). States that wish to minimize the consequences of misaligned incentives need to find ways to structure Medicaid in such a way so as to encourage providers to act appropriately. One approach has been to establish an extensive set of state and federal regulations that nursing homes must comply with if they are to be reimbursed for patients insured by Medicaid (Miller and Mor 2008). These regulations govern many aspects of the services offered, as well as the manner in which services or treatments are rendered. They are implemented via national surveys, although the federal government actually contracts with state staff to serve as inspectors, following federally stipulated survey protocols. Consumers exert considerable influence here by focusing on regulations and enforcement of non-compliance.

States also seek to align providers' interests with their own through controls and incentives built into state reimbursement systems. Indeed, state governments design their methods of reimbursing nursing homes to achieve desired policy objectives related to facility cost and quality, access to care, payment equity, service capacity, and budgetary control (Miller, et al. 2009).

- Concern for provider costs is reflected in prospective payment (especially flat-rate reimbursement), rebasing frequency, cost categories/ceilings, ancillary service provisions, and efficiency incentives.
- Concern for beneficiaries' access is reflected in case-mix adjustment, high Medicaid census add-ons, and equalization of Medicaid and private payments.
- Concern for payment equity is also reflected in case-mix, Medicaid census, and rate equalization provisions, in addition to peer groupings, hold harmless stipulations, provider tax programs, and 100 percent property tax pass-through policies.
- Concern for system capacity is reflected in minimum occupancy standards and capital valuation and preauthorization requirements.
- Concern for overall budgetary control is reflected in the use of legislatively derived inflation factors and overall funding caps.
- Concern for quality is reflected in settlement procedures, wage pass-through programs, pay-for-performance, cost categories/floors, and private room incentives.

Modifying the way nursing homes are reimbursed provides a largely untapped means for encouraging culture change and other innovations for improving quality (Koren 2010). Prevailing evidence suggests that the manner in which nursing homes are reimbursed—the level of payment and type of methodology chosen—has ramifications for achieving policy objectives such as these (Feng, et al. 2009, 2010; Holahan and Cohen 1987; Intrator and Mor 2004; Mor, et al. 2011).

The incorporation of multiple, sometimes conflicting incentives into state reimbursement systems has resulted in enormously complex and demanding methodologies that inhibit consumer participation in state rate setting decisions. Thus, although resident advocates have been successful in influencing major changes in both nursing home rules and regulations and in encouraging culture change (Miller, Mor, and Clark 2008), few have been

involved in the development or modification of state methods for reimbursing nursing homes. Simply put, many consumer advocates do not understand rate setting well enough to knowledgeably participate in state policy making discussions; few appreciate that the way payment systems are structured can directly affect quality and other outcomes (e.g., cultures change).

One indication of a lack of knowledge is that consumer advocates from around the country have sought help from project staff after being approached by state officials to participate in discussions regarding reimbursement system modifications and overhauls. These contacts reveal little understanding about how reimbursement systems can be designed to further desired policy goals.

Another indication of a lack of knowledge is a survey conducted by the Long Term Care Community Coalition (LTCCC) in 2008, which indicated that many state ombudsmen and citizen advocates do not understand the nursing home reimbursement systems in their states (Rudder, Mollot, Holt and Mathuria 2009). This is reflected in the finding that just 25% of state ombudsmen and 11% of consumer advocates were very familiar with their state's systems, while 12% of ombudsmen and 11% of advocates reported no familiarity at all.

A third indication of a lack of knowledge is research indicating that consumer advocates frequently lack the expertise necessary to effectively engage state Medicaid officials and nursing industry representatives in discussions regarding the arcane intricacies of state payment systems (Miller 2008, 2011; Miller and Banaszak-Holl 2005). Here, interviews indicate that elder advocates focus almost exclusively on nursing home quality and workforce issues, and not reimbursement. Thus, while one state official and one industry representative were deemed expert enough to be interviewed about changes in Medicaid nursing home reimbursement methods and rates in each of 26 states studied, only in five states—California, Michigan, Minnesota, New York, and Oregon—were consumer advocates deemed sufficiently expert to be interviewed about this topic as well.

Without doubt, the interests of advocates may differ from those of state officials and nursing home industry representatives. This is reflected in the Commonwealth Fund Survey of Long-Term Care Opinion Leaders, which identified substantial differences in views between consumer advocates and other constituency groups across a number of issue areas, including quality improvement, financing, culture change, and regulation (Miller, Mor, and Clark 2010). Such differences prevail in the reimbursement area as well. In general, industry representatives prefer to maximize payment and flexibility under state methods for reimbursing nursing homes (Miller 2008). This is in contrast to advocates who also tend to favor maintaining payment levels but prefer that systems be promulgated that incentivize quality by holding providers accountable for performance and outcomes (Miller 2008; Rudder, Mollot, Holt and Mathuria 2009). Perhaps the advocacy position is best illustrated by the LTCCC survey of state ombudsmen and citizen advocates cited earlier (Rudder, Mollot, Holt and Mathuria 2009). On the one hand, the majority of respondents did not feel that the current reimbursement system in their states contained incentives that encouraged quality of care. On the other hand, when asked what state payment systems

should be designed to achieve, respondents reported feeling that, ideally, they should be designed to improve staffing levels (and time spent with residents), promote culture change innovations, and emphasize positive clinical and quality of life outcomes.

States typically employ taskforces when making major changes to the way nursing homes are reimbursed under Medicaid (Miller 2008, 2011; Miller and Banaszak-Holl 2005). In most cases, membership includes program administrators, industry representatives, and their respective consultants. Legislative staff and union representatives are sometimes included as well. Less often included are consumers/residents' advocates, perhaps because policymakers believe they have less to offer or do not have the expertise to "be at the table." And, when at the table, consumers/residents' advocates participation tends to be less consequential given their prevailing lack of interest and expertise in this area. Where sufficiently influential, providers have proven successful in steering state reimbursement in such areas as provider taxes, capital valuation, cost reports, and wage mandates toward their interests (Grogan, 1999; Miller 2006a, 2006b, 2008; Miller and Banaszak-Holl 2005; Miller and Wang 2009a, 2009b; Miller, et al. 2010, In Press). No such relationship has been found between the level of influence exhibited by consumer advocates and the adoption of reimbursement system characteristics such as these.

Together extant evidence suggests the importance of including the voice of consumers in state reimbursement policy discussions. Lack of consumer involvement has the potential to result in the promulgation of reimbursement methodologies more favorable to industry and government than residents and families. Lack of consumer involvement also has the potential to result in less creative changes to state reimbursement systems than might otherwise have been possible. Since all stakeholders must be at the table if truly informed reimbursement policy reform is to take place (Arling, et al. 2009; Cooke, et al. 2009), we examined the experience of consumers in New York and Minnesota, two states where consumer advocates have been effective in influencing the development and implementation Medicaid nursing home reimbursement.

METHODS

This study analyzed consumer participation in the design and implementation of Medicaid nursing home reimbursement in New York and Minnesota using archival resources and in-depth open-ended interviews with key stakeholders. New York and Minnesota were chosen for study because preliminary research indicated that consumer advocates had proven effective in influencing Medicaid nursing home reimbursement in these two states (Miller 2008, 2011; Miller, et al. 2009; Miller and Banaszak-Holl 2005).

Semi-structured interviews were undertaken with people chosen through a combination of purposive and snowball sampling (Patton 2002). With purposive sampling, prospective respondents are chosen for specific purposes and for specific representation. Snowball sampling first identifies respondents who meet the criteria for inclusion and then asks them to recommend others they know who also meet the criteria; these in turn recommend others, and so on. Thus, using a combined purposive-snowball approach, selection of

respondents was initially based on our own knowledge regarding the individuals who could best inform our study. Later, however, we based more of our choices on information provided by our respondents in terms of those additional individuals who might prove appropriate for inclusion.

In general, we sought to conduct interviews with individuals with known or demonstrable experience with Medicaid nursing home reimbursement in New York and Minnesota. Four open-ended interview protocols were developed—one each for consumer advocates and other stakeholders in each state studied. This ensured that all subjects were asked the same questions and given the opportunity to comment on the same areas while, at the same time, the interviews were oriented toward each subject's respective strengths as an informant.

Through our interviews we sought to identify which consumer advocacy groups had been active and/or influential in Medicaid nursing home reimbursement policy and which had not. In doing so, we asked our interview subjects to provide concrete examples of consumer activity in this area. We also asked them why they felt some consumer groups have not typically been active or influential in this area. We further sought to understand what the basic prerequisites were for active and/or influential consumer involvement and what activities and strategies consumer advocacy groups have undertaken to influence nursing home reimbursement policy making. We sought to identify both the most and least effective strategies undertaken as well.

Twenty-four interviews were conducted with 27 individuals between February 2, 2011 and June 20, 2011, 12 each in New York and Minnesota. Interview length ranged from 30 minutes to 3 hours, though most were about one hour long. Interview subjects included state legislators/legislative staff (6 individuals), officials within the pertinent state administrative agencies (6 individuals), consumer advocates representing both citizen advocacy groups and the state ombudsmen program (8 individuals), union staff (2 individuals), and nursing home industry representatives (5 individuals).

Including a diverse array of stakeholders should ensure the acquisition of a wealth of information that "accounts for the diverse structural conditions" of the phenomena being studied (Glaser and Strauss 1967). Doing so is important because the degree to which the perceptions of people from a variety of different roles and locations converge, the more likely that those perceptions provide a reasonably accurate portrayal of the policy process being studied (Jick 1979). It also is important because employing multiple types of informants minimizes the threat of single-source information bias while maximizing the breadth of the information provided (Pothas and de Wet 2000).

All interviews were recorded and transcribed. Transcripts were subsequently coded to identify recurring themes and patterns in responses (Miles and Huberman 1994). This was an emergent process to the extent that we formulated new categories and revised old ones as we read through the transcripts. Once a full set of codes were developed, we went back and recoded all transcripts using the common set of themes that we developed. Quotes illustrative of each theme were excerpted.

In addition to key informant interviews, pertinent statutes and regulations were identified and collected; so too were relevant government reports, memos, press releases, and other documents. Information was collected from consumer advocacy groups and other non-governmental entities as well. This includes journal articles, news articles, policy briefs, position papers, and analytical reports written on Medicaid nursing home reimbursement in the two states studied. Documents were used to cross-validate the descriptions and perspectives of key informants (Jick 1979). They also provided useful historical background.

CONSUMER PARTICIPATION & INFLUENCE

As expected, consumer advocacy groups in both New York and Minnesota have been active participants in the Medicaid nursing home reimbursement. Advocates in both states played a critical role in the development and implementation of case-mix reimbursement, which is intended to improve access and quality for medically complex nursing home applicants by adjusting payment for resident acuity. Whereas advocates in New York convinced policymakers to enact a number of rate setting components intended to improve access, quality and efficiency, including pay-for-performance (quality pools) and adds-ons for dementia and other high needs residents with accompanying requirements, those in Minnesota have successfully supported such reimbursement system attributes as rate equalization and wage encumbrance. Rate equalization stipulates that facilities cannot charge private paying residents more than the Medicaid rate. Wage encumbrance earmarks increases in reimbursement for wages and benefits for direct care workers. Advocates in Minnesota have also successfully argued for the disproportionate weighting of staffing measures in pay-for-performance.

Although active in both states, consumer advocates in New York and Minnesota participate in nursing home reimbursement policy discussions differently. Elder advocacy groups in Minnesota sometimes work together on specific issues; for example, advocating with unions on behalf of nursing home residents and direct care staff through a coalition, Seniors & Workers for Quality Care. Other times, the heads of several different consumer groups have taken the lead in advocating on behalf of residents in state reimbursement policy discussions. Indeed, a number of the consumer advocates interviewed in Minnesota believed that at one time or the other it was their group that took that lead where Medicaid nursing home reimbursement was concerned. Thus, according to one Minnesota advocate, *"we are the primary voice of the individual on this issue. We are seen as the voice of the Medicaid...consumer at the state Capitol, and with the Governor's Office, and the Commissioner of the Department of Human Services, which oversees the Medicaid program, so, we play a very, very significant role."* Our findings indicate, however, that there have been multiple advocacy groups that have been active. *"The big three,"* according to one union representative, have been the *"AARP, Alzheimer's Association, and ElderCare Rights Alliance."* It was reported that the ElderCare Rights Alliance has struggled with an increasingly challenging fundraising environment and, as such, has had to direct limited time and staff resources more toward quality of care rather than reimbursement issues. In

turn, the AARP and Seniors & Workers for Quality Care have played a larger role in nursing home reimbursement issues in recent years.

