



The NELS Advocacy Toolkit for Health and Aging Services Administrators

An Introductory Guide for Advancing Policy



Produced on behalf of NELS by
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The Purpose of this Guide

The [National Emerging Leadership Summit's](#) (NELS) purpose is to provide next generation leaders in the field of health and aging services the ability to engage in discussions of current best practices with other leaders, meet with representatives of key professional organizations, gain an inside perspective on the legislative process, and explore solutions for attracting and retaining other Generation X and Generation Y leaders. The NELS Summit strives to engage participants from a variety of long-term care (LTC) organizations providing supports and services, such as skilled nursing facilities, nursing homes, assisted living settings, continuing care retirement or life plan communities, home care, hospice, and adult day care services. Many professionals currently in the LTC field recognize there is a need to prepare future LTC leaders to work beyond silos of service and adapt to changing consumer demands.

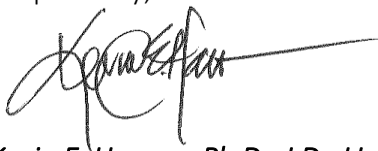
Advocacy efforts are needed at every level: local, state, regional, and national. While national efforts are often a work of strategic partnerships, the individual administrator can still make their voice heard with effective advocacy. Individual leaders may be involved in local efforts to effect change, but their expertise has broad applicability on the larger stage, too.

Effective policy advocacy, whether related to laws or rulemaking processes, continues to be of paramount importance for the field of health and aging services. Information that next generation administrators can provide to policy makers is crucial in the development of new laws, new rules, and new regulations. As such, the 2015 NELS attendees felt the need to develop a “toolkit” to enhance the advocacy efforts of next generation leaders in the field to help ensure that their voice is included in policy discussions.

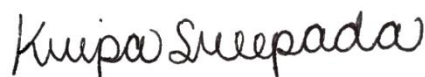
This guide was developed as a result of the 2015 NELS Summit, where participants felt the need to produce a toolkit to ignite the production of critical dialogue within larger circles. This toolbox was also designed to give NELS participants, and others in the administrator profession, the ability to provide continuity in communications for promoting legislative and regulatory advocacy on issues affecting the field. This includes staying apprised of legislation in Congress and across state legislatures, as well as changes from state and federal regulatory agencies.

Our goal with this guide is to aid you in successful advocacy efforts on all levels across a multitude of issues. Please contact the [NELS leadership](#) if you want to get more involved in policy making and need assistance to do so.

Respectfully,



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Chapter 1

Empowerment and Getting Involved

Your voice matters

Advocacy begins with *you*.

When facing a complex situation involving residents and their family members, when determining how to meet resident needs with shrinking budgets, or when you're working to attract and retain highly competent staff in an increasingly competitive market – **YOU** are the person confronting these challenges and crafting innovative solutions.

You are the expert whom elected officials, state or federal agency representatives, and other policy makers can call upon to offer wisdom, experience, and feedback on a host of policy initiatives that could potentially be pursued. How you elect to define and pursue issues can have broad-ranging influence on the policy making process.

Now, more than most points in history, is the time to be strategic, thoughtful, and relentless in the pursuit of effective policy changes. As noted in "Beyond the Cause: The Art and Science of Advocacy,"¹ advocates for policy change face numerous hurdles: a multitude of "voices" competing for different policy change, monetary influence to elected (and appointed) officials, and shrinking public funding to support individuals who may not be able to pay for their own needed care.

YOU must be the advocate for your care setting, your staff, and your residents, and this guide will give you many of the tools needed to be successful in this pursuit.

How the legislative process works

The legislative process varies from state to state and between the state level and the federal level (i.e., Congress and regulatory agencies). While there are variances, there is a great deal of commonality, too. This section is intended to give a brief overview of the legislative policy making process to guide interactions with representatives, senators, staff members, or the various policy or finance committees in legislative and rulemaking bodies.

In both state legislatures and Congress, an elected official must introduce any suggested change or addition to existing laws as a bill. When introducing a bill, a legislator will often seek out co-authors and co-sponsors for the new legislation, frequently from their own party. Bills that have

¹ Independent Sector: "Beyond the Cause: The Art and Science of Advocacy." Section 1: Essentials of Successful Advocacy. https://www.independentsector.org/beyond_the_cause

bipartisan support from co-authors do exist and can gain greater traction than a bill authored by only one party, but it has become increasingly rare in recent years.²

When a new piece of legislation is introduced as a bill, it is assigned a number for tracking (e.g., H.R. 895, S. 2651); the bill is then referred to a committee for a hearing.³ Committees are formed around subject-matter jurisdiction (e.g., Health and Human Services, Commerce) and proposed legislation addressing a committee's jurisdiction must be heard by a committee's members before going to the main floor of a legislative body for a vote. In a bicameral legislature, the bill is first reviewed in the body where it was introduced.

Depending on the breadth or scope of the new legislation, the bill may have to be heard in multiple committees, though it will often start in the committee that has the main subject-matter jurisdiction for the newly-proposed policy. It is then referred to other committees as needed. A committee chairperson can decide whether he or she feels the legislation needs to be heard in the committee or not. During committee hearings, the author may accept or contest amendments to the proposed legislation. After discussion and any amendments, the committee members vote.

After a bill is reviewed through the committee process, the legislation is referred to the main floor for "readings" and to be voted on by all members of the legislative body. It is then referred to the other legislative chamber (in the majority of legislatures that are bicameral) to go through the same process outlined above. Some legislation moves in tandem through both the House and the Senate, which can make scheduling hearings more difficult for proponents advocating the bill's passage.

After both bodies have heard, potentially amended (or "marked up"), and passed the new legislation, it may have to go to a conference committee.⁴ This committee is made up of members from both the House and the Senate to work out any and all differences between the two bills. Usually, legislation moving through one body is not amended differently than in the other body, but it can happen. After the conference committee agrees upon changes, the legislation is voted on again by both bodies and sent to either the Governor (state legislatures) or the President (Congress). The Governor or President can sign the legislation into law, or can veto the proposed changes, either through a "regular" veto or by using a "pocket" veto.⁵

If the Governor or President vetoes the legislation, the state legislature or Congress can override the veto in many situations.⁶ Often, to override a veto, a two-thirds vote is required in both

² Pew Research Center. <http://www.pewresearch.org/fact-tank/2013/07/17/partisan-polarization-in-congress-and-among-public-is-greater-than-ever/>

³ National Low Income Housing Coalition: 2016 Advocates' Guide.

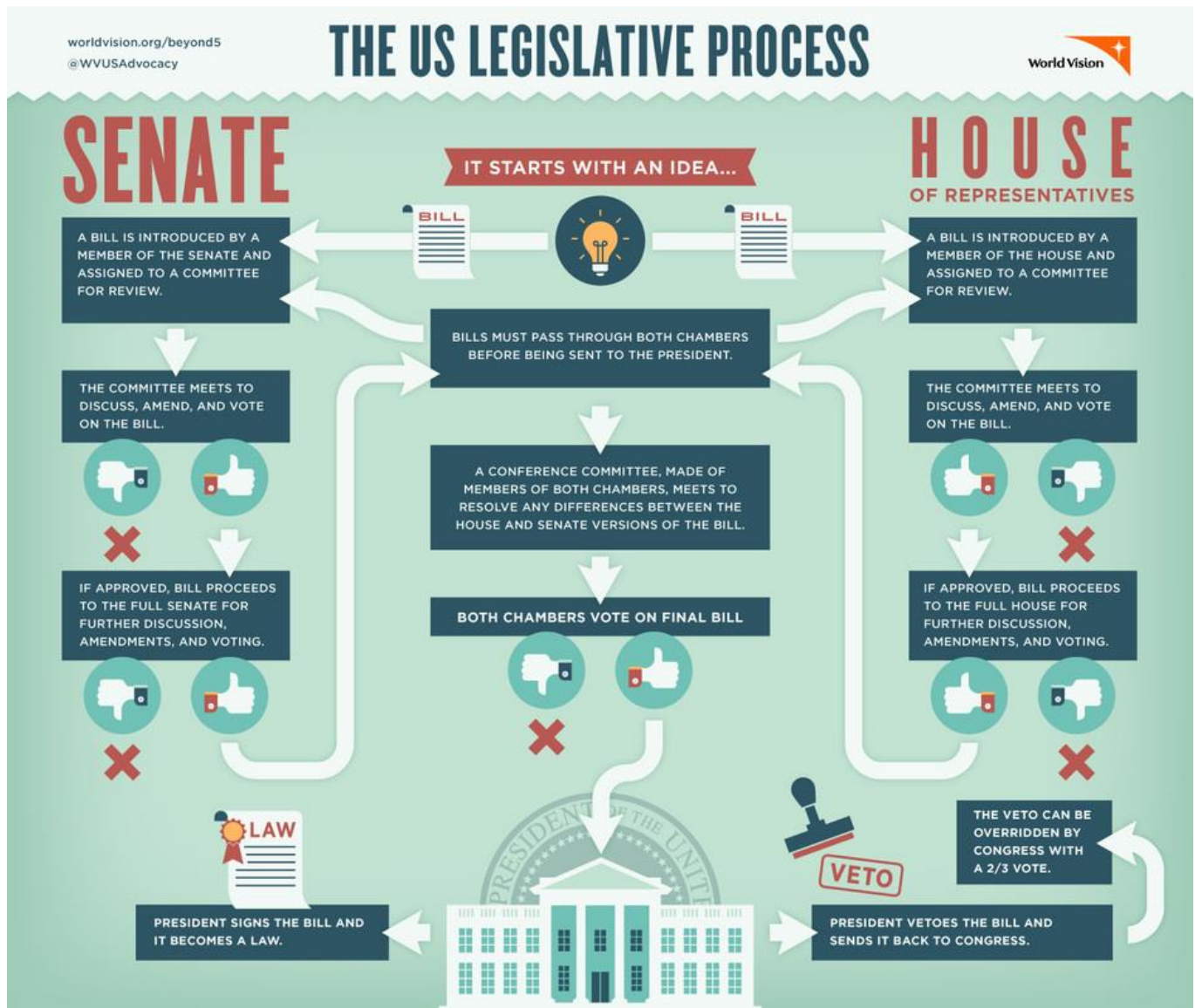
⁴ United States Senate. http://www.senate.gov/reference/glossary_term/conference_committee.htm

⁵ National Governors Association: Governors' Powers and Authority. <https://www.nga.org/cms/home/management-resources/governors-powers-and-authority.html>

⁶ United States House of Representatives: Presidential Vetoes. <http://history.house.gov/Institution/Presidential-Vetoes/Presidential-Vetoes/>

legislative bodies, though this varies (depending on the state, whether the legislation is in Congress, and on the type of veto from the Executive Branch). For Congress, the procedures to override a veto differ depending on which body originated the legislation.⁷

The following graphics is a sample depiction of the legislative process:



If the legislation makes it through the legislative process and is signed by the Governor or President, there is often an “effective date” when the changes become enforceable law. If not directly specified, there are procedures for when an “automatic” effective date is applied.

⁷ Congressional Research Service. <http://www.senate.gov/CRSReports/crs-publish.cfm?pid=%270DP%2BP%2CC%3E%23P%20%20%0A>

⁸ Source: http://hughsonhighamericangovt.weebly.com/uploads/4/8/4/7/48478293/6661813_orig.jpg

How the regulatory process works

The regulatory process is often called the “rule making” process. It is the process by which federal and state agencies of the Executive Branch develop policies to put into effect laws passed by the legislature, or to develop rules for running programs under a specific agency’s purview. In short, this is the implementation phase of the policy making process. This is often a public process with the opportunity to provide comment and feedback on proposed policies, rules, or regulations.

When a federal agency develops a new rule or seeks to modify an existing rule, there is a comment period or a “notice-and-comment” period during the rule making process.⁹ From the Center for Effective Government, there are three steps for effective commentary during the rulemaking process:

- 1.) **Know your rule.** This involves searching the Federal Register¹⁰ to find those proposed rules currently open for public comment.
- 2.) **Find your rule online.** After you’ve determined the rule you want to comment on, you need to visit the federal comment site¹¹ to locate the exact rule. This site indicates rules that have “Comments Due Soon” and “Newly Posted” rules, too.
- 3.) **Submit your comments.** Remembering that the general public can see your comments (e.g., your name and location), you are able to post comments that the agency proposing the rule, or modifying the rule, will see.

Your comment(s) don’t have to address every aspect of a proposed rule or proposed modification to an existing rule – they can be very specific and address only a portion that you feel affects you or your care setting. For federal agency rules, you are also provided with a comment tracking number.

On the state level, the process is very similar. You may have a greater chance of being involved in a workgroup or taskforce initiated by a state agency to craft policy or rules before the public comment period ends. This may be a more effective way to have your voice heard, rather than waiting until the public comment period prior to rule enactment or rule change. Whether or not your state agency has a workgroup or taskforce to be involved with, there are “open meeting” laws in many states that allow the public to access work product of agencies even if not directly involved in the rulemaking work.

Key committees in legislative bodies to work with

Depending on the issue and the legislature (whether state-level or for Congress), there could be several committees with which you should become familiar. For health and aging services

⁹ Center for Effective Government: How to Comment on a Rule. <http://www.foreffectivegov.org/node/4059>

¹⁰ National Archives and Records Administration: Federal Register. <https://www.federalregister.gov/>

¹¹ Regulations.gov. <http://www.regulations.gov/>

providers, the most common committees on the state level relate to Health and Human Services. Your state may use a similar name, but these committees tend to take up policy matters relative to nursing homes, assisted living facilities, home- and community-based services, and funding relative to these care settings. Some states will split Health and Human Services into a policy committee and a finance committee, so keep that in mind.

In the United States Senate, the committees that primarily work on health care-related matters are the Committee on Health, Education, Labor, and Pensions (or HELP) and the Senate Finance Committee.^{12,13} In the U.S. House of Representatives, the relevant committees are the health subcommittees within the Energy and Commerce Committee and the Committee on Ways and Means.¹⁴ There is also a subcommittee for the Appropriations Committee called Labor, Health and Human Services, Education, and Related Agencies.¹⁵

Additionally, some issues pertinent in health care revolve around the workforce or other economic considerations. Some issues may involve a state-level Commerce committee, or a Labor or Pensions committee.

Lastly, many proposals for new legislation contain items that require new spending or spending existing funds differently. Bills that alter existing funding or require new funding often must pass through the main Finance committee for each chamber (which could have item-specific subcommittees), such as the Senate Finance Committee or the House of Representatives Committee on Ways and Means.

These committees hold hearings, which are a public forum to draw attention to relevant topics of interest (e.g., the Health Subcommittee of the Senate Finance Committee held a hearing entitled, “Alzheimer’s Disease: The Struggle for Families, a Looming Crisis for Medicare”). It is sometimes possible to testify before committee hearings to offer your perspective on how the proposed legislation or changes to existing legislation would affect your ability to offer care and services, your site in general, or your residents receiving care. This is more likely in state legislatures, but there are opportunities to testify before Congress as well.

Key agencies (federal and state) to work with

On the federal level, the main agency that addresses issues related to long-term care is the Department of Health and Human Services (DHHS).¹⁶ DHHS houses the Centers for Medicare and Medicaid Services (CMS),¹⁷ which oversees the Medicare and Medicaid programs, as well as

¹² U.S. Senate Finance Committee. <http://www.finance.senate.gov/>

¹³ U.S. Senate Committees. <http://www.help.senate.gov/about/issues/health>

¹⁴ U.S. House of Representatives Committee on Ways and Means. <http://waysandmeans.house.gov/>

¹⁵ U.S. House of Representatives Committee on Appropriations. <http://appropriations.house.gov/subcommittees/subcommittee/?IssueID=34777>

¹⁶ U.S. Department of Health and Human Services (DHHS). <https://www.hhs.gov/>

¹⁷ Centers for Medicare and Medicaid Services (CMS). <https://www.cms.gov/>

the Children's Health Insurance Program (CHIP). CMS promulgates rules that affect many aspects of long-term care including funding, regulations, and resident/patient rights.

Newly created in 2010 (with the agency starting work in 2011), the Consumer Financial Protection Bureau (CFPB)¹⁸ is an independent agency of the federal government that represents consumers in a number of financially-related matters. This has some implication in long-term care as far as the agency's work with reverse mortgages, debt collectors, and other financial services that affect and target older adults.