In New York, by contrast, consumer advocacy in the reimbursement policy arena is more concentrated, occurring primarily at the behest of a single organization, the Long Term Care Community Coalition or LTCCC. The LTCCC is a long standing coalition of consumers, civic groups, and professional associations that focus on long-term care. It is the Directors of the LTCCC that have taken the lead on nursing home reimbursement issues within the state. *"The LTCCC has been more involved in discussions about nursing home reimbursement than any other consumer groups I can think of,"* reported a provider representative in New York, *"I don't know that there are other groups that have been much involved in those types of discussions. The Coalition's mission is pretty closely aligned with nursing home residents in their daily lives. They've just got a more vested interest."* Furthermore, unlike advocates in Minnesota who have formed a coalition with the primary caregiver unions around specific reimbursement issues; advocates in New York have not collaborated with union representatives where reimbursement is concerned.

Although consumer advocates have been active and influential, interviewees in both New York and Minnesota believed that ombudsmen were not nearly active in influencing nursing home reimbursement policy as they could be. *"The Ombudsman kind of does its thing,"* reported a New York provider, *"when they get a complaint they investigate and follow-up, but like in terms of playing at the policymaking level, I don't see any evidence that that's kind of a role that the Ombuds Office has seen as part of its charge, because you don't see them at the table."* Reasons that Ombudsmen have not participated include lack of independence due to placement of the ombudsman program within a government agency. This view is reflected in the observations of a union representative in Minnesota, *"[the ombudsmen] have to be very careful. They couldn't really directly lobby for anything...because they're a sort of government agency...I don't know if it was a real legal restriction, or just sort of pragmatic, 'we don't want to tick off the legislature, because they'll eliminate our funding.'"* Reasons for the lack of ombudsmen involvement also include a focus on individual complaints rather than systematic impediments to quality and access. Explained one advocate, *"[the ombudsmen] don't [engage in advocacy] as much [they] would like simply because [they] don't have the staff. [They're] really typically just swamped with all the activity that [they] have in terms of responding to the calls and complaints that [they] get from the residents out there."* Finally, there was general consensus that the ombudsmen typically lack the expertise necessary to be knowledgeable participants in this area. *"[They] keep track of rates but [they] really have no input into the reimbursement policy and what people are getting,"* another advocate pointed out, *"[they] don't have good knowledge of the reimbursement system."* Still, a number of interviewees felt that like other advocates around the country, nursing home reimbursement is an area where ombudsmen need to become more actively involved. *"They should become aware that in their focus on nursing home issues,"* asserted one New York advocate, *"[that] reimbursement should be at the top of their list, just like inspection and quality care."* Seconded a Minnesota legislator, *"I think they need to be involved in educating legislators into where there might be shortcomings or deficiencies in how we fund nursing homes, or how our policies impact patient care."*

WHY DO CONSUMER GROUPS NOT BECOME INVOLVED?

Several reasons were identified for why some consumer groups do not become actively involved in Medicaid nursing home reimbursement. These can best be summed up in three words: knowledge, resources, and mission. Explained one New York provider: *“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, or care much about what the reimbursement is; their only interest is patient care issues, so that’s what they focus on. And then you bring up, ‘Well, what about the reimbursement to meet the issues?’ They don’t want to talk about that.”* Given their predominant focus on quality of care issues, advocates have historically focused on improving the survey and certification process. That is where the calls for greater government involvement and oversight tend to be focused. Many have been reluctant to recognize the potential linkage between reimbursement and quality. Consequently, *“if I were to make a hierarchy of the level of informed knowledge on this issue,”* according to the opinion of one Minnesota legislator, *“I would [first] put Department of Human Services staff in this particular area, then I would put the industry groups, and then the advocacy groups under that.”*

Part of the reluctance to wade into reimbursement issues stem from the belief that a focus on reimbursement may divert attention from quality. A larger part of this reluctance, however, seems to derive from the absence of the knowledge and expertise necessary to understand the complexities of nursing home reimbursement, in addition to the absence of the staff and other resources needed to participate actively in these discussions. Although both sets of reasons were identified by interviewees in both states, our New York subjects tended to emphasize the prevailing lack of knowledge and expertise, our Minnesota subjects the prevailing lack of staff. In New York, it was pointed that most consumer advocacy groups were not involved because nursing home reimbursement system was *“too complicated,”* has *“too much minutiae,”* gets *“very, very detailed,”* *“can be particularly esoteric,”* is *“very difficult to organize around,”* is *“too technical,”* and consists of *“five pages of dull language that you have to read 42 times to understand.”* In Minnesota, it was pointed out that insufficient consumer advocacy involvement in nursing home reimbursement derived largely from resource limitations. *“Because of their limited funding and limited staff,”* reported one advocate, *“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 the way that they would like to.”* *“We don’t have a lot of money as a coalition,”* indicated another advocate, *“so we only staff a part time person. I am a volunteer.”*

It was reported that consumers were not nearly as well organized or as well financed as the providers. This gave providers a leg up on most consumer advocacy groups, particularly when interacting with state legislators on a more or less routine basis, whether through personal relationships, fund raising, or grassroots electioneering. *“We don’t have a lot of friends in the Legislature,”* admitted one New York advocate, *“and that’s probably because we don’t have the clout and the money etc.”* Explained a Minnesota advocate, *“[the providers] are better grassroots organizers than we social workers are...They get involved with people’s*

campaigns at the start, and they make friendships, and they are very, very good at inviting lawmakers to their facilities, so much so that there are lawmakers, no matter what you tell them, who believe that the nursing home administrators speaks for the workers, and speaks for the families, and nobody else needs to do it...Now that's a real achievement in organizing! I'm envious." That the latter sentiment may exist among some lawmakers in New York is reflected in the comments of a state agency official who reported that *"there is an opinion out there that the associations do a pretty good job in terms of bundling all of what would be the agenda of the nursing home environment...either the operator [or] the resident...That [it's] kind of dealt with under this one umbrella."*

"It's much more usual for legislators to have a tight relationship with the owner of their home," according to one New York staffer, than the residents or their families, or the people who advocate for them. Thus, reported one knowledgeable lawmaker, *"there have been several instances where we have tried to get a bill reported from the Health Committee that was strongly supported by consumer groups but not by the owners and operators of nursing homes, and it has been frustrating to me that we occasionally lose those votes, because some of my...colleagues accept the lobbying message of the owners and operators."* In addition to lacking the resources necessary to permit a continual presence in the state Capital, advocates face challenges connecting lawmakers to residents and families, the actual consumers of care. *"The consumers of long-term care are almost inherently unable to be very vocal,"* the above legislator continued, *"if you're a nursing home patient, or a homebound home care patient, you're not going to rallies, or getting on buses to Albany. You're probably not writing a lot of letters, or sending emails, and the family members of the consumers [are] sort of spread out and probably don't meeting one another on a regular basis."*

Two very different types of advocacy groups that minimize their involvement in nursing home reimbursement were identified. On the one hand, there were those groups with very narrow interests, whether in the way of nursing home quality or expansions in home- and community-based services, who are overwhelmed focusing on their own mission, let alone adding nursing home reimbursement to the mix. Furthermore, many advocacy groups struggle just to survive, something that has been exacerbated in the current fiscal climate. If you cannot survive as an organization, then you cannot do advocacy. But if you focus your efforts on fundraising, then you reduce the amount of time in which effective advocacy can be done. It's a catch-22. *"I'm scared for the future,"* observed one Minnesota advocate, *"it's kind of Maslow. They just have to keep their doors open and see clients...The movement isn't as big as it was."* Reported one New York advocate, *"I've got a budget of [a small budget] and we've got some major work that's been on our plate...I'm struggling to stay alive...I'm the fundraiser; I'm the administrative assistant; I'm helping to implement programs...I feel guilty about it but we've just been really completely subsumed with the important work that we have for [the group] at this point."*

On the other hand, there were those groups that were much less involved in nursing home reimbursement because, while they may have had the resources to participate, doing so did not comport with their broader interests and goals. The most frequently cited example in New York was AARP, both with respect to the specific populations on which they focused and programmatic depth. Explained one legislator, *"[the AARP's] active members are not in*

nursing homes, and one of their main concerns in life is probably to make sure that they never are in a nursing home, and so I would guess it may be difficult to get them activated on those issues...It's not something they want to think about...AARP is much more involved in things like home foreclosures and our elderly pharmaceutical program...property [taxes]...a whole series of thing." It was felt that AARP had made conscious decision to court the 50 to 64 year old age group rather than frail, elderly poor people in nursing homes. It was also felt, according to one provider representative, that the AARP had *"many more sort of purposes on their plate [than, say, the Long Term Care Community Coalition], and [as such, were] involved in a broader range of activities at the service level, at the kind of think-tank level, maybe at the business level in some cases, so that the public advocacy and policy part of the menu, is just a part of the menu, relative to other organizations."* Even in Minnesota where AARP has been active in nursing home reimbursement, some felt that this activity was not as extensive as it might be otherwise due the organization's other concerns. *"They've been interested in things like property tax relief, prescription medications... expanding family leave,"* reported one Minnesota provider, *"those are the caregiver kind of things that they have focused on. We are one of the two states that have equalized rates and that is probably the one strong [nursing home reimbursement-related] position that they have."*

THE IMPORTANCE OF BEING "AT THE TABLE"

For a number of the interviewees, it is important to have consumer advocates at the table, because they represent the residents of nursing homes, and the reimbursement system should, fundamentally, be focused on furthering resident wellbeing. The advocacy role in keeping residents at the forefront of nursing home reimbursement policy discussions is reflected in the comments of one Minnesota state official who observed that *"consumers are very important; they're representing the constituency that this is all about."* Said another, *"they're representing a vulnerable population that people don't want bad things to happen to....Even now with the worse budget crisis Minnesota's ever seen, there's this call...to protect the elderly."* The advocacy role in keeping residents at the forefront is also reflected in the comments of a New York state official who observed that *"instead of the discussion being just about cost and labor and that kind of stuff...the Long Term Care Community Coalition has 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."* This activity has, in turn, influenced how other stakeholders think about the issue. Noted another New York official, *"[the Long Term Care Community Coalition] did a very good job about...making sure that folks don't forget quality as we talk about reform, and that it be an element of reimbursement...That whole concept of what are we getting for our money."*

Interviewees also felt that it was important to have consumer advocates at the table because they can serve as a counterpoint to other stakeholders in the policy process. This is reflected in the comments of one New York advocate who explained that *"you have providers in this situation who always want more money. You have the state that is looking for any way to cut money. And we're kind of in the middle saying, 'maybe both sides have some reason, but it has to be done in a way that protects the consumer.'"* Nursing home providers

generally want to increase their rates with as much flexibility as possible. Thus, according to one Minnesota legislator, it is useful to have the advocates *“provide some check on the industry...Because otherwise it’s very easy for nursing homes to advocate in areas where they’re implying that we would be improving the lives of nursing home residents when really we might not be; we might be improving the bottom line for our nursing home owner.”* For example, *“the industry has a proposal just about every year to eliminate, repeal rate equalization,”* according to one Minnesota state official, *“and that motivates the consumer advocates to get out there and kick butt....They tend to be a very effective balance against nursing home industry representatives.”* Advocates can also serve as a useful complement to state bureaucrats whom legislators may view suspiciously, believing that they may just be making life difficult for providers and easier for themselves. In this regard advocates can support some of the things state officials are doing to hold providers accountable while being viewed as having fewer conflicts of interest. *“It’s really helpful,”* reported a state official in Minnesota, *“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’s other opinions that do exist out there, and it isn’t just us as the bureaucrats who have to say that. They’re at the table, also, to say it. I find that to be a helpful thing.”*