Additionally, there may be some work done by the U.S. Department of Commerce¹⁹ that affects the long-term care industry. This department works to develop rules and policies that affect businesses in the United States, such as the health care industry. The Department of Commerce works on issues such as health information technology, fosters international relationships between U.S. and foreign health care policy makers, assists the business community in understanding health policy (e.g., requirements under the Affordable Care Act), and contains the National Institute of Standards and Technology, which houses the Malcom Baldrige Performance Excellence Program.²⁰

Like DHHS and Commerce on the federal level, there are state agencies that handle similar matters and develop state-level policy and rules. These policies could be to implement federal rules or programs, or to develop programs and policy that supplement federal programs.

Often, for health care-related policy, these are Departments of Health, Departments of Human Services, or Departments of Health Services – usually some variation of these terms – on the state level. These agencies sometimes house the licensing agencies for facilities or individual administrators, (e.g., Board of Examiners for Nursing Home Administrators), if those licensing agencies are not separate entities. For financial policy, there is often a Department of Commerce or Department of Consumer Affairs in some states, and some states use a Department of Finance – again, there will be a variation on these terms, depending on your particular state.

¹⁸ Consumer Financial Protection Bureau (CFPB). <http://www.consumerfinance.gov/>

¹⁹ U.S. Department of Commerce. <https://www.commerce.gov/>

²⁰ NIST: Baldrige Performance Excellence Program. <https://www.nist.gov/baldrige>

Chapter 2

Being Informed on Contemporary Issues

The 2015 NELS cohort identified an important barrier to organized advocacy efforts from long-term care administrators: timely issue identification. Without knowing which legislative issues are a priority for lawmakers and whether agencies are soliciting feedback on final regulations, it is difficult for administrators to make a meaningful and relevant impact. The following sections provide many avenues for administrators to be informed on contemporary policy issues.

Using available information from professional and trade associations

Administrators may overlook the benefit of belonging to any of the professional and trade associations for long-term care administrators (e.g., ACHCA, AHCA/NCAL, LeadingAge, NAB). The email lists and website resources of these organizations inform recipients of news related to the long-term care profession. Often, this includes regulatory news and specific calls for administrators to take action and contribute their voice to the policy making process, whether through legislation or rulemaking.

- 1.) American College of Health Care Administrators (ACHCA).²¹ Visit the ACHCA website to learn about available resources for the public. Members receive email alerts and regular newsletters on important issues, training, and upcoming events. **See Appendix A.**
- 2.) American Health Care Association/National Center for Assisted Living (AHCA/NCAL).²² Visit the “Advocacy” section of their website for AHCA/NCAL news from Washington. You can also register for regular updates from the AHCA/NCAL Care Advocacy Center.²³ You do not need to be an AHCA member to register. There are also many great resources on the Advocacy page, including their “Guide to Political Action and Grassroots Lobbying,” though you do have to be a member of AHCA/NCAL to access these resources.
- 3.) LeadingAge.²⁴ Visit their website to join the Seniors Action Network (SAN), a joint initiative of LeadingAge and Volunteers of America (VOA). SAN helps advocates engage directly with lawmakers on issues impacting Medicare, Medicaid, quality care, and affordable housing. You do not need to be a LeadingAge member to register for SAN.
- 4.) National Association of Long-Term Care Administrator Boards (NAB).²⁵ Stay apprised of recent news, changes affecting the licensure of administrators, and other pertinent issues for the field of long-term care by visiting the home page and “News” section of their website.

²¹ ACHCA: Email List. <http://www.achca.org/>

²² AHCA/NCAL: Advocacy. <https://www.ahcancal.org/advocacy/Pages/default.aspx>

²³ Care Advocacy Center. <http://cgrcengage.com/ahca/app/register?5&m=12133>

²⁴ LeadingAge: Engage. <http://www.leadingage.org/engage/>

²⁵ NAB: News. <http://www.nabweb.org/recent-news>

- 5.) McKnight's Long-Term Care News.²⁶ You can sign up for daily and weekly news alerts on long-term care topics of interest on their website. McKnight's contributors and the resources and reports on their website provide long-term care professionals with the "News You Need."

Visiting your local, state, and federal representatives' websites

It is often the case that your local, state, and federal representatives are passionate about health policy issues that affect long-term care. Depending on who your representative is, his or her website may have an easy way for you to subscribe for regular email updates about active legislation in the pipeline. With the following links, you can locate the name of your representatives. You can also visit USA.gov,²⁷ which is a one-stop shop to locate federal, state, and local representatives.

- 1.) Federal Representatives: Visit the Senate website²⁸ to locate your U.S. Senators and the House of Representatives website²⁹ to locate your county representative in the U.S. House of Representatives.
- 2.) State Representatives: Learn how to contact your state Governor by visiting USA.gov³⁰, and find your state legislators through the State Legislature Website using the U.S. Congress website.³¹
- 3.) Local Representatives: Find your local mayors through the Conference of Mayors website³² and contact your local government by visiting USA.gov.³³

Email distribution lists for federal and state legislative committees

Your federal and state representatives may sit on committees with legislative and oversight jurisdiction over health care, long-term care, long-term services and supports, or budgetary decision-making authority in these areas. Members on these committees hold key influence in shaping final legislation.

Federal Legislative Committees

To sign up for the email list for the House of Representatives Committee on Ways and Means, visit their website³⁴ and enter your email in the "Subscribe" section on the right hand panel. To

²⁶ McKnight's. <http://www.mcknights.com/newsletters/>

²⁷ USA.gov: Elected Officials. <https://www.usa.gov/elected-officials>

²⁸ Contact information for Senators: http://www.senate.gov/general/contact_information/senators_cfm.cfm.

²⁹ Contact information for Representatives: <http://www.house.gov/representatives/>.

³⁰ USA.gov: Governors. <https://www.usa.gov/state-governor>

³¹ U.S. Congress. <https://www.congress.gov/state-legislature-websites>

³² Conference of Mayors. <http://www.usmayors.org/meetmayors/mayorsatglance.asp>

³³ USA.gov: Local Governments. <https://www.usa.gov/local-governments>

³⁴ Committee on Ways and Means. <http://waysandmeans.house.gov/contact/>

receive email alerts from the House Energy and Commerce Committee, visit their website³⁵ and follow the instructions.

There are no email distribution lists for the Senate committees of jurisdiction (i.e., Senate Finance Committee and Senate Health, Education, Labor, and Pensions (HELP) Committee). However, you should note whether your federal representatives sit on these important committees of jurisdiction. His or her position on these committees amplifies your voice should you contact your federal representative.

State Legislative Committees

Not all state legislatures have committees of jurisdiction. However, if they do, we suggest the following steps to determine which of your state government's committees of jurisdiction host email lists:

- 1.) Visit the websites for your State House of Representatives and your State Senate.
- 2.) Locate a listing and description of the committees in each chamber, and determine which committees oversee healthcare, long-term care, and LTSS.
- 3.) Search for websites of the identified committees of jurisdiction. Visit these websites to determine whether they host email lists.

Email distribution lists for state and federal regulatory agencies

Federal Agencies

- 1.) The Centers for Medicare and Medicaid Services (CMS): CMS is the agency within the U.S. Department of Health and Human Services (DHHS) of greatest relevance to long-term care administrators. CMS issues notices of proposed rulemaking (NPRMs) to solicit comments from the public on the impact of the specific regulatory language and how the agency should adjust the language before the rule is final law, as noted in Chapter 1. Long-term care administrators should keep informed of these NPRMs and contribute their voice during the comment phase. To sign up for NPRMs and other regulatory notifications from CMS, visit the "About Us" section of their website³⁶ and click "Receive email updates." After entering your email address, select the box, "Regulations and Guidance," to assure your email will receive all new regulatory news. You can also browse other topic areas and select those that are of personal interest.
- 2.) Department of Health and Human Services (DHHS): Beyond CMS, there are other agencies within DHHS that interact with the provision of medical and non-medical services to older adults in non-institutional settings. In particular, the Administration for Community Living (ACL, formerly the Administration on Aging, Administration for

³⁵ House Energy and Commerce Committee. <https://energycommerce.house.gov/subscribe-ec-emails>

³⁶ CMS: About Us. <https://www.cms.gov/About-CMS/Agency-Information/Aboutwebsite/EmailUpdates.html>

- Children and Families Administration on Developmental Disabilities, and the Office on Disability) is meant to support older adults who continue to live in their own homes and communities. ACL combines the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the HHS Office on Disability into one federal agency that serves older adults and people living with disabilities across their lifespan continuum.³⁷ ACL does not offer an email distribution list. However, to stay informed of the rules released by ACL and other agencies within DHHS, visit the DHHS webpage, “Comment on Open Rules.”³⁸ This is a central location to find all DHHS agencies with rules open for public comment.
- 3.) Department of Veterans Affairs (VA): The Veterans Health Administration (VHA) is the health services arm of the VA. The VHA is the largest integrated health system in the country. VHA Geriatrics and Extended Care Services (GEC) serves older veterans by promoting their independence and reducing the burden of their disability on veterans, their families, and caregivers.³⁹ Within the umbrella of these services is information and direction on how to select long-term services and supports and find long-term care facilities. To stay informed of Congressional news related to the VA and the GEC, visit the VA Office of Government Relations website and subscribe to receive email updates at the bottom of the home page.⁴⁰
 - 4.) Department of Labor (DOL): The Office of the Assistant Secretary for Policy (OASP) within the DOL advises the Secretary on policy development, program evaluation, regulations, budget, and legislation to improve the lives of workers, retirees, and their families.⁴¹ Given the labor-intensive nature of long-term care facilities, OASP’s rulemaking is of particular interest to long-term care administrators. To learn about the DOL’s regulatory priorities for the coming year, visit OASP’s webpage on rulemaking and regulations and select the “Unified Agenda of Federal Regulations” option.⁴²
 - 5.) Department of Commerce (DOC): The Department of Commerce promotes economic growth, technological competitiveness, and sustainable development.⁴³ Though the Department of Commerce has a very broad jurisdiction, long-term care administrators would be most interested in the industry-specific standards promulgated by the department. For regular email updates on news from the Department of Commerce, visit its website, where you will be automatically directed to sign up for regular email news.⁴⁴

³⁷ Administration for Community Living. “About ACL” http://www.acl.gov/About_ACL/Index.aspx

³⁸ DHHS. “Comment on Open Rules” <http://www.hhs.gov/regulations/comment-on-open-rules/index.html#>

³⁹ VHA. “Geriatrics and Extended Care Services (GEC)” <http://www.va.gov/geriatrics/>

⁴⁰ VHA. “Welcome to the Office of Governmental Relations” <http://www.va.gov/oga/index.asp>

⁴¹ DOL. “Office of the Assistant Secretary for Policy (OASP) Our Mission” <https://www.dol.gov/asp/mission-statement.htm>

⁴² DOL. “Rulemaking and Regulations” <https://www.dol.gov/asp/regs/rulemaking.htm>

⁴³ Department of Commerce. “Mission Statement” <https://www.commerce.gov/about>

⁴⁴ Department of Commerce. <https://www.commerce.gov>

- 6.) Consumer Financial Protection Bureau (CFPB): The CFPB is a federal agency that serves as a watchdog over banks, lenders, and other financial companies.⁴⁵ The CFPB produces tools and resources to help protect older Americans, who may be particularly vulnerable to financial scams. Nursing home administrators can turn to the CFPB for information on how to help residents protect their financial assets.

State Agencies

Given the localized nature of the regulation of long-term care facilities, state agencies may have oversight over the rulemaking that is most relevant to your daily management and operation of your facility. The relevant agencies differ by state, but there are clear starting points for a state agency search:

- State Departments of Health or Public Health
- State Departments of Human Services
- State Department of Aging Services or Disability Services
- State Departments of Labor or Wage and Hour
- State Department of Licensing

After determining the relevant rulemaking agencies in your state, visit their websites, and determine the best way to stay informed of their activity pertaining to policy development. This might be through email lists or regular newsletters.

⁴⁵ Consumer Financial Protection Bureau. <http://www.consumerfinance.gov/>

Chapter 3

Doing your Homework

Research the issue

When researching your issue, building a strong case in support of your policy position is essential when meeting with lawmakers or agency representatives. This often requires in-depth research into various aspects of your proposed policy position. Key questions to ask and answer include:

- 1.) Who are the other individuals or groups that might support this position? What information might they have to help you craft your message and affect decisions by policy makers? Sometimes, discovering partnerships with similar organizations strengthens your research by bringing in multiple viewpoints to support your policy. See Chapter 4 for more information on this.
- 2.) What is the impact of your stance or proposed policy? Determining who or what will be impacted, and how much, may help you frame the work you do with policy makers. It may also help you tailor your position based upon the legislator or agency with whom you're trying to work.
- 3.) What are you hoping to achieve with your policy? Is there a specific outcome you have in mind or a specific outcome you're trying to prevent from happening? You should consider the impact of your policy, but also the time: are your goals short-term or long-term? And if you're successful, what will be the short-term effects and the long-term effects of your policy? Clearly delineating these goals and effects will help you articulate your policy position when you meet with policy makers and will help you answer questions that policy makers might have.
- 4.) Is there a financial or fiscal cost to your position or proposal? In the world of tightening budgets, it is important to gauge the financial aspects of a policy change, realizing that it may be more prudent to wait for the right moment if your policy requires substantial financial resources from government sources. If you can demonstrate how to offset associated costs, this is often helpful to policy makers.
- 5.) Additionally, who might be an opponent of your policy? Who is the opposition and why do they oppose your position or what you've opposed? What is the best method to address their opposition? You may find it advantageous to involve opponents early on in the policy formulation process to work out differences in advance of approaching policy makers. This can be difficult work to find consensus, but a group of individuals from all sides of the table can have a bigger impact when affecting a policy change and it helps to eliminate any surprises when working to implement your policy.

Part of your research will involve answering the questions above. You may want to consider any potential information you could obtain from professional and trade associations (see Chapter 4) to use in preparation for meetings or for testifying before legislative committees. These associations may have knowledge of draft language of policy proposals, the anticipated effects of

a policy change, how issues may affect more than just one state or region, and how other organizations or regions are addressing the same or a similar issue. While having a honed message for the individual legislator's constituency or the specific subject matter over which an agency has jurisdiction is often wise, showing the magnitude of an issue or change in policy has merit, as well.

Research the policy makers or agencies you want to work with

While it is paramount to have in-depth knowledge regarding the particular issue you're working on and the effects your policy might have, you should also research who you're anticipating working with and their background as it relates to your issue of interest.

When meeting with legislators, it is important to understand which committee(s) a particular elected official belongs to. It is also important to understand the composition of each legislative committee that you might work with, including the chairperson (who is a member of the majority political party at the time) and the ranking member (who is a member of the minority political party at the time). While you may work with one person, keep in mind that the power shifts on these committees based upon the composition of legislatures and Congress following elections.

In addition to understanding the shifting power dynamics of committees, you should also understand an individual legislator's voting history. For both U.S. Representatives and Senators, you can easily search their voting history on each bill that has been presented before Congress. This is a window into their views on a particular issue, though it may not be the whole story (e.g., party politics might motivate a legislator to vote a certain way despite their personal feelings to the contrary). You can also research the voting history for state legislators by visiting the website for your state legislature and the websites of individual elected officials. Pay attention to their professional backgrounds (e.g., police officer, doctor, teacher, farmer), which may be another relevant point while you are advocating your policy stance or request.

Meeting with regulatory agencies can be more complicated, as there is less public information available for individual staff members of these agencies. You can research the public policy positions and information available on the public agency's website, including any NPRMs (see Chapter 2 regarding NPRMs) the agency may have recently published. Additionally, reading any public memorandums⁴⁶ (see **Appendix B**) or guidance issued by a federal or state agency will assist you in determining that agency's stance on a particular issue. As you work more with a particular agency, you will learn the staff members and their role in shaping policy. You will also discover ways that you can work with those individuals, including participation on task forces or workgroups that may form.

⁴⁶ CMS Policies and Memorandums to States and Regions. <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SURveyCertificationGenInfo/Policy-and-Memos-to-States-and-Regions.html>

Tell your story

Advocacy on issues requires that you craft an effective message and think of various methods you can use to deliver that message. Your audience may be as narrow as a select group of lawmakers on a particular committee, or as broad as the entire community at large. As part of telling a story that will yield results, you also need to understand your issue in-depth and understand who you will be working with to advance a policy change. This includes those who are proponents of your cause and potential opponents as well.