Perhaps most fundamentally, interviewees felt it was important for consumer advocates to be at the table because how providers are reimbursed affects access, care quality, quality of life, and other potential outcomes. It was pointed out that the financial incentives built into state payment systems can influence achievement of desired policy objectives. *“We did studies of New York State’s inspection system as early as the late ‘80s, early ‘90s,”* reported one New York advocate, *“it was very clear to me that how you make inspection 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 like all wrapped up into one. You can’t look at one without the other.”* *“Reimbursement policy is an important tool,”* concurred a provider in New York, *“and depending on how it’s designed it will incent certain outcomes and behaviors, and it will potentially be a de-incentive to other outcomes and behaviors, and it’s important that when designing it that there’s a broad representation, and that the people that are going to be affected by those decisions have an opportunity to be part of the thought process around it.”*

It is often up to the advocates to make the connection between reimbursement and quality explicit. *“Reimbursement is tied so closely to the care that people get,”* argued one Minnesota advocate, *“and the Medicaid rates are so inadequate, and are not covering the cost of what nursing homes are actually providing. I think we need to brainstorm as much as possible to bring everybody to the table, but especially for advocates to be in there, and to talk about how low rates affect the care that people are getting.”* Indeed, consumer involvement is especially important because it directs attention to how the money paid to nursing homes can be used to benefit residents. This is reflected in the observations of one New York legislator: *“There are some groups who from year-to-year would be voicing a fairly simple message of...don’t hurt our nursing homes. The Long Term Care Community Coalition is much more focused on the details of how the money is going to be spent...And I think to a certain extent the Coalition can count on...the owners and operators, and the unions to focus on the*

quantity, and so the Coalition gets to focus, and needs to focus more on the fine details.” This is also true in Minnesota. Take wage encumbrance, for example. *“If there’s legislation that will give the nursing homes more money, [the consumers],”* according to one legislator, *“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 their quality of care.”* Thus, in 2007, 80 percent of the rate increase granted that year had to be directed toward wages and benefits for Certified Nurse Assistants and other direct care staff.

PREREQUISITES FOR SUCCESSFUL CONSUMER INVOLVEMENT

Experience in New York and Minnesota suggests certain prerequisites for successful consumer participation in Medicaid nursing home reimbursement. Perhaps three words sum these attributes up best: reputation, information, and credibility. First, it is important to develop a reputation in this area by making reimbursement a visible priority for the organization over a long period of time. Second, it is important to develop and demonstrate knowledge and expertise; how else can one’s reputation be built? Third, it is important to further develop one’s credibility by sharing information on Medicaid nursing home reimbursement with other constituency groups. *“How did I get a seat [at the table]?”* asked one New York advocate, rhetorically, *“first of all, because I’d run the Association [for many years]. People knew me, and then second....I’d written a lot of papers about what needs to change. That’s really, I think, at the heart of it, is if I could again try to sum up as simply as possible.”*

Prioritize Consumer Involvement in Nursing Home Reimbursement

Prioritizing reimbursement means instilling nursing home reimbursement policy as an important issue in the organization. Doing so begins with the organization’s leadership. *“It comes down to the focus and interest of the Executive Director, a couple that we’ve mentioned here,”* reported one Minnesota provider, *“both had a particular interest in the relationship between reimbursement and quality, and both had a deep working knowledge...of the reimbursement system.”* *“It seems like organizations sometimes reflect their founders, and their leadership,”* explained a state official in New York, *“and I guess New York State and its 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.”* Many interviewees reported that the priorities of the Long Term Care Community Coalition in New York was driven largely by the organization’s founder, and that such had become so ingrained in the organization’s culture over the last 20 to 25 years that reimbursement as a priority would continue irrespective of that person’s continued involvement.

The continuing prioritization of nursing home reimbursement in the LTCCC contrasts with Minnesota, where the involvement of various consumer-oriented organizations in this area has waxed and waned with the participation of a single, high profile individual who one provider representative described as *“a very visible, very strong advocate...The single person most instrumental in making sure the [rate equalization] law...stayed on the books...The voice of consumers for well over a decade.”* The impression was that although groups such as the

Elder Rights Advocacy Alliance and Alzheimer's Association have remained involved in reimbursement, the level and depth of activity declined somewhat once this individual left, a decline that has been reinforced by prevailing fiscal challenges. There is also concern that the older generation of advocates had been *"ineffective at encouraging another generation of advocates to get excited about [the] minutiae...in anything outside of the basic issues of reimbursement level, and rate equalization,"* though the details about reimbursement system design are critical for promoting achievement of desired policy objectives as well. There is *"a fair tension,"* it was reported, *"between those who simply want to give up on the nursing home situation and put all the effort into home- and community-based care, and those who want to make sure that there is still a nursing home system for those who come to need it."*

In addition to instilling reimbursement as an important continuing issue, prioritizing reimbursement means being a *"persistent," "consistent,"* and *"assertive"* advocate from the consumer point-of-view. Indeed, these were among the more frequently used adjectives to describe the most influential consumer advocates in this area in both New York and Minnesota. *"We in the organizations that I've been with have had the luxury of being a half-hour from the Capitol,"* reported an advocate in Minnesota, *"so proximity and presence, and visibility and [constancy]; it's nudging. Chronic, chronic presence."* Explained one New York state official, *"one of the attributes that I think of when I think of the [Long Term Care Community Coalition] is perseverance. Organizations get recognized because of the people in them. And [this leader of this organization] has been a persistent and consistent advocate. She been clear about what issues she has researched and brought to bear, the research she has done and translated that for policymakers. Persistence is a big key factor here for how successful that consumer advocacy group has been."*

Being persistent has proven especially important for taking advantage of windows of opportunity that develop with which to influence Medicaid nursing home reimbursement over time. This has been especially true in New York given the ongoing fiscal crisis and growing desire to change the way nursing homes are paid. Proposed simplifications to the reimbursement system where every facility would receive the same price, adjusted for case-mix and perhaps a wage index, has provided additional opportunities for advocates to pull quality into the discussion. According to one state official, *"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 the reimbursement methodology and what the discussion is about how to link that...We spend a lot in New York State, so there is a desire to shore up the relationship between the dollars spent and the quality of service. [The Long Term Care Community Coalition] has been saying that, and kind of like the perfect storm; you get two or three folks who are thinking about reform, the advocacies coming together and there's a drive to make that happen."*

In Minnesota, by contrast, opportunities to influence nursing home reimbursement to promote positive change have been relatively rare in recent years. Thus, besides encumbrance, advocates have focused primarily on fighting reductions payment and the repeal of the state's rate equalization law. Part of this may reflect a growing lack of interest among the next generation of advocates in the minutia of reimbursement, as noted above. A

large part, however, reflects the absence of opportunities to insert the advocacy voice into reimbursement policy discussions. Since 1999 nursing homes in Minnesota have been paid under a relatively simple system in which facilities are reimbursed their historic rates plus inflation and/or other legislatively determined adjustments. In 2007, the Legislature enacted a new cost-based system developed by the Department of Human Services in concert with providers and advocates based on biennial rebasing. This system—known as “rebasings”—was to be phased in over eight years. Due to the state’s fiscal crisis, however, implementation of “rebasings” has been suspended. As a consequence, the state’s methodology for paying nursing homes has remained static, opening up few additional topics for negotiation. This, perhaps, is best reflected in the Department failing to convene its nursing home reimbursement advisory committee over the last two years.

Develop and Demonstrate Knowledge about Nursing Home Reimbursement

Perhaps the most important indicator that reimbursement has become a priority for an organization is for its membership to become knowledgeable about it. Indeed, advocates in both Minnesota and New York made sure that they understood the nuts and bolts of nursing home reimbursement policy, not only in their states but around the country; expertise that they subsequently brought to the table to influence policy. Knowledgeable advocates commanded respect and were listened to; in both New York and Minnesota there was at least one advocate that was seen as always being there and having the answers. *“They really try to be well informed,”* reported one Minnesota state official, *“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.”* It was reported, for example, that the Elder Rights Coalition was successful in influencing the debate over reimbursement because their advocate *“had a compelling story. She would have focus groups to back up what she was saying, so she’d have people behind her who would support her. I think to that extent, that’s why she was successful.”*

In New York, the Long Term Care Community Coalition developed policy papers and conducted research and made presentations, thereby increasing their reputation for understanding the issue. When case-mix reimbursement was first considered in New York in the early 1980’s, for example, the LTCCC (known then as the Nursing Home Community Coalition of New York State) conducted a number of studies on reimbursement from the consumer perspective. They brought together representatives of a number of different constituencies, researched the issue and produced a paper discussing the potential positive and negative effects of a case-mix system. As the years passed, they continued to study and research the effects, thereby developing a reputation for being the only consumer group in the state knowledgeable enough to sit at the table. In fact, the then Director of the LTCCC was asked to be one of the consumer representatives on CMS’ advisory committee as it developed its Resource Utilization Group case-mix system for Medicare. It was explained that *“at the time and even now policymakers 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...When things came up,*

whatever they were, we actually [did] research on it.” “The studies, the research, the data I think [are] incredibly effective,” reported another New York advocate, “that’s what is going to really capture the attention of state policymakers.”

In addition to the advocates, the importance of developing and demonstrating knowledge is reinforced by the state agency officials and legislators interviewed. *“As for how to be effective,” suggested a New York, legislator, “being very well informed, knowing solidly what the issues are and how things play out on the floor of the nursing home, having solid credibility that you are advocating for residents.”* Agreed a New York state official, *“you’ve got to cozy up to that complexity [in the reimbursement system], and try to understand it. That is probably one of the chief things that [the Long Term Care Community Coalition] has done. You look at [their] information [and they give] you a sense of how does New York State’s reimbursement methodology works.”* *“Knowledge is power,”* asserted a state official in Minnesota. *“If you want something changed,”* added a legislator in that state, *“you’d better have an idea of how it should be changed. You’d better have a methodology to suggest, because otherwise nothing’s going to happen.”* To be viewed as credible participants, advocates need to learn how nursing home reimbursement works, the acronyms that get floated about, the distinctions about what happens at the federal- and state-levels, with all of that being communicated clearly and directly and in plain English.

A particularly useful source of information for advocates is other states. This is both with respect to identifying strategies with which to influence reimbursement and to evaluating the potential applicability of various reform options. The former is reflected in the experience of one Minnesota advocate who reported being *“very, very tight [with advocates in other states] and it’s really easy to pick up the phone, and call [Jack] down in [another state] and say, ‘I haven’t a clue how to approach folks on this. Have you guys dealt with this issue? What have you done?’ Or, ‘I heard that you guys were doing X,’ or, ‘I just read that Michigan is working on this issue, too. Tell me what you guys are doing.’ That’s where the value is. It’s tremendous. We are not above plagiarizing what’s happening in other states, and vice versa.”* The latter is reflected in the experience of one New York advocate who reported that *“[we looked] at what was going on in other states and we talked to other stakeholders and the ombudsmen, all kinds of consumer groups. We gleaned a lot from that in terms of our recommendations, and that informs our work now.”* Most provider representatives, legislative staff, and state agency officials interviewed reported that the information collected by advocates about what was going on in other states added to the debate and discussion about Medicaid system redesign in their own state.

Learn Key Pressure Points in the Policy Process

It is important for consumer advocates to become knowledgeable not only about the ins and outs of nursing home reimbursement but also about the location of key pressure points for influencing the direction of state policy making in this issue area. Especially key is being able to identify where in the policy process is best to exert influence. As one New York state official reported, *“what the [Long Term Care Community Coalition] has, I think, consistently done is...understand how the policy making [process] works, meaning legislation, executive*

budget, the budget process, and then how regulations and policies affect directly providers which obviously directly affect consumers...From a consumer advocacy perspective they have been very good at...understand[ing] all the pressure points if you will of public policy and how it can affect the consumer."

An interesting example where advocates sought to exploit knowledge of the policy process occurred in Minnesota. Recently, the Republican majority in the state legislature has sought to repeal rate equalization which, as noted earlier, requires that private pay patients be charged the same rate as Medicaid beneficiaries. In response, advocates commissioned a question about rate equalization in a survey of 1,000 Minnesotans across the state over the age of 18. Results indicate that 86% of respondents supported maintaining the law, a finding that persisted across political party affiliation—Democrat, Republican, and independent. "[It] is key," according to one advocate, that "[most] Minnesotans, who call themselves Republicans support maintaining the law...We had one of our interns hand deliver a love note from me with a copy of the survey attached to every member of the committee on Wednesday before the hearing yesterday on Thursday."

Share Information and Expertise about Nursing Home Reimbursement

Not only is it important to be knowledgeable about the issue and process but it is important to share resulting information and expertise, as doing so can generate good will and trust among other constituency groups, which may pay off in the long run. This is especially true of state legislators and bureaucrats. Suggested a union representative with experience in this area, *"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."*

Key to influencing how legislators and their staff think about reimbursement is information sharing. In New York, this is reflected in the dissemination and use by state legislative staff of Long Term Care Community Coalition reports on pay-for-performance. *"The largest role the [Long Term Care Community Coalition] played was certainly with respect to the quality pools,"* reported one legislative staffer, *"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, effective in really helping at least me understand and parse out some of the facts; one of the critical things is always fact versus rhetoric, and which things really will cause the sky to fall, versus which things are they just saying will cause the sky to fall? 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, versus, yeah, this would actually cause a rather negative outcome."* The provision of information such as this has paid off. This is reflected in the comments of one New York legislator who reported that *"over the years we've learned that when an issue falls in our lap, we don't wait to hear from the Coalition. We reach out to them...We try to touch base with them on almost everything, because I think we've learned over the years that almost everything in the field has consumer and quality implications, even if we don't see it on the face of it. And frankly, I am as certain as can be that New York, and me in particular, would have taken numerous wrong turns or*

stalled in our path without the Coalition.” The provision of information has also helped improve consumer advocates’ relationships with the state bureaucracy. It is clearly appreciated.

MAJOR STRATEGIES FOR INFLUENCING REIMBURSEMENT

Establishing a reputation as credible and knowledgeable players in the world of nursing home reimbursement policy is a necessary but not sufficient condition for exerting influence. Doing so opens the door. Strategies must be put into place to walk through it to effectuate change. *“The LTCCC...are the ones with the...expertise in this set of issue areas,”* explained a legislative staffer in New York, *“when people in the Legislature think about consumers and nursing homes, that’s who they call...There was a Nursing Home Work Group that was created in legislation during the first budget that was meant to work out some of the issues in the regional pricing methodology. [The LTCCC] were appointed members of that work group...They also engaged in direct advocacy/lobbying; they would talk to myself; they would talk to members, other staff, to get their point across and push their position.”* A similar dynamic has played out in Minnesota. Noted one advocate, *“it’s been a matter of finding friends in public office, and in the state agencies and [understanding] what the issues are...and how decisions will be made so that we can elbow our way into the process.”*

In short, advocates in New York and Minnesota have pursued a variety of strategies which have proven effective in influencing state policy making in the Medicaid nursing home reimbursement arena. It includes volunteering and/or insisting on participating on state work groups and taskforces targeted at revising the way nursing homes are paid under Medicaid. It also includes developing and accessing relationships with key public officials in the legislative and executive branches of state government. Indeed, it is particularly important that advocates target key government officials in the Legislature and pertinent state agencies. Changes in how providers are paid can be accomplished in two ways depending on the law. It can be done administratively through the state bureaucracy, or it can be done through the State Legislature, typically a part of the state budget process. As a consequence, it behooves advocates to target both legislators and state agency personnel when pursuing policy change in this area. Thus, reported one knowledgeable staffer in New York, *“[the advocates] are quite active in speaking with legislators, policymakers, and the like...They target very specifically who they meet with, and it is individuals in the Department of Health; it is individuals on the second floor of Governor’s Office, and they focus almost exclusively on the Chairs of their respective [legislative] committees.”*

STATE LEGISLATORS & LEGISLATIVE STAFF

In New York, the Health Committee in the State Assembly has legislative jurisdiction over the regulation of nursing homes, as well as the Medicaid budget. The budget is officially in the Assembly Ways and Means Committee, but the Assembly’s positions on issues in the Medicaid budget are developed primarily by the Health Committee Chair in consultation with the Assembly Speaker and his staff, and the Ways and Means Committee staff. The Assembly has a Democratic majority. The State Senate in New York is structured similarly,

although they have a Republican majority. A comparable structure exists in Minnesota, although, after many years of Democratic control, both the Minnesota House and Senate are currently controlled by Republicans.

Relationships can be built and access with state legislators and their staff obtained through one-on-one meetings, legislative testimony, and making issues “local” and “real” by having constituents, residents, family, and direct care workers tell their stories. Indeed, the interaction between consumer advocates and legislators can be quite varied. It includes, according to one Minnesota legislator, *“individual legislative meetings with members, testifying in committees, being present and visible with buttons and red shirts, and all those things in which that presence could be easily seen.”*

Targeting key legislatures but not forgetting the “back benchers”

Meeting with key legislators and their staffs is seen as effective in both New York and Minnesota. Here, the focus tends to be on particular, key legislators rather than the Legislature as a whole. This includes the Chairs of the Health and Aging Committees and their staff, sometimes the Appropriations and Budget Committees and Assembly/House and Senate leadership. Reported a provider representative in New York, *“[the Long Term Care Community Coalition] is a bit more focused on...sympathetic legislators who are in positions of influence...On the Assembly side...the Chairman of the Health Committee [is] a very consumer oriented individual...[The LTCCC] has a long history with him. A lot of effort kind of focuses on that one legislator and the counterpart of that legislator in the Senate, rather than my perception being that it’s a lot of diffuse broad-based messaging to every single person in the Legislature.”* In Minnesota, confirmed one key legislator, where *“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.”*

It was generally felt that advocates in New York tend to have more sway with Democratic legislators than their Republican counterparts or the governor’s office, no matter party affiliation. This is well-summarized by one legislative staffer who observed that *“[the LTCCC] has been pretty influential and very influential on some points. Their influence...it is fair to say has depended on having at least one house of the legislature in Democratic hands. They get a lot more response from us than from the Senate Republicans, or from the executive branch, regardless of party. The latter perception is reinforced by a New York legislator who observed that “Democratic Governors listen to them a lot more than Republicans...but even Democratic Governors are not as responsive as I would hope...largely because they are overwhelmed...There are just so many things they can work on is a real factor.”*

There was evidence to suggest that Republicans were less sympathetic to the advocacy point-of-view in Minnesota as well, particularly now that a Republican majority has been elected in both chambers. *“In the years when...both houses of our Legislature was led by Democrats,”* reported one provider representative, *“and that’s really been much of our recent history, there really was never a negotiation around reimbursement that there wasn’t a consumer advocate or two or three at the table.”* However, *“health care reform has really polarized legislators,”* explained an advocate, *“and it has created a new crop of legislators*

who are so anti-health care reform that they're anti any group that supported health care reform, so we kind of almost feel like this legislative session, we're almost starting from scratch, at least with the Republican side. Democrats still love us [but] we need both sides of the aisle to work with us...It's hard to get heard; it's hard to get an appointment; it's hard to even get your point across when you're sitting across from them, because they have a preconceived notion that we're the enemy when we walk in."

Although most interviewees emphasized the importance of targeting key legislators, others suggested the importance of lobbying and educating those who were not in key decision making positions as well, though the resources available for doing so were, admittedly, limited, particularly among consumer groups who are increasingly struggling to survive in the current fiscal environment. *"[The advocates],"* according to one New York staffer, *"primarily, and maybe sometimes to their detriment, focus almost exclusively on the Chairs of their respective committees [who have] a tremendous amount of weight in what goes through...But...when you're talking about the budget, they might lose the ability to (A), bring other members along, just into their line of thinking, and (B), teach them that there are other people involved, that it's not just the providers."* It was suggested that advocates could strengthen their activities amongst others who are not currently in a key decision making position but could be one day, or ultimately, will have to cast a vote one way or the other.

Educating legislators about the consumer point-of-view

Meetings with legislators are important because they provide advocates with opportunities to educate key decision makers about the consumer vantage point. Many legislators feel that nursing homes providers in their district are their constituents. Thus, they need to hear from the other side to better understand that nursing home residents are their constituents as well. In New York, interviewees felt that the advocates had impacted the way key legislators thought and acted with respect to nursing home reimbursement. *"We have changed the way people think,"* reported a leading advocate in the state, *"people like [the Chair of the Assembly Health Committee], even people on the Republican side, believe that we have made them more aware of some of the issues surrounding nursing home reimbursement as it affects quality. And that has been a major shift in the state's thinking."* The same is true for Minnesota. *"It's sitting down with the legislators and talking one-on-one,"* explained one advocate, *"and helping them understand, and it's not just one of my lobbyists or me sitting down with a legislator, it's sitting down with a legislator with one of our volunteers who's had a loved one in a nursing home...who's been in a nursing home."*

In both Minnesota and New York, interviewees felt that although much less well-resourced, one advantage advocates have over providers when trying to influence legislators is that unlike providers, they are not seen as having a self-interested agenda other than helping the nursing home residents for whom they advocate. *"My observation about the leverage that consumer advocacy organizations have that to some extent provider organizations don't,"* observed one provider representative in Minnesota, *"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."* *"Their ability to*

tap into a true network of real consumers,” agreed a state official in New York, *“lends to their credibility, and the people that represent the organization are clearly credible...it’s clear that they have a compassionate connection to the issues...They’re members of a coalition that represents real people, meaning real consumers, people who are residents of nursing homes and their families.”* Largely for this reason ensuring a consumer voice has been a priority for some legislators where, according to one New York staffer, the *“Health Chairs...very much value consumer interest input, and when you have the Chair on your side things like when a workgroup is being created, the Chair writing the language is going to make sure to involve consumers. And that just creates a culture where consumers are then involved in the process.”* Several interviewees pointed to a culture of inclusiveness in Minnesota where stakeholders of various types are expected to gather around the table to work issues out. Thus, *“a characteristic of our public policy development in Minnesota for decades,”* reported one provider representative, *“has been that stakeholders, when they gather to discuss public policy, run the gamut from providers to consumer advocates to those representing workers or organized labor. That’s just been a way that we do business here.”*

Testifying at legislative hearings

Deemed crucial for influencing legislators in Minnesota was face-to-face, in person testimony at legislative hearings. *“Certainly, having someone at the Capitol representing consumers for all of the major hearings on bills,”* reported a Minnesota provider, *“[is] something they’ve done for decades.”* This is important because, as one state official noted, *“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...to some degree.”* Testimony is particularly useful because it helps to make otherwise dry and antiseptic issues real. This is reflected in the comments of one Minnesota legislator who observed that *“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.”* *“They individually have to know how it affects them,”* asserted one Minnesota advocate, *“how it affects their constituents...Everyone’s got a grandma, or a sister, or a friend who came back from the war who’s in a nursing home, so we try to personalize it a lot.”* It is important, another advocate noted, that it is not just the professionals *“up there spouting off policy...because they hear from the professionals all the time. It’s important for them to hear from [their] constituents.”*

Public testimony enables advocacy groups to draw on the experiences of individuals whose integrity and caring for residents is beyond question. *“The family member, the direct caregiver, the nursing assistant who’s on the line, the nurse,”* reported a provider representative, *“they would bring forward spokespeople in the interest of their issue whose caring was just unquestioned, whose motives were unquestioned.”* This has helped to generate sympathetic responses on the part of legislators. A recent example, according to one Minnesota advocate, has been *“testimony from elder seniors who are private paying for their spouse in a nursing home and now would be punished if we repealed rate equalization. Those have been pretty effective testimonies.”* Experience in New York suggests that bringing

issues to life is important too. Thus, reported one advocate, *“it’s incredibly valuable to maintain a real grassroots consumer voice to the extent that you bring residents to the table, families to the table. If they’re at the table the nature of the conversation is very different.”*

Legislative testimony is also important because it helps to make issues “local” by having constituents of particular legislators tell their stories. Rate equalization was one example highlighted in Minnesota. Here, legislators felt that it was quite powerful when individual constituents came to explain how the high costs of nursing home care had forced them onto Medicaid. *“Bringing people down that are local,”* noted one legislator, *“and that understand the community that Legislators come from is very important. I think that’s their most effective way to do it.”* *“The biggest and most effective thing,”* confirmed another legislator, *“is the localization of the issue...[If] residents within a nursing home in a legislative district are calling and are direct constituents and are able to express how a potential decision is going to impact them, it takes the personalization one step further [than having one] elderly man testifying in committee [because the latter] is only one legislator’s constituent.”*

STATE AGENCIES & AGENCY PERSONNEL

In addition to targeting state legislators, developing and accessing relationships with officials in key state agencies is believed important for influencing reimbursement. Thus, in addition to spending *“roughly 50 percent of [their] effort”* with the legislature, a provider representative in New York reported that his *“perception is that [advocates have] probably focused at least 50 percent [of their effort] with the administration.”* Specific activities that advocates engaged in included one-on-one meetings with state Medicaid, survey and certification, and/or other state staff, not to mention bringing otherwise non-communicating agencies together and helping frequently overwhelmed officials do their jobs through the provision of timely information and expertise.