While facts and data are essential to supporting an advocacy initiative, the story that you tell can sometimes have a greater effect on shaping policy and changing the mind of policy makers. When you're meeting with legislators or staff members from federal or state regulatory agencies, it's important to agree on the "story" you'll tell in advance. Helpful guidance on this comes from the ACHCA Grassroots Advocacy Guide:⁴⁷

- 1.) **Who and What.** Succinctly describe who you are, why you are meeting with that particular policy maker, and what you're there to discuss.
- 2.) **Know Your Issue.** Ensure you have completed thorough research on the issue and the policy maker or agency you're meeting with (see below). You may need to get some supplemental information from state or national trade and professional associations to use during the meeting.
- 3.) **The Story.** Tell your side of the issue, or explain why you do what you do, in your own words. Reading from a template letter or generic information has less of an effect than an authentic story or experience that you communicate well. Be brief and concise. Give helpful examples to illustrate the point(s) you are making. Explain the policy that you want changed, or elaborate on how a potential change posed by that policy maker might affect you, your site, or your residents.
- 4.) **The Ask.** Sometimes you are asking for a change in policy to happen, or for a policy maker to abandon or alter a change in policy that's been proposed. Be clear on what you'd like and how that particular person or agency could help, including specific goals or language to present, where possible. Also, be reasonable – don't request the impossible.
- 5.) **The Closing.** Reiterate your stance or request to assure clarity, and provide contact information for the policy maker to use in the future for any questions or involvement in future work. It's usually a good idea to keep lines of communication open so that the policy maker knows you're a willing partner to help shape policy and someone they can rely upon as an expert in your given area.

⁴⁷ American College of Health Care Administrators. "Grassroots Advocacy for the Long Term Care Administrator Profession: A Step-by-Step Guide." Updated September 2014.

Chapter 4

Determining the Appropriate Approach

There are many ways to advocate for or defend against a specific policy change: schedule a visit with your federal, state, or local representatives regarding a specific piece of legislation; provide written comment on proposed rules from federal or state agencies; write letters or make telephone calls; work with coalitions to increase the depth of your advocacy voice; or organize a social media campaign to create broad-based awareness and public attention. The appropriate approach depends on timing in the journey from idea, to bill, to law, to implementation.

Ideation

Forming ideas and concepts that can turn into public policy

At the federal and state level, policy ideation is ongoing. Staffers of member offices and committees are working constantly, either proactively or reactively, to determine the best legislative or public relations response to a public policy issue. In federal and state agencies, staff are determining the best ways to implement new laws or to evaluate and improve upon existing policies.

The best ways to get involved during the ideation stage are to stay informed of what is happening in different legislative and executive offices (see Chapter 2) and to hone your networking skills. Establishing positive working relationships and maintaining personal connections will establish you as a valuable resource for policy staff. Through professional friendships, you will be viewed as a trusted ally and as a person that staffers will want to bring to the table when brainstorming policy solutions or fixes.

Bill text

Turning the idea into legislation

After conducting background research, brainstorming ideas with fellow staffers, working with the other Congressional chamber, soliciting bipartisan support, assessing the political environment, and soliciting feedback from key stakeholders, policy moves from an idea to bill text. This stage is ripe for stakeholder engagement, as draft bill text is only the starting point to gain broad-based buy-in and ultimately pass the bill so it becomes a law.

Remember, bills must be marked up in the committee of jurisdiction before they can move to the floor for a vote. Keep an eye out for committee hearings on topics related to issues of interest to you and your facility (e.g., long-term care and LTSS, Medicare and Medicaid financing). At the federal level, you may be able to watch committee hearings online and submit your comments for the record by following the specific instructions.⁴⁸ Check out whether the

⁴⁸ See the Senate Finance Committee process as an example. Visit <http://www.finance.senate.gov/hearings>, select a hearing topic of interest, and follow directions listed on the website to submit your comments for the public record.

federal committees of jurisdiction (e.g., Senate Finance and Health, Education, Labor, and Pension (HELP) Committees and House Energy and Commerce and Ways and Means Committees) have a hearings section with directions on how to submit a public comment. You should also check whether your state legislative committees of jurisdiction (see Chapter 2 on State Legislative Committees) have a comment process for you to engage on hearing topics. Your timeliness in submitting a formal comment is integral, as committees usually establish comment deadlines shortly after a committee hearing.

Your engagement with proposed bill text can go far beyond participation in committee hearings. By paying attention to news from legislative offices and establishing positive relationships with member and committee staffers, you can contribute by getting in touch with the offices of your representatives and legislative committees. The bill text will provide you with an agenda and will help you develop a specific “ask” for the offices you communicate with (whether that communication happens in person, via formal letters, or through social media). It may be helpful to write a letter to your elected officials expressing the urgency of their vote, or informing them of the impact the proposed law or policy could have on you, your site, or your residents. Two helpful guides on writing letters to elected officials, including how to appropriately address the elected official, can be accessed from the Community Tool Box at the University of Kansas⁴⁹ or from the National Council of Teachers of English.⁵⁰ Also, see Chapter 5 for more on contacting elected officials through other means, plus several of the documents included in the Appendices at the end of this toolkit.

Once the bill text is finalized, schedule visits with your representatives to educate them on how the bill would positively or negatively impact the population you serve, the workforce you employ, or the long-term care professional generally.

Policy implementation

Turning law into practical policy

After a bill passes both chambers and is signed by the executive office, it becomes the law of the land. Usually, the law (i.e., statutes) authorizes a federal or state agency to carry out the provisions of the law. With this authority, agencies work to interpret the statutory language and draft a proposed rule based on that interpretation. Agencies may issue an Advanced Notice of Proposed Rulemaking (ANPRM) to formally engage stakeholders to contribute to the proposed rule. More often, agencies draft the proposed rule and then issue a Notice of Proposed Rulemaking (NPRM) as a formal call to the public to review the proposal and submit comments to the agency. Participation in the “Notice and Comment” period of policy implementation is the epitome of the democratic process. Any member of the public can participate (**see Appendix C for a sample comment letter on a proposed federal rule change**). It is important to remember deadlines for submitting comments, as agencies strictly follow these timelines. The federal and

⁴⁹ Community Tool Box (Chapter 33, Section 1). University of Kansas. <http://ctb.ku.edu/en/table-of-contents/advocacy/direct-action/letters-to-elected-officials/main>

⁵⁰ Writing Your Elected Officials. National Council of Teachers of English. <http://www.ncte.org/action/write-legis>

state rulemaking processes are largely similar, though the state process may not be as formal. Consult “A Guide to the Rulemaking Process,” prepared by the Office of the Federal Register, for more in depth information on federal rulemaking.⁵¹ Review “Know the Rules: An Overview of State Agency Rulemaking” for details on the state rulemaking process.⁵²

After agencies collect and assess all public comments, they release a final rule with an effective date on which the rule holds as the final version of implemented policy. It is important to review the final rule in depth, as it discusses the agency’s thought process on drafting the final language based on stakeholder feedback.

If you are unsatisfied with the final rule, you always have the opportunity to share feedback with the agencies, which may issue technical assistance documents in response to widespread concern or uncertainty with certain provisions of the final rule. If you believe the finalized policy requires a statutory change, then you can work with your representatives and the relevant committees of jurisdiction to advocate for the advancement of a new bill. Remember, your participation in the policy making process lasts over the life span of the policy in question, and your relationships with staffers in Congress and agencies should be just as long-standing.

Partnering with national and local organizations

Increasing your impact through power in numbers

Regardless of timing, you should always partner with national and local organizations. Such partnerships are a great way to stay informed of policy issues that are relevant to your residents, employees, or profession. More importantly, partnerships increase your voice, drawing more attention to your cause through the sheer power of numbers. You can form partnerships through memberships of organizations (e.g., professional organizations for long-term care administrators) or through participation in coalitions. To find these coalitions, pay attention to whether there are co-sponsoring organizations at events hosted by your member organizations. These are the groups that are most likely to care about issues similar to your own, and they might be members of the same coalition. You should also determine whether your member organizations have an advocacy arm, which frequently directs members to partnering organizations and broader coalitions.

⁵¹ Office of the Federal Register. “A Guide to the Rulemaking Process”

https://www.federalregister.gov/uploads/2011/01/the_rulemaking_process.pdf

⁵² Change Lab Solutions. “Know the Rules: An Overview of State Agency Rulemaking”

http://www.changelabsolutions.org/sites/default/files/Know_the_Rules_FINAL_20150709.pdf

Chapter 5

Media Relations and Using Social Media

How to involve the media

ACHCA provides a helpful overview of the importance of media relations for successful grassroots advocacy efforts. This section on involving the media is largely drawn from ACHCA's Grassroots Advocacy Handbook.⁵³

It Pays to be Proactive

If you have a positive story to tell, you want to make sure that it gets media coverage. For that to happen, you have to be proactive. Media outlets will not come to you automatically.

Normally, you have to work to get noticed. To increase the chances of getting attention, you have to continually disseminate your name and the long-term care subject you want covered by a given media outlet.

The appropriate contact and submission procedures for each media dissemination tool are different, and it is important to determine these differences in advance of engaging with a given media outlet. Later in this chapter, we will identify the general process for engaging with the media via social media outlets, press releases, letters to the editor, and op-ed pieces.

Cultivation Helps

Cultivation is the critical but hidden characteristic of successful media relations. There is no magic to it. You simply need to be organized, thorough, clear, timely, persistent, and willing and able to understand and meet the needs of media.

The following suggestions will help in your efforts to work with media sources:

- 1. Be organized.** Create a contact list of your local health beat reporters and update it regularly to account for changes. You don't need to have news to call them up. Instead, you can contact them with the purpose of learning which stories are of most interest to them and how they like to receive information. If possible, try to schedule an in-person meeting to cultivate a positive working relationship. This thoughtful gesture should tell the media outlet that you probably are someone they should think about using as a source. As part of the visit, leave behind general information about you and your facility. This will set the stage for greater receptivity, interest, and empathy for your perspective when a long-term care story breaks in the news.

⁵³ American College of Health Care Administrators. Grassroots Advocacy for the Long Term Care Administration Profession: A Step-By-Step Guide.

https://achca.memberclicks.net/assets/docs/ACHCA%20Advocacy%20Booklet_140916%20r.pdf

2. Be thorough. Pay attention to what your local media covers and how they cover it. Follow what news they highlight and what they editorialize about to get a good idea about what they consider important. If they run a dry statistical account of an issue, perhaps you could suggest a human interest angle as a follow up story. Watch for the coverage they announce or preview — it may give you ideas for spin off stories to suggest as well as opportunities to write a Letter to the Editor or an Op-Ed. Make sure that any material you disseminate to the press is error-free (common mistakes: typos, incorrect spellings, wrong names) and has complete contact information. Also, make sure that everything is accurate. If you are the least bit unsure of something, leave it out or don't mention it until you can confirm its accuracy. One inaccuracy can create distrust that can hamper your media relations.

3. Be clear. Two basic points you should be clear about are 1) what is your news/story about, and 2) why should your local media be interested in it? If you can't readily and succinctly answer both questions, chances are you will have difficulty prompting media coverage.

4. Be timely. Using a simple calendar, you can easily predict the more opportune times for attempting to get the media interested in long-term care stories. Appropriate timeframes include the end of year holidays, the onset of legislative or budget-setting sessions, public observances devoted to aging or some relevant aspect of health care delivery (e.g., Long Term Care Administrators Week, third week of March annually), and assumption of office by senior officials. Be proactive and contact the media about your story ideas at least a month in advance. Reporters live and die by deadlines. Return their calls promptly. Quickly provide whatever information they need. Your goal is to make their lives easier. Doing so will make reporters more inclined to remember you as a helpful resource worth contacting again in the future.

5. Be persistent. For fair and regular coverage, you have to be dogged. You can increase the odds of succeeding in obtaining media coverage by approaching as wide and diverse a universe of potential media outlets as possible. Bear in mind that, in the interest of making an effort for fresh perspective, editors sometimes direct their reporters (or reporters direct themselves) to change sources. This is another reason to diversify. Remind yourself that how you're doing today is hardly a predictor of how you'll do tomorrow. In general, the media is open to ideas case by case. Think through in advance your reasons for suggesting a story. Don't be shy about promoting your story, but don't carry on to the point where you turn people off. You want to be greeted with interest when you go back to reporters with another idea.

6. Be willing and able to meet the needs of the media. If your local paper wants a five-hundred-word op-ed piece, give them 500 words. If you know that the media in your community favor certain emphases to stories, frame your ideas using those emphases. If they want contact information with cell phone numbers, have the numbers appear. If

they need to talk to sources or have information by certain deadlines, meet those deadlines.

Steps like these will not only increase your odds of succeeding, but they will also boost your standing as a source.

Coordinating with legislators and their staff

In general, legislators, committees, and their staff have their own communications teams or staff that issue press releases, op-eds, or otherwise engage with the media. It is important to respect this process. As the *ACHCA Grassroots Advocacy Handbook* points out, you need not involve the press about a meeting or event you participated in or arranged for unless the legislator or committee specifically requests it. Press coverage could inhibit staff from sharing advice and information.⁵⁴

After a meeting or event takes place and is safe to become public knowledge, you should consider publicizing the meeting with a press release. However, first inform your legislator or committee's office of these plans. Coordinate this with communications staffers, who may make available a list of district media outlets or may be issuing their own press release, which you can use to draw greater attention to your own public communication.⁵⁵

Posting on social media sources

Social media has revolutionized the way organizations communicate with the public.⁵⁶ Common social media platforms include Facebook, Twitter, Instagram, Pinterest, and Tumblr, but new tools are unveiled every week.⁵⁷

The recommendations that follow are drawn from the American Association of University Women (AAUW) social media resources for insight on how to best leverage social media tools and create a social media advocacy strategy.⁵⁸

As you develop your organizational strategy, keep in mind that social media is a conversation, not a monologue.

⁵⁴ American College of Health Care Administrators. *Grassroots Advocacy for the Long Term Care Administration Profession: A Step-By-Step Guide*.

https://achca.memberclicks.net/assets/docs/ACHCA%20Advocacy%20Booklet_140916%20r.pdf

⁵⁵ Ibid.

⁵⁶ National Rural Housing Coalition. *Advocacy Toolkit: Social Media Advocacy 102*.

http://ruralhousingcoalition.org/wp-content/uploads/2013/03/Advocacy-Toolkit_Social-Media-Strategy_05132014.pdf

⁵⁷ American Association of University Women. *Social Media 201: Leveraging Social Media to Increase Your Visibility*. <http://www.aauw.org/resource/how-to-use-social-media-for-advocacy/>

⁵⁸ Ibid.

Creating a Social Media Strategy

The first step in using social media is to create a strategy. Here are some helpful tips:

- 1. Set your objectives.** Is your goal narrow (publicizing a notice of proposed rulemaking) or broad (building and engaging with a community or coalition)? Clarify the exact [call to action](#) that you want to elicit from your campaign.
- 2. Identify the audience you would like to reach.** Who are you speaking to? Who is most likely to be moved by your content? These are important questions to answer, since your message — and the way you tell it — should differ based on your intended audience and include different content depending on who you want to reach.
- 3. Define your message.** What story are you telling? Be clear on what kind of values, problems, solutions, and actions are involved.
- 4. Choose the social media platform(s) that make the most sense.** Different social media platforms have [vastly different demographics](#). For example, Twitter users tend to be more young and urban than Facebook users, and Pinterest users overwhelmingly tend to be women. Decide which platforms to use by thinking about the specific objectives and intended audiences for each of your campaigns or efforts. The most popular social media platforms are Facebook and Twitter, so focus on those if you plan to use only one or two platforms. Later in this section, there will be more information about how to use Facebook and Twitter as advocacy tools.
- 5. Creating a social media account.** Depending on your advocacy strategy, you may want to create accounts for social media as a single community, as an entire coalition, or as part of a larger professional association. It is fairly simple to set up social media accounts as long as you have an email address. However, it is important to develop “Page Roles” for individuals who will run your social media accounts. Consult the AAUW Social Media 101 guidebook for further information on drafting social media page roles.⁵⁹

General Principles for Using Social Media

Be genuine. Determine the tone of your messaging. Let your personality show and use humor when appropriate. Try not to simply broadcast; rather, when possible, speak as an individual, to individuals. This will help grant you credibility as a trusted source.