In recent years, there has been more interaction between consumer advocates and state administration personnel in New York than Minnesota where advocates seem to focus more on state legislators and their staffs. That the legislature seemed to be the primary target of advocates’ activities in Minnesota to the relative exclusion of the state bureaucracy is reflected in the substantially greater emphasis placed on legislative testimony in that state by our interviewees. This is in contrast to New York where interviewees placed considerably greater emphasis working with state agency officials.

One-on-one meetings with state administrative personnel

In New York, meeting with a broad array of state bureaucrats and other officials is viewed as an effective strategy for influencing nursing home reimbursement. This includes officials in the Medicaid and quality sections of the Department of Health, in addition the Division of the Budget and governor’s office, and, potentially, the Offices’ of the Attorney and Inspector Generals. Reported one advocate, *“the big piece that we’ve used in strategy really is trying to work with the agencies. Most recently, that’s been our focus. The only agencies involved with Reimbursement are really the Health Department and the Governor’s Office. But in other*

areas, we have brought in the Attorney General's Office, the Office of Medicaid Inspector General...We try to work with a lot of different agencies, and bring some synergy to them around these issues...That has been our modus operandi."

This perception is reinforced by state administrative personnel who reported that moving forward *"the most effective venues for influencing policy [would be] in person meetings with the Division of the Budget, the Governor's Office, as well as the detail work...with the reimbursement people [in the Health Department]"* because the executive branch had been successful in *"[wrestling] control back of the details of reimbursement from the Legislature."* Thus, while the Legislature authorized development of the state's new regional pricing methodology for reimbursing nursing homes, it was left up to state administrative personnel to develop the details. Consistent with other interviewees, one legislative staff felt that the advocates *"generally...have more sway with the Department than...with the Legislature, as a whole"* and when they *"make a pitch to the Health Department they have a fairly good chance of being responded to."* The most salient recent example has been the incorporation of quality pools into the reimbursement system. *"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, so we worked with them a lot on what other criteria should be, like staffing based upon payroll....Putting things like resident satisfaction in...Identifying valid and reliable measures."*

The two primary agencies with which advocates interact in New York include the Office of Long-Term Care and the Division of Health Care Financing within the Bureau of Long-Term Care Reimbursement of the Office of Health Insurance Programs, both within the Department of Health. At the time of the study, the Office of Long-Term Care was charged with surveillance and certification activities and monitoring of all long-term care providers, which, in addition to nursing homes, includes certified home health agencies, hospice, licensed home care services agencies, assisted living, and adult homes. By contrast, the Division of Health Care Financing was charged with the day-to-day responsibilities of promulgating reimbursement rates for the various long-term care providers paid for under Medicaid when the study was undertaken. *"In our state,"* reported one advocate, *"we tend to meet mostly with the quality people, who also know about reimbursement, as it turns out. But we also meet with the Medicaid people themselves and with the Governor's people."*

Although the focus of the Office of Long-Term Care is on survey, certification, and licensure, it, along with the Office of Health Insurance Programs, informs nursing home reimbursement policy making within the state. One state official pointed out, for example, that *"the Office of Long-Term Care works very closely with consumer advocates as it relates to the care of nursing homes; the conditions of nursing homes, all of which, frankly, are very related to reimbursement."* In addition to having quarterly, sometimes monthly communication with the LTCCC, the work of the Office of Long-Term Care is informed through communication with actual residents and their families. Thus, it was reported that *"one of the most effective interactions that affect [the Office of Long-Term Care in terms of] policy, program, and knowledge is through [its] consumer complaint hotline...And through [the] surveillance process, whereby Department of Health staff are out in facilities and*

interacting with residents of nursing homes. That's a real critical interaction that [they] have that informs [them] and allows [them] to also look at broader issues."

Like New York, most interviewees believed that advocates in Minnesota have had a good, long term relationship with technical personnel within the Department of Human Services (DHS). This is reflected in the perceptions of one state official who reported that *"there's mutual respect and that's that. I've never felt that there's been any sort of really negative, like, 'oh, those people at the Department don't know what the heck they're talking about,' in anger, it's always been a very respectful exchange of opinions."* That advocates and Departmental personnel have a good working relationship is also reflected in the perceptions of one advocate who reported that *"it is generally speaking possible to initiate a meeting, certainly with [one particular agency official], who has been in that role for many, many years. If [an advocate] wants to talk with him while bills are still in progress to understand what he sees as the potential impact, he will almost universally grant a meeting."* But while *"consumer groups [have] had sort of long, established relationships with the Department,"* according to one union representative, they have not had *"many relationships [with] the Governor's political office"* and other higher-level appointees. Furthermore, most interaction with the Department seems to have been through general stakeholder advisory groups and forums rather than one-on-one meetings with Departmental staff. *"Primarily my working relationship with consumer advocates,"* reported one state official, *"is through this advisory committee...It's good to have them at the table, hear their perspective [though] the...committee has not been active over the last few years."* It was also reported that the Department meets jointly with advocates and other stakeholders during the annual budget cycle to go through and seek feedback on pertinent, reimbursement-related provisions.

Serving as a conduit to bring state agencies together

One of the useful roles that the Office of Long-Term Care serves in New York is to translate what they find in the field about facilities, from a surveillance and quality perspective, in their dialogue with other offices within the Health Department as well as with advocates, including with respect to reimbursement. Thus, recently, both the survey and certification and Medicaid reimbursement arms of the Department have contributed to development of regional pricing and quality pools, with, for example, the Nursing Home Reimbursement Work Group established to acquire stakeholder input in this area, being co-chaired by the Directors of the Office of Long-Term Care and Bureau of Long-Term Care Reimbursement.

It was felt that advocates can serve as a bridge for state agencies who might not communicate with one another as frequently as otherwise would be optimal. This can be to the benefit of the issues that advocates care about. This is illustrated by the experience of one consumer advocacy group in New York which reported that *"we meet now on reimbursement issues 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."* It was important for this organization to bring the quality and reimbursement people together because, for example, *"you can convince the quality people that something makes sense in terms of quality of residents and then it's the technicians who*

say, 'Well, how do we measure it? How do we monitor it? Is this going to give us an extra burden? They're focused on that. So you have to bring in the quality people who say, 'but it's important for quality, so we have to make it work. You need to work with both.'

Account for, and, perhaps ameliorate the workload burden of state officials

When interacting with state agencies it is important to account for and, perhaps, help ameliorate the workload burdens that the people who work within those agencies face. This may help influence the way state bureaucrats think about reimbursement and how it affects residents, while generating a certain amount of good will and trust in the process. "We have a good relationship with the state Medicaid officials," reported one New York advocate, "it's because not only do we meet but we show concern for their workload. And we do try to help them...We try not to recommend things that they can't do because they don't have the people. It's a balance. They appreciate that." For example, "saying to them, 'yes, we want the add-ons to demonstrate that providers use the money, and that there's a positive outcome, but we're aware that you can't monitor that outcome now, so as a first step just at least collect the information, and require them to put it down. I think they appreciate that we're not insisting and fighting that [they] monitor it [as well]."

It was reported that a long term decline in central staffing has impacted almost all areas of policy, not only within the Health Department but all agencies in state government. Explained one legislator, "we've had major budget deficits in New York State every year for the last 20 years, and when the time comes for the Legislature to restore funding for something, central staffing in the state agencies is about the last thing that we're going to think to put money into...Nobody ever marched on Albany saying, 'We need more Assistant Commissioners.'" In light of prevailing shortages in critical personnel, advocates can serve a useful role by offering up another pair of hands. Thus, for example, one advocate suggested that the Department of Health look at staffing levels in nursing homes related to reimbursement using payroll data, not self-reported information. Recognizing that state Medicaid personnel lacked the time to investigate this matter themselves, this advocate "went to Kansas, got their schedule on how they collect that information, and sent it on to the Department in New York. It's now in the cost report that providers must complete annually." Although this information is not yet being used to reward facilities under the quality pools, it is available when the quality pools go into effect over the next couple of years.

Advocacy group assistance is clearly appreciated by state officials: "We're always confronted with limitations," one New York official observed, "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 [this one advocate] 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...There's an open dialogue...It's a great working relationship." And the flow of information and expertise sometimes goes the other way as well, from state officials to consumer advocates. This is true both in Minnesota and in New York. "We talk a lot," said one Minnesota official, "sometimes it's more of an informal scene. Sometimes they'll come over here, or I'll go over there to talk about various ideas, or they'll ask me to help educate them about a specific law, or aspect of the whole thing." Said one New York official, "we've

really helped on her reports. The assembly actually gave her a line item in the budget...so we manage that contract for her...It's been pretty productive."

TASKFORCES & WORKGROUPS

As noted in the introduction, states typically employ taskforces when making major changes to the way nursing homes are reimbursed. Typically included are state Medicaid personnel, provider representatives, and their consultants. Often included are union representatives and state legislative staff. Included less frequently are nursing home residents and/or their advocates. In New York and Minnesota, however, taskforces and advisory work groups have served as especially important conduits for consumer advocacy participation and influence in the Medicaid nursing home reimbursement arena.

Being assertive in promoting consumer advocacy representation

Advocacy groups have been particularly assertive in promoting consumer advocacy representation on reimbursement-related panels. Thus, one Minnesota state official observed that consumer advocates are involved *"in state advisory groups; they pretty actively follow along and participate in almost any opportunity that they have."* *"If there is a group convened around...reimbursement,"* reported a provider representative in that state, *"invariably there is one or more consumer advocates present for those meetings."* Up until the last few years the Minnesota Department of Human Services routinely convened advisory committees on nursing home reimbursement which, in addition to consumer advocates, included state agency personnel, labor union staff, and representatives from the two major trade associations representing nursing homes—Aging Services of Minnesota and Care Providers of Minnesota.

"New York State is very, very interested in [consumer advocacy] input" as well, reported a New York provider, *rarely do they put together a group that deals with these issues that they don't include consumer input. They have been actively involved—no question about it."* Indeed, *"serving on a taskforce or work group is one of the most important forms of participation,"* according to one New York advocate, *"it's crucial to be at the table as much as you can...Some advisory panels that were appointed we had to ask, 'why isn't there a consumer on [there]?' And there were some [we] were on where we had to ask why there weren't more consumers on and...we fought very hard to get other consumer representatives on and had to actually show the Department where the law [required this to be the case]."*

Due, in part, to the assertiveness of certain advocacy groups in seeking to obtain a seat at the table, there is increasing sensitivity among both elected and administration officials to making sure that there is not just greater transparency in reimbursement-related policy work, but that there is representative stakeholder participation, which almost always includes some clearly specified standards that there should be consumer representation in those policy group meetings. *"Part of our role,"* explained one influential New York legislator, *"is whenever we are setting up any kind of advisory panel in legislation, usually as*

part of the budget, I make sure that it not only includes representatives of the industry and labor, and/or local government, etc., but also consumer representation.”

Consumer representation is valuable but limited

Advocates in Minnesota have successfully used participation on the Department’s advisory panels to participate in the development of nursing home reimbursement, with consumer representatives being drawn from Seniors & Workers for Quality Care, AARP, and the ElderCareRights Alliance. The Department spent a number of years working with its advisory panel to redesign aspects of the state’s reimbursement system. This included transition from a Minnesota-specific to case-mix system to one based on Resource Utilization Groups (RUGs) in 2002 and implementation of pay-for-performance in 2006. With respect to the former, one state official reported that *“[advocates] were very involved in [transition to the new case-mix system]. It was a pretty collaborative deal where everybody kind of agreed on the goal and the methodology wasn’t terribly controversial...I’m not remembering it as having a lot of fights or disagreements. It was more like, ‘Hey, how do we do this?’”* With respect to the latter, this official reported *“extensive involvement of consumer advocacy”* in efforts to *“[use] the payment system to create incentives for improving quality...and staffing through the quality add-on.”* While the Department preferred to weight outcomes such as quality of care and quality of life more heavily, both consumer advocates and nursing home industry representatives preferred placing more weight on staffing, including in relation to retention and turnover, levels, and use of pool staff. Largely as a result of this preference, 50 points out of a possible 100 that a facility could be rewarded were devoted to staffing during the system’s first year; 35 out of 100 during the second, since which it has been suspended, though these and other measures are still included in the state’s nursing home report card. In other areas, advocates’ influence has been much more limited; for example, what eventually became the new, now suspended “rebasement” system was developed primarily through negotiations between the Department and the Long Term Care Imperative, a collaboration between the two major nursing home trade associations.

In contrast to Minnesota, there appears to be a small pool of advocates from which to draw upon for participating in New York State’s workgroups and taskforces. This is because while consumer input is valued, the number of knowledgeable advocates is limited since the Long Term Care Community Coalition is often the only consumer group actively trying to influence nursing home reimbursement policy in the state. But although invariably outnumbered by provider and state interests, the Coalition has, in the views of most interviewees, nonetheless, provided valuable input to the benefit of resident interests. Reported an advocate from another organization, *“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. 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.”* Two advisory groups were highlighted more than any other: the State Hospital Review and Planning Council and the Nursing Home Reimbursement Workgroup.

The State Hospital Review & Planning Council in New York

The State Hospital Review and Planning Council (SHRPC), though now defunct, included providers, lawyers, business leaders, and consumer and union representatives. The SHRPC was previously charged with adopting and amending rules and regulations overseeing the hospital, nursing home, home health, and hospice industries in New York State, subject to the approval of the Health Commissioner, including in relation to reimbursement, construction, service approval, operational standards, and other issue areas. The Council consisted of 31 members serving three year terms each, no more than six years during a 12 year period. One of the leading advocates interviewed had been appointed to the Council during the 1980s and 1990s. Another believed participation on the Council helped educate this former individual about the intricacies of nursing home reimbursement. *“The Council had subcommittees on fiscal policy,”* it was explained, *“so if you engaged at that level of policymaking you dealt with financing issues. There were whole books that you reviewed in preparation for those meetings...[You] couldn’t participate in a responsible way without learning all of that stuff. So there was a structure and the structured imposed a learning process.”*

Most interviewees believed participation on the Council provided this advocate with an excellent opportunity with which to influence the development of the state’s nursing home reimbursement system, largely by continually raising the relationship between proposed changes and quality *“That was very significant being at the table,”* it was recalled, *“I had a vote and I’m very outspoken...I was the one who was always raising this issue that we had to look at ceilings and we had to keep looking at floors, and I think it did have an influence on how the final system developed.”* It was reported that as a member of the Council this advocate was instrumental in getting the state to adopt a regulation requiring facilities to show how they used additional payment received for dementia residents. It was also reported that participation on the Council provided this and other advocates an avenue with which to influence the development and implementation of case-mix reimbursement. *“The major piece was focusing the Health Department on monitoring the system,”* it was reported, *“for example, in the beginning, every few years the state would do an analysis...showing how much money providers were getting under the new system, and how much was going to patient care. My success was more in forcing the Department to keep monitoring what was happening, and bringing it to the State Hospital Review and Planning Council, so that we could see that...My major concern was how do we make sure that if facilities get this money that they actually spend it?”*

The Nursing Home Reimbursement Workgroup in New York

The Nursing Home Reimbursement Workgroup, which operated from June 2007 through October 2010, was established by the New York State Legislature to inform Health Department implementation of a new regional pricing system for paying nursing homes under Medicaid, that was initially proposed by the Department and a Joint Association Taskforce on Nursing Home Reimbursement consisting of representatives of the three statewide associations representing for-profit, not-for-profit, and hospital-based nursing

homes, including the New York State Health Care Facilities Association, New York Association of Homes and Services for the Aging, and the Healthcare Association of New York State, respectively. Although after several delays the legislature eventually approved the Department's proposal as part of the 2011-2012 budget process, with a projected implementation date of October 1, 2011, the statutory language for regional pricing was initially open-ended. It essentially said that there shall be a statewide pricing system that will be adjusted based on wages, either on a facility or regional basis. *"It was largely a blank slate,"* according to one provider representative, it was up to the Department to put *"flesh on the bones. It wasn't really highly prescribed in the legislative language."*

The purpose of the workgroup was to address specific implementation and policy issues relating to the new methodology; for example, identifying regions and allowable costs, examining cost differences across facilities, considering special facility/unit rates, and determining transition payments. It also left open the possibility for quality pools and other additions. Initially, membership on the Workgroup consisted of survey and certification and Medicaid reimbursement staff within the Health Department, statewide and regional representatives of for-profit, not-for-profit, and county-owned nursing homes, and organized labor. Consumer advocates were added by the State Legislature in 2009 at the urging of Long Term Care Community Coalition. *"We went to the Chairman of the Health Committee of the Assembly,"* it was reported, and *"we said, 'How come this doesn't include consumers?' And he said, 'Oh, my God, I can't believe it.' Anyway, so the next year the law was passed to include consumers."* Ultimately, it was only the Long Term Care Community Coalition that served. Although the relative representation of advocates and providers *"probably could [have been] more balanced,"* admitted one knowledgeable state official, the Health Department *"didn't really know who to ask, frankly."* Now that the Workgroup has expired in statute, interaction between former participants with the Health Department is now more informal, though recently the Health Department has turned to the Joint Association Taskforce on Nursing Home Reimbursement to continue work on the new pricing system, further fleshing out details related to pricing and peer groups, wage adjustment, quality pools, case-mix, and system transition.

A number of interviewees expressed disappointment with the Nursing Home Reimbursement Workgroup. Some felt that the Workgroup did not *"conclude in an orderly fashion with a report but kind of got dismantled by the change in administration and the budget,"* including the initiation of more comprehensive Medicaid restructuring. A number of the providers, in particular, *"viewed the entire thing as a sham and figured the Department was just going to do what they wanted anyway."* *"They form these committees to make people feel like they have a voice but I don't think anything meaningful ever comes out of them,"* asserted one union representative, *"it's just like Cuomo's Medicaid Restructuring Team right now. It's a way of neutralizing their opposition."* There were also doubts about *"whether there was even the will to go forward with the new reimbursement system that was being discussed."* This, in turn, hampered the ability of the group to make decisions, to feel like they had a real deadline to operate under.

However, several interviewees, including some of the more skeptical ones, believed that the Nursing Home Reimbursement Workgroup served several useful purposes. On the

one hand, the results of the Workgroup's deliberations did contribute to subsequent legislation codifying regional pricing and the quality pools, as well as recent Health Department and Joint Association Taskforce work in this area. Furthermore, *"the information that is being shared and bandied back and forth with the [Medicaid Restructuring Team],"* according to one state legislator, *"[has] definitely [been] informed by the conversation of the Workgroup that preceded it."* The Workgroup also served as the primary place where key stakeholders could join together to discuss and analyze the issues. This view is reflected in the observations of one provider representative who reported that the *"it provided a forum for people to come and sit around the table together and kind of put their positions out there. [And while the group really did not have] the opportunity to make a lot of final decisions...it was at least a useful place for a lot of issues to be discussed and kind of analyzed and debated."*

Interviewees of all stripes believed the Long Term Care Community Coalition was successful in influencing the development of the new system while a member of the Workgroup by both helping to frame the nature of the debate and the Department's ultimate recommendations. It was felt that regional pricing, quality pools, add-ons, and other factors that can have a real influence on the quality of life in the nursing home were more on the table than they were at the beginning of the conversation due to the LTCCC's participation. *"[The LTCCC has] been critical...on the quality issue,"* reported one state official, *"because in a consistent way for the last several years, that construct has been on the table of there has to be a quality component to whatever payment system we're using, and...they've been very effective at keeping that sound alive."* Noted a provider representative, *"the [LTCCC] entered the fray, and it began talking about quality pools being an important priority, and continued to do that very single-mindedly, and repetitively, and it's then kind of consistently a part of the conversation...You could probably draw a dotted-line connection there that the effort that the [LTCCC] has put into advancing quality pools has kind of sunk in from the perspective of the State as there's almost a presumption that quality pools at least have to be a part of the discussion."* Although not successful in limiting regional pricing to the indirect care side of the rate, believing that its application to the direct care side would comprise quality, the LTCCC was successful in advocating for the inclusion of funds to help facilities facing considerable financial losses under the new system but requiring them to demonstrate how they planned to use those funds to help them transition. Furthermore, quality pools will be implemented over the next two years, with facilities being paid to report quality data during the program's first year and rewarded, in part, on the basis of that data in subsequent years. Nursing homes will be required to demonstrate that all add-ons for dementia, bariatric, and other special needs populations were spent as intended as well.

SUPPLEMENTS TO HIGHER LEVEL PARTICIPATION

Our findings suggest that consumer advocacy groups sometimes supplement higher level interactions with state legislators, agency officials, and reimbursement policy taskforces with more grassroots-oriented approaches to influencing government policy in this area. The most frequently used grassroots strategies include action alerts, email and letter

writing campaigns, and legislative lobby days. It was suggested that developing coalitions and relationships with other consumer-oriented groups, unions, and, potentially, provider organizations, could enhance advocates' grassroots presence and effectiveness.

GRASSROOTS STRATEGIES

It seems that the general purpose of the grassroots strategies identified is to complement higher level participation by letting key decision makers know that advocates have large numbers of people behind them who support their goals. The idea is that although demonstrating knowledge will get you a seat at the table and allow you to contribute productively, the more traditional grassroots tools may be necessary to bring political pressure to bear should direct negotiations with the state legislature, governor, and state bureaucracy stall. *"We first try to see if we can get the powers that be to be somewhat responsive,"* explained one New York advocate, *"if they're not responsive we have to go after them. It's something we have in reserve."* By way of example this advocate reported that *"[quality pools] originally was done first through the people in the Health Department...the quality and Medicaid people. Then it was done at the Nursing Home Reimbursement Taskforce...And then we met with legislative people because it had to go into the budget. And then it was passed in the budget...But at one point when we saw there might be...pressure against it...We then started our action alerts with the legislature and the Governor...at that point we started grassroots on it."*

It was observed that the number of supporters matter, both in New York and Minnesota. *"We are a coalition of groups and individuals,"* explained one New York advocate, *"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 affect change."* This perspective was reinforced by the views a legislator in that state who observed that in *"the vast majority of legislative offices, numbers count a lot...and so if consumer advocates are going to be effective, they not only need a quality message and a well-defended and explained message, they also need to focus on having a large, popular base, as well, that can voice their message."* A staffer reported that *"if you can generate 150 phone calls to a legislator's office in a day or two, he'll pay attention."* Similarly, in Minnesota, a legislator observed that *"they come and lobby, 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."* Especially as the legislature gets closer to votes and hearings, emails and phone calls become much more prominent.