Stay focused. The people and organizations that follow you on social media have certain expectations about the type of content you post and the way you engage with them. If you stray too far from your objectives, you will lose the trust and attention of your community.

⁵⁹ American Association of University Women. (November 2016). Social Media 101: Getting Started with Facebook and Twitter. <http://www.aauw.org/resource/social-media-handbook/>

Be reliable. Share quality content from trusted sources, and avoid amplifying erroneous messages from unreliable sources. Reliability also means posting to your social media services regularly. Frequently sharing reliable, meaningful content helps establish you as an important source of information and ideas for your community.

Get social. Above all else, social media is about conversation. Share and comment on other people's or organizations' posts to start new conversations, and join in the conversations that are occurring on your social media pages. The more you engage with your followers, the more they will understand that your priorities are their priorities, too.

Facebook

Keep it short and sweet — really short! Most Facebook users skim their newsfeeds, so they're most likely to interact with content that is brief and concise. Facebook posts of [up to just 40 characters](#) — a few words, or a short sentence at most — generate the highest engagement.

Make it visual. Photos and images are overwhelmingly the [most engaging type of content on Facebook](#), generating a whopping 87 percent interaction rate from page followers. Avoid text-only Facebook posts at all costs, and be sure to [include an image whenever possible](#).

Post regularly. The more you engage with your audience, the better off you will be. Try to post to your Facebook Page at two or three times a week, but not more than once a day. To help with the lift, you can [assign posting privileges](#) to multiple people, and you can use the [Facebook scheduling tool](#) to schedule out your content for the week.

Activate your biggest fans. Every time an individual shares, likes, or comments on posts on your Facebook page, your page is made visible to that individual's own Facebook friends. That means potentially hundreds of users see your content! Encourage your organization's members to share and like your posts. It's an easy lift with huge rewards. You can also encourage them to [turn on "notifications"](#) to find out whenever there is new content on your page, so that they can be sure not to miss a beat.

Promote your advocacy events. You can easily [create events on your Facebook Page](#) and invite your Facebook friends, who can then invite their friends, and so on. Consider creating a Facebook event to advertise events such as coalition meetings, advocacy days, and deadlines for submitting comments on newly proposed rules.

Twitter

Use the right hashtags. If you're not using [hashtags](#), you're more or less talking to a brick wall. Don't let that happen. Avoid creating your own hashtags, since it's incredibly hard to create hashtags that take off. Instead, do some research to [identify popular hashtags](#) about your advocacy mission. You can look at the Twitter accounts of other

long-term care facilities, coalitions, and professional associations to see which hashtags are popular and useful. Don't forget to use local hashtags. For examples, specific hashtags often exist for state and local elections. Jump onto those existing hashtags to amplify your work and message.

Tweet regularly. Don't appear inactive. It's best to tweet not more than once every hour. If you're just starting off, aim to tweet at least once a day, or about five to ten times a week. The key is not falling dormant. To help with the lift, use a free tool like [Hootsuite](#) or [TweetDeck](#) that allows you to schedule tweets.

Make it visual. You can get a [150% increase in retweets](#) just by attaching images. Try to [attach an image](#) to a tweet whenever possible, even if it means shortening your word count. Remember to snap photos at your events, and tweet them live.

Perform direct outreach to key influencer groups. Social media is all about interaction. If you follow an account, that user will receive a notification and will likely follow you back. Follow, follow, follow! It's also important to reach out to these accounts directly about your work. The goal, of course, is for them to engage and share your message.

Community collaborators. Tap into the right audiences. Be sure to follow your [local community groups](#), and reach out them with links and information about relevant events and advocacy issues. Don't be shy – it's [highly effective](#) to ask accounts to retweet your links. Retweets help your message reach entirely new networks, so the payoff is invaluable.

Members of the media. Find the Twitter accounts for local [journalist and bloggers](#), and tweet them links to your events, announcements, or press releases. Many journalists list their Twitter handles in their bylines, or you can Google the journalist's name and the word "Twitter" to find it.

Elected officials. Twitter is a great way to interact directly with elected officials, who are often highly active on the platform. Working on a petition, pushing for legislative action, or looking to thank a politician for her or his vote? Tweet the official with your message. You can also write a sample tweet and encourage your followers to tweet the link or message to the elected official.

Spread the word about your work and programming. Just as with Facebook (and any other social media outlet), you always want to direct users to visit content on your own website or content that is about your work. Tweet links to your events, announcements, and press releases. You can also tweet articles about your advocacy message and any news you receive from relevant email distribution lists.

Press releases, letters to the editor, op-eds, and other media suggestions

This section provides an overview of the general process for engaging with the media via press releases, letters to the editor, and op-ed pieces. Content here is largely drawn from the Hospice Action Network's Mini Guide for Media Advocacy for suggestions on how to successfully leverage these media tools.⁶⁰

Press Releases

A press release is a timely, one-page announcement about breaking news, a newsworthy policy issue/statement, activity or event issued to the media immediately following the occurrence.

Follow these steps drawn from the Hospice Action Network when writing your news/press release:

- 1. Start with the "Release Date."** This tells the reporter when the information on the release can be published or broadcasted. The document can be released immediately to the public, in which case you can put "For Immediate Release: 00/00/00" at the top of the page with the current date. Reporters can also hold the information until a future date. In that case, you would need to put "Embargoed Until: 00/00/00" with the date the information is to be released. The release date is typically located on the top left-hand corner.
- 2. Place your contact information in the top right-hand corner of the page.** This includes your name (or the name of the person handling media inquiries), a phone number, and your email address.
- 3. Next, write your headline.** A headline is a short phrase summing up the essence of the release. Example: Congressman Visits Local Hospice Program
- 4. Then, include a "dateline."** The dateline is the location of the story, which usually includes the city/town and state. Example: ALBANY, NY – A bill signed into law today ensures access to quality and compassionate end-of-life care for the 1.4 million patients and families who seek hospice care each year.
- 5. The body of your press release will follow the dateline.** This is where you will tell the reporter/editor the "who, what, where, when and why" of your story. Your release should follow a "pyramid" style of writing, where the most important information or newsworthy "hook" appears first, and is followed by supporting information. This writing style is necessary for any news materials, because your readers (reporter/editor) are busy and receive many different pieces of news. The reader may not have time to get through

⁶⁰ Hospice Action Network. Media Advocacy Basics: A Mini Guide for Hospice Advocates and Professionals.

the entire page, so you must give the most important information – the reason why they should pursue a story – at the beginning.

6. The first paragraph, the “lead,” should be the most powerful. This is where you should tell the most important information of the release, in order to get the interest of the reporter/editor reading it.

7. Keep your sentences and paragraphs short and use plain language. Avoid acronyms and jargon. Also, you should try to keep your release to one page.

8. Be sure to include a quote. This puts a human face on the news you write. The quote should substantiate the lead, be from a significant person, and add value to the point of the release. Try to place the quote in the first three or four paragraphs of the release.

9. Finish with a “tag.” This is usually one paragraph of “boiler plate” information about your organization and its involvement with the issue covered in the release.

10. End. Reporters/editors look for a symbol (### or -30-) at the end of a release to let them know that the release is complete. If your release is more than one page, it is important to add “—more—” at the bottom of the first page to indicate that there is another page to the release. These symbols (### or -30-) and instructions (--more--) should be centered at the bottom of the page.

11. Photos. Photos from a meeting or an event can be helpful in getting coverage. Digital copies are the easiest to submit. Include a brief caption that has information about the people in the photo, and the purpose of the event. (Note: Notify your contact that you will be emailing a photo before you send it. Emailed photos often weigh down a system, or may get caught up in a “spam” filter file.)

See Appendix D for a sample press release.

Letters to the Editor

Letters to the Editor are written to a newspaper editor by a private citizen or organization in response to content covered by the press outlet. Generally, these letters are no more than 250 words in length.

Here are a few things to keep in mind, before you start crafting your letter to the editor:

A letter to the editor can be used to:

- Impact policy/legislation;
- Generate coverage of an issue;
- Correct factual inaccuracies;

- Deliver a specific message; or
- Change behaviors.

Tips for writing a letter to the editor:

- Before writing, be clear about what message you want to convey.
- Refute or support specific statements; address relevant facts that have been ignored.
- Support your facts, but keep it concise.
- Make it pointed and punchy.
- Keep your letter to 250 words or fewer.

Here are some steps to follow when writing a letter to the editor:

1. Start with the salutation. A good salutation is “Dear Editor.”

2. Choose ONE ISSUE for your letter. Example: “Two cuts are too much for the hospice community to absorb and continue to effectively provide compassionate and quality, end-of-life care.”

3. Write a sentence or two identifying your organization and/or interest in the issue. Example: As an employee of hospice I have learned and studies have shown that, when faced with a life-limiting illness, most people are more concerned about the impact it will have on their family, not themselves. Hospice care, like that provided by Hospice of Central Iowa, allows patients to live their last days completely and without pain while helping their families treasure final moments.

4. Write one or two sentences of background information. Example: November is also National Hospice Month, a time to raise awareness of quality end-of-life care. With the hospice system currently facing two big cuts—a regulatory cut proposed last year and enacted last month as well as the projected health care reform reductions—this is more important than ever.

5. Write one or two sentences on your opinion. Write a sentence or two about your story if you feel comfortable. Example: If passed, many Iowa hospices will be forced to close our operations or severely limit service areas. This is particularly so for those living in rural areas, where hospice care is often the most expensive to deliver.

6. In one or two sentences, offer a solution and encourage readers, policy makers, etc. to take a specific action (i.e., contacting an elected official, voting a certain way). Example: I urge everyone in our state to contact Senator Charles Grassley and Senator Tom Harkin to tell them that “Two Cuts Are Too Much for Hospice!”

7. Add your full name and contact information (phone, address, and email) to the end of your letter.

See Appendix E for a sample Letter to the Editor.

Op-Eds

Op-eds are opinion pieces written by a newspaper or magazine's reader on issues relevant to the outlet's audience. These are typically no longer than 750 words in length and published opposite to the editorial page.

Here are a few things to keep in mind, before you start crafting your op-ed. An op-ed piece can be used to:

- Impact policy/legislation;
- Generate coverage of an issue;
- Correct factual inaccuracies; or
- Deliver a message.

Tips for writing an op-ed:

- Before writing, be clear about what message you want to convey.
- Keep your op-ed between 500-750 words (most newspapers and online publications have guidelines that fall within this range, but it might be worthwhile to contact your local media outlet to find out what their limit is before you start writing).

Follow these general steps when writing your op-ed piece:

1. Choose ONE ISSUE for your Op-Ed. Make sure you present the information in a way that qualifies you as an expert on this issue, highlighting relevant knowledge, background and supporting data.

2. Identify a significant problem. Search for a specific problem within your issue that clearly threatens the general public or at least some large segment of that public. You must focus. Clearly identify the problem, the audience it affects and how you might go about solving it.

Example: Before hospice, I had a series of frequent, short-term hospitalizations, followed by periods of being at home with no support services. Now, with in-home hospice care, I have intensive support from a nurse, social worker, physical therapist, chaplain, and volunteers, with family members providing ongoing care, and a hospice doctor providing overall supervision in consultation with my primary care doctor. Hospice staff is available on call 24 hours a day, seven days a

week. If these programs are cut, patients like me will be forced to revert back to constant, costly short-term hospital care with no in home support – we will suffer!

3. Write a bold opening statement. Open your op-ed by making a bold statement or asking a pointed question that forces the reader to read on. Make sure it is punchy and hard-hitting because the opening statement is you one chance to grab the reader. It will determine the focus of your article. It will dictate the evidence you offer to support your statement.

Example: Insurance companies and drug companies make billions of dollars in profits, but when Congress has gone looking to cut “waste, fraud, and abuse” in the health care sector why have they focused instead on programs that operate on tiny budgets such as hospice programs.

4. Continue writing your first paragraph. You should spend a lot of time on this. Weigh whether or not you would read-on if you saw the first paragraph of your piece in the paper. It never hurts to have a friend or trusted acquaintance read the paragraph to see how it flows.

5. Defend your statement. Use facts and statistics, but only those that apply directly to your statement. Don't go off on tangents. Space is limited so you will need to craft clear, concise arguments in support of your bold opening statement.

6. Cite sources and be emotive. To prove that your assertions can be proven include references to documents, studies, surveys, public statements, white papers, books, articles and the like to mirror your point. Keep in mind that facts provide the reasons to agree with the statement, but emotion moves people to take action. No emotion, no action. That's just how the human mind works.

7. Propose a solution. Wrap up your story by proposing at least one clear, bold and practical solution to the problem you have identified. Proposing a solution to the problem demonstrates that you aren't just complaining, but that you actually have crafted a solid advocacy argument. Sidestep proposing a solution and you will lose your audience.

See Appendix F for a sample op-ed piece.

Other Media Suggestions

Increasingly, publications are switching exclusively to emailed submissions of things like Letters to the Editor and Op-Ed pieces. Be sure you check first. Simply call the main number, succinctly say who you are and what you want to send in, and then ask for the name of the recipient and the procedures involved. The operator may be able to help you, or you may get routed forward.

This is simpler than it may sound and it is necessary. You can have the most compelling information imaginable, but it may end up discarded as soon as it's received simply because you didn't follow the correct procedures.⁶¹ Below are specific distribution suggestions for press releases, letters to the editor, and op-eds from the Hospice Action Network.

A. Press Releases

Once your media advisory or press release is written, getting it into the right peoples' hands is of utmost importance. Here are a few things the Hospice Action Network suggests you should consider when determining how to disseminate your press release:

- **Social media** is becoming an increasingly comfortable and convenient way to engage within communities and expand professional and personal networks. Reporters for newspapers and publications – both big and small – have embraced social media tools as a way to disseminate and more importantly, receive news and story ideas. Twitter is currently among the most popular forms of release. If you have an existing Twitter account:
 1. You'll want to make sure you are following a few (at least two) health/health policy reporters at your local papers, or general reporters if you're in a smaller city or town. Make note of their Twitter handles.
 2. Develop a "hook" or short description of the information you are submitting as news, no more than 100 characters in length (e.g., "Hospice Care of SC Pres meets with Sen. Jim DeMint about hospice and health policy on the Hill" (95 characters)).
 3. After you've developed your "hook," you will want to post your advisory or press release to a landing page on your hospice Web site and copy and paste the URL for that landing page.
 4. Then, go to www.tiny.cc (or another website that will shrink your URL) and input the link into the input area and click the "tiny" button. Copy your new tiny URL; add it to the end of your "hook" (e.g., "Hospice Care of SC Pres meets with Sen. Jim DeMint about hospice and health policy on the Hill <http://tiny.cc/x5yjl>").
 5. Next, you can EITHER Tweet to the specific reporter you are interested in approaching about your story by adding his/her handle to the beginning of your tweet OR do a broad tweet to all of your followers.
 6. Lastly, monitor those publications to see if your tweets result in a story.
- **Email and Fax** are more traditional and still very effective means of disseminating your media tools if social media is not an option for you (depending on the reporter preferred contact method). If emailing a press release, it's most important to put the text of the release into the body of the email. Avoid sending emails with attachments to reporters as

⁶¹ American College of Health Care Administrators. Grassroots Advocacy for the Long Term Care Administration Profession: A Step-By-Step Guide.
https://achca.memberclicks.net/assets/docs/ACHCA%20Advocacy%20Booklet_140916%20r.pdf

they are likely to be caught by spam filters and may not be delivered to the intended recipient.

B. Letters to the Editor and Op-Eds

After spending hours crafting the perfect letter to the editor or op-ed, getting it printed can be a little complicated. Here are a few things the Hospice Action Network suggests you keep in mind when trying to get your pieces placed in local media:

- Only send one letter to the editor or op-ed at a time. Editors prefer not to be inundated with opinion pieces from a single source.
- Do not send query letters or call editors to discuss op-ed ideas.
- In most cases, completed letters to the editor or op-eds should be sent by fax or email, especially if the piece is timely and could become dated quickly. Check the specific newspaper's submission policies for their preference on this.
- Op-ed editors are busy people. Many