Newspaper coverage, advertisements

While advocates have been successful in obtaining press coverage of survey and certification, quality and elder abuse issues, it is little used in the context of nursing home reimbursement. *"The press releases and media is probably the least effective strategy on the reimbursement side,"* explained one New York advocate, *"because they're not interested in that. They're interested in quality issues and they always pick up on media alerts on enforcement and stuff...Reimbursement [is] not as juicy, so that's why I would say that's*

probably the least effective.” The one exception noted in Minnesota appears to be AARP-driven coverage of rate equalization. This includes placement of advertisements in the State’s most widely circulated newspapers. Reported one provider representative, *“the most effective is when AARP puts...ads out and hits every member...It has been a while, but in the past they have done ads that say, ‘Don’t Cut Seniors’ and/or ‘Make Seniors a Priority,’ ‘Don’t Repeal Rate Equalization,’ or something like that. That’s been very effective, especially if it’s during an election year.”* It was also reported that AARP would tell legislators that they were closely watching them on rate equalization and would inform their constituents how they voted and *“oh, by the way, we’ll be thanking publicly those legislators who support maintaining this important law with a lovely thank you note in the Star Tribune.”*

Action alerts, letters, emails

Action alerts, which reach out to people about specific issues, were found useful in activating broader networks of individuals and organizations to generate letters and emails with the aim of moving policy by getting policymakers to take notice. The AARP in Minnesota has used “robo call” technology to stimulate communication on the part of its membership. *“We can reach anyone at any time,”* it was reported, *“and encourage [our membership] and influence them to make a phone call, send an e-mail, show up at an event, and depending on the issue, we’ve had a very, very high success rate, and we utilize...robo calls, for example, where I record a message, and then we dial our members in a particular area. We can be very targeted. We can say, ‘Okay, we want to reach our members between ages 65 and 70 who are retired and live in this zip code and are very interested in health care issues.’ And those are the members that are called. That’s where we know we’ll get a 30 percent participation rate. If we dial 1,000 of them, then we know 300 will make a phone call.”*

One Minnesota legislator stressed the importance of communications such as this: *“If you’re doing something because you’ve got four nursing homes in your district that want it...but if you’ve got AARP membership in your district, you’ve probably got hundreds of people that don’t....[Advocacy groups] need to lean more heavily on their membership to contact their legislators...If you’ve got a lot of your constituents that are writing to you, then it certainly would have to make you question your position on something.”* During the last legislative session, AARP generated approximately 6,000 phone calls and emails advocating against the repeal of rate equalization.

The Long Term Care Community Coalition in New York has promulgated action alerts through postings on the Coalition’s newsletter and web-site. *“One of the best things we ever did was invest in one of these action centers,”* it was reported, *“this is a web-site where you can put a message on it, and you can reach out to people and have them send letters automatically with one click...They look at the sample letter that’s been written which is short and sweet. We permit them to change the letter in any way and we also say to them that their first few sentences should be very individual. Who they are; why this is important to them. Some people do that; some people don’t.”*

Currently, the LTCCC has 3,000 individuals across the State on its action alert list. They also forward their action alerts to stimulate other organizations' memberships to generate emails and letters. Some interviewees felt that the action alerts have been more effective at opening doors than influencing policy. This is reflected in the views of one state official who believed that *"email-campaigns are okay but my experience is they don't really move policy; they just get people in the door to have meetings and stuff."* Others felt that the LTCCC had indeed been successful in using action alerts to shape reimbursement. Quality pools were the example most frequently mentioned. *"Certainly in terms of grassroots organizing,"* observed an advocate from another organization, *"they've been very successful at utilizing these email campaigns [to influence the quality pools and regional pricing debate]."* *"That's the way we got the quality pools into the Governor's Office,"* it was explained, *"he got over 400 emails across that state from residents and people. It made a huge difference."*

Mass rallies, legislative lobbying days

In addition to writing emails and letters, advocates in Minnesota, at least, have occasionally been effective at stimulating large numbers to lobby state legislators and their staffs directly on behalf of nursing home reimbursement issues. This has occurred primarily under the auspices of the AARP who make their members visible by having them wear buttons and red shirts on designated lobbying days and, during the last legislative session, were successful in having volunteer leaders make personal visits to lobby against the repeal of rate equalization. AARP has also participated in Seniors & Workers Lobby day, which had as one of its issues, nursing home reimbursement. It was reported that *"we've always been able to get anywhere from 100 to 200 people to show up at the lobby days to support those initiatives and to visit with legislators and hand out materials."* Indeed, *"when they do a rally,"* confirmed one Minnesota provider, *"they turn out huge numbers, and the other thing I would say about AARP is that they wear red, so they've been effective...in identifying themselves visually in the numbers of people who are daily at the Capitol, or at a hearing."*

By contrast, advocates in New York have not engaged in this activity. *"There have been issues where they have bought [in] 15 to 20 people,"* reported one legislative staffer, *"but I've never seen the full, red-shirted AARP army. When [AARP] decide[s] to fully engage, they can bring 2,000 people to the Capitol....I've never seen them particularly do much organizing around nursing home issues. I have not seen the tons of people come up."* As pointed out earlier, the Long Term Care Community Coalition and other nursing home-related advocacy groups possess few of the resources necessary to bring large numbers of people to Albany. Alternatively, AARP in New York is much less active and interested in nursing homes than other consumer groups although they *"bring up busloads of people [to Albany] practically every week"* to lobby on other issues, according to one legislator.

Focus on the big issues, keep the messages simple, make it personal

Interviewees generally agreed that grassroots strategies work better when the messaging is kept simple and the focus is on larger issues to which people can more readily

understand. *"We only go to grassroots when it's really bigger issues that we can get [people] to connect to,"* reported one New York advocate, *"you can connect to quality pools; you can even connect to the add-ons...It's hard to get someone to write a letter saying I think the floor should be such and such a percent or whatever."* Furthermore, people are more likely to connect to a message that, says, under-reimbursement of health care facilities may adversely impact quality of care than the details that specify how each facility is reimbursed. Thus, according to a union representative in Minnesota, *"you can mass mobilize people around 'let's increase the funding.' You cannot mass mobilize people on the, 'we want to change the factor that goes into the quality bonus of X percent to weigh this much.' People...their eyes glaze over."* The simple message is also better for stimulating advocacy. *"When you put out a grassroots notice for everybody to get a hold of legislators,"* suggested a provider representative in New York, *"you don't steep yourself in the details a lot, because you'll lose people; the old KISS method, 'Keep It Simple Stupid'...It's hard to transmit a message at a grassroots level that gets too complicated."*

The interviews also suggested that not all forms of communication are created equal; some have more credibility than others. In particular, the less effort devoted to communicating with state officials the less effective those communications are likely to be in influencing the behavior of those who were contacted. Reported a Minnesota legislator, *"the same exact e-mail on the same exact issue; hundreds over. I understand that they come from my constituents, but I don't see them as being thought out well. I don't see them as being individual words, but instead regurgitated talking points. It's the most impersonal, least effective strategy in my opinion."* *"Each thing has varying weight established to it,"* explained one legislative staffer in New York, *"there's the personalized e-mail; there's the form e-mail; there's the postcard that's just sent; there's the actual letter that's written. 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."* Even stronger than phone calls, however, is individual personal contact with legislators.

DEVELOPING COALITIONS WITH OTHER GROUPS

To increase the likelihood of policy impact, advocates could develop coalitions and relationships with other key constituency groups, whether additional consumer-oriented organizations, unions, or individual providers or provider associations. Consumer-oriented coalitions have been important in New York but not in Minnesota. By contrast, coalitions with unions have been important in Minnesota but not in New York. Neither state has seen much in the way of coalitions between consumer advocates and nursing home providers, though collaboration between the two groups could prove effective in influencing the direction of nursing home reimbursement to the benefit of both parties.

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). These include: the Coalition of Institutionalized Aged and Disabled (CIAD), PHI, AARP, Alzheimer's Association, Center for Independence of Disabled in New York, Grey Panthers, New York State Nurses Association, New York StateWide Senior Action Council, Women's City Club of New York, United Hospital Fund, and the Ombudsmen Programs of Nassau, Suffolk and Nassau Counties, among other groups. Participation of these groups in the LTCCC has increased the coalition's impact in reimbursement and other discussions. It is known that the coalition's executive staff speaks for large numbers of constituents. Thus, although LTCCC staff takes the lead on nursing home reimbursement, the LTCCC draws strength and support from its membership. This is manifested in a number of ways, including informing and providing feedback on LTCCC strategy, expanding the lobbying strength of the LTCCC, and enhancing the perceived legitimacy of the efforts that are made. It was reported that *"a lot of our organizations have much broader mandates than nursing homes, so they're involved in lots of other things...[Even] groups [that] are focused on long-term care...we are still the designated experts, and they come to us then they support us, either through action alerts, or when they do lobbying, or putting a briefing paper together on issues; most of our stuff ends up in their brief related to reimbursement."*

Informing Strategy. Staff at the LTCCC translates information about nursing home reimbursement for other organizations that do not have the level of knowledge and expertise that they have. This enables the Coalition's constituent members to provide productive input that can then be used to inform the LTCCC's participation in higher level discussions with policymakers and other stakeholders. *"I depend on the [LTCCC] to keep me informed on what's happening in New York State regarding nursing home issues,"* explained one Coalition member, *"the meetings that we've had that have been convened by the [LTCCC] have provided a platform for there to just be a dialogue, and just some give and take, and input from a variety of different organizations working on different aspects of the system...just helping to define and refine a position, and coming up with a strategy...They have always been interested in engaging and getting advice and feedback from others."*

Expanding Lobbying Strength. Another advantage of the LTCCC's structure is that it promotes further dissemination of the organization's messages about reimbursement and other issues to policymakers and other state officials. This can be through the action alert driven communication discussed earlier, or through direct contact with state legislators and agency officials by the Coalition's constituent members. *"Other groups come to us and ask questions,"* it was reported, *"and so when the AARP, [for example,] goes to visit a legislator they have the information they need on reimbursement though they're focused on so many other issues."* *"Developing allies in other organizations that can chime in with you [is important for influencing policy],"* explained one legislator. Thus, it was suggested the LTCCC do whatever it could to encourage the AARP to take on the Coalition's agenda because, according to this lawmaker, *"there's no way that the Coalition is going to have the resources to bring scores or hundreds of people...into the legislative office building every week. But AARP does that...It's very effective. You can tell from the other end of a block, 'Oh, the AARP people are here,' because there's scores of people in bright [red] T-shirts."*

Increasing Perceived Legitimacy. Finally, being organized as a coalition helps increase the perceived legitimacy of the LTCCC's work; that LTCCC staff are not just representing one organization but all members of the Coalition's membership. *"They do work very hard to be a coalition,"* reported one member, *"that they're representing an array of voices: CIAD, AARP, the Alzheimer's Association, the Nurses Association. 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."*

Unions

In Minnesota, senior groups have formed a coalition with the unions: Seniors & Workers for Quality Care (www.seniorsandworkers.org). This group includes most senior-oriented groups in Minnesota, including the AARP, League of Women Voters, Alzheimer's Association, ElderCare Rights Alliance, Older Women's League, Minnesota Adult day Services Association, Minnesota Nurses Association, and National Association of Social Workers. The Coalition also includes the Union Coalition of Long-Term Care Workers, which consists of SEIU, the American Federation of State, County and Municipal Employees, United Food and Commercial Workers, UNITE HERE!, and United Steel Workers. Seniors & Workers has worked because the unions and advocacy groups that constitute it have assumed complementary roles. This has enabled the Coalition to serve as a countervailing weight to the nursing home industry and to successfully influence aspects of the State's payment methodology to the benefit of residents and workers.

Assuming Complementary Roles: The goals and skill-sets that union staff and residents' advocates bring to Seniors & Workers complement each other well. The unions wish to increase both overall staffing levels and compensation and other supports for direct care workers. The advocates wish to improve the quality of care received by residents. Thus, one *"reason [Seniors & Workers] has been successful,"* according to one union representative, is that both parties recognized *"that the workers needed better pay and benefits. And if the workers got that, there would be better staffing and people would be better taken care of, and if you had more money in the system for staffing, there would be more people to take care of the folks in the homes. That was a real iron clad commonality of interest."* Another reason is that the strengths of each group reinforce those of the other. Thus, continued the union representative, *"what makes the Coalition effective is the combination of labor [having] a very strong...electoral political arm that has a lot of clout with legislators, and citizens' organizations [having compelling stories] to tell and a very good...inside lobbying game."*

Countervailing Weight: By working together in Minnesota, consumers and unions have sought to counterbalance the interests of the nursing home industry in nursing home reimbursement policy decisions by emphasizing the needs of both residents and direct care workers in reimbursement policy discussions. Reported one union representative, *"I would say citizen advocacy groups that partner with labor organizations have a lot more clout than*

they would otherwise...I would say we are the sort of balance to the industry trade group...We both advocate for greater funding for nursing homes, but they tend to focus more on just sort of the generic needs of the industry, while we...try to emphasize the needs of consumers and the workers who actually work in the homes.” It was reported that Seniors & Workers was formed, in part, as a reaction to the Long Term Care Imperative, a coalition of the for-profit and not-for-profit nursing home associations.

Having Policy Impact. The perception is that Seniors & Workers for Quality Care has proven effective, particularly in encumbering 75 to 80% of additional state funding for nursing homes for worker salaries and benefits. It has also helped to lead the fight opposing repeal of the state’s rate equalization law. *“Where there have been inflation adjustments allowed by the Legislature,”* reported one state official, *“the consumers and the workers, their Coalition, has been completely effective in an agenda item that’s important to them, which is that the money has to be used for specified purposes. New money has to go for compensation related costs for workers, salaries and benefits, and associated taxes...They’ve been able to get those provisions, which are vigorously opposed by the industry.”* Reported one union representative, *“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 gets to the front line caregivers, because that makes the biggest difference in their lives’...And the industry hates that. The other big thing is rate equalization, which says that you can’t charge private pay people more than you charge public.”*

Providers

Interviewees in New York and Minnesota generally agreed that having consumer advocates work with providers on nursing home reimbursement would be effective; that there would be greater strength in numbers. *“At the end of the day,”* explained one Minnesota provider, *“the kind of transformation that we’re wanting to see in old adult services really only happens through collaboration, so the bigger the stakeholder group, the better.”* Suggested one Minnesota official, *“if they as a group, consumers, the workers, and the trade associations came in jointly with a proposal to deal with something...They could get anything they wanted, regardless of our position.”* Despite its potential, the development of coalitions between advocates and providers has been difficult to accomplish and, as such, has been little used so far. On the one hand, according to one union representative in New York, *“the advocates could play a role in bringing together the for-profits and not-for-profits, and upstate and downstate homes, and the different associations, but they don’t.”* On the other hand, *“the provider community would have to shoulder some of the blame,”* according to a provider representative in Minnesota, *“in that...we did not reach out beyond the provider community.”*

The dearth of collaboration between the provider and consumer communities largely derives from the adversarial relationship that exists between the consumer advocacy groups and industry associations, though advocates in both states reported working with individual facilities around quality issues but rarely reimbursement. A number of suggestions were made to improve the relationships between advocates and providers, however. This includes distinguishing among different types of providers—some may be

more productive and natural coalition partners than others. It also includes finding common ground around issues related to quality, spending levels, and mission; incorporating provider input into advocates' proposals for reforming reimbursement; not unduly antagonizing providers—that is, being more empathetic to the realities of running a nursing home, particularly in an increasingly difficult funding environment; and, where possible, co-opting providers' positions in such a way that they complement your own.

Developing Better Relationships. Interviewees in both New York and Minnesota reported that providers and advocates rarely come together, particularly on reimbursement. Indeed, the relationship between providers and advocates was variously described as “*inherently uneasy*,” “*contentious*,” and “*intense*.” Perhaps the prevailing dynamic is best illustrated by the observations of a legislative staffer in New York, “[*the consumer groups*] are very clear that they’re kind of in most cases at war with the provider, so it’s very rare where they join up with them...By nature, the provider is going to want to do everything they can to make money, and many of the things that a consumer group pushes for will be things that cost the provider money.” Concurred a provider representative in Minnesota: “*Part of it is the dynamic that grew up here over the years where consumers consistently were on the other side of the table from providers. That has proven a difficult gap to bridge.*”

Although predominately adversarial, interviewees felt that it was important for advocates to develop better relationships with at least some providers, particularly if they wanted to make more progress on certain issues than they have to date. Believed one New York advocate, “[*the advocates*] have to stop seeing the parties as black and white, bad and good...You have to leave your judgments of people...your old mental models at the door; you have to be open, and engage people on a common basis...There just has to be far more dialogue.” “*The resources are going to be tougher for the consumer groups*,” explained one Minnesota legislator, “*and that’s going to be a constant struggle. Vocalizing the issue and trying to build those coalitions as needed is going to have to happen.*” “*There’s an old adage,*’ suggested an advocate in Minnesota, “*‘hold your friends close, but hold your enemies closer.’ I’m serious. It’s an exceptionally important strategy and it works.*”

Recognizing That Not All Relationships Are Created Equal. Despite the general antagonism that exists, the relationship between the advocates and some providers is better than the relationship between the advocates and other providers. This is true in both New York and Minnesota. In Minnesota, for example, a leading advocate used to have informal lunches with good friends in the states’ provider associations, at which time progress in reconciling the advocacy and provider views on certain reimbursement issues took place. In New York, the LTCCC and other advocates used to sit down on a regular basis with representatives of one of the provider associations to work on various issues together, though these interactions tended to be around survey and certification rather than reimbursement and, by mutual agreement, ended once progress on the issues discussed stopped being made.

Perhaps the varying relationship between the providers and advocacy groups is best relayed by the following observations of a legislative staffer familiar with the operation of New York’s recent Nursing Home Reimbursement Work Group: “[*On the Work Group she*] had a very good relationship with...two or three of the nursing home representatives.

Generally, they were in New York City, and believe it or not, large, private pay institutions who had higher rates of quality. If [she] is sitting there talking about quality, and on all these measures of quality, you're going to score very well, then you would like this proposal. She would generally have support amongst those members. Amongst the members who were either on the Board of one of the industry groups, or amongst the members who were the industry groups, she generally had less support, and they would just kind of, 'Oh, that's [her],' and some people would almost go so far as to almost ignore her." This suggests that while there are some providers or provider groups' advocates are unlikely to develop collaborative relationships with, there are others who may prove to be productive partners in this regard. Said one New York advocate, "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 that are trying to do some really amazing things."

Finding Common Ground. When identifying providers to work with, it is helpful to identify areas of common ground. More generally, this may be with respect to mission; more specifically, with respect to quality performance and, perhaps, overall spending levels on nursing homes. This was the position of several interviewees, including one New York provider who suggested that *"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."*

One example where advocates have collaborated successfully with providers is in relation to workforce policy in Minnesota. *"By the 1980s, reported one advocate, "there had been a number of sessions in which consumers to some extent were able to exercise power by...aligning with the industry...[One situation they] [have worked] on the same side [was] to put some restrictions on what temporary nursing services could charge...We've worked on a number of [other] staffing reimbursement-related issues [as well]." Advocates and providers, as noted above, were also able to come together over the relative importance of staffing as a measure in the state's pay-for-performance system.*

Incorporating Provider Input. The desirability of seeking provider input into consumer advocates' proposals to reform the way nursing homes are paid was highlighted. This may help to generate good will and trust in addition to helping to separate providers who are willing to collaborate from those who are not. *"Instead of saying, 'You're not doing X,'" explained one New York advocate, "it should be a question, 'What do you need in order to do that?' And if they say, 'I'm not going to do it at all,' fine, you can write them off. If they want to do it, i.e., improve care. 'Where should we start? How do I help you get what you need to do that?' That's an entirely different frame."*

This approach was illustrated in the context of New York's prospective repeal of its long-term home health care program, Nursing Homes Without Walls, which had underwritten the costs of nursing homes for many years. In response, this advocate noted, *"we wrote...a proposal for change. We then went to key nursing home administrators and showed it to*

them, and said, ‘we don’t want to hurt you in this proposal. What do you we need to do to make it okay for you?...How can we help you transition to something else?’ And they told us, and so we put it in our proposal, and then we met with them individually. We’re continuing to meet with them. People that we consider real leaders in the nursing home community.”

Avoid Antagonizing Providers, Instead Co-Opt Them. Several interviewees stressed the importance of not unduly antagonizing the other side, recognizing that although there may be substantial disagreement on certain issues, there may be some providers or provider groups that may otherwise be willing to work with consumer advocates to further positive change. *“When...the Department of Health sets up a table to review how they’re going to distribute this money,” explained one New York advocate, “I think you have to be very careful in your language that you not indict all the providers in ways that are not constructive...You can’t come to the table and say they’re all crooks, and they’re all overpaid...and have people want to work with you...I would prefer to see a better tone of conversation. I don’t think you always have to be adversarial.”* *“How you behave and how you’re seen in your other sort of advocacy activities,” argued a provider representative in that state, “bears on your ability to have a positive collaborative relationship with providers...Because obviously, if you’re throwing bombs and hand grenades, figuratively...that’s not going to lend itself to finding common ground and developing common working relationships.”*

Alternatively, there may be ways to garner provider support or minimize their opposition by framing their arguments in such a way that they naturally complement your own. This has occurred in New York, according to one legislative staffer, who noted that *“you want even your opponent’s argument to work for your cause...In the nursing home realm, and I’ve seen [this one advocate] 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.”*

TOWARD INCREASED CONSUMER INVOLVEMENT

In conclusion, experience in New York and Minnesota suggests 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 involvement. These are outlined as follows:

- **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

Together the findings suggest the importance of developing, demonstrating, and volunteering expertise in nursing home reimbursement as a means of gaining credibility as a legitimate actor, which, once earned, will lead to an ongoing role in state reimbursement policy discussions. They also suggest strategies for using that knowledge and credibility to effectuate change. These include participating on state work groups and taskforces targeting nursing home reimbursement. They also include developing and accessing relationships with key public officials in the legislative and executive branches, in addition to supplementing taskforce memberships and stakeholder meetings with grassroots activities—e.g., action alerts, legislative lobbying days—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 consumer-oriented groups, unions, and perhaps, even provider organizations capable of marshaling the resources necessary to conduct mass rallies, letter writing, email, and other broader-based 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, [develop] 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

"I would say that the strategies have been pretty typical of a policy campaign: Emails, phone calls, especially as we get closer to votes and hearings...become much more prominent, and then citizens' presence and testimony at the Capitol, and in committee. [One advocacy group] had done town meetings, kind of statewide roundtables, and educational efforts...They definitely meet with the Department of Human Services."

--Legislator, Minnesota

"[They have] prevailed on relationships they have with key legislators who would have an ability and a forum...[and who are] known to the folks who are involved in this...They've published reports, and put out other information that would suggest that [reimbursement] needs to be a focus...They've tried to engage a broader public on the issue, and they've certainly engaged with our executive branch here at the State Health Department, and the Governor's office on the need to try to have certain features in the reimbursement system. So, I think it's a combination of advocacy and information [that] they've utilized."

--Provider Representative, New York

"[Our success] has largely been a matter of trying to cultivate champions at the Legislature among people who had enough power in their committees to be champions....Our groups [have also] served as interveners on the side of the Department of Human Services in...court hearings...It's 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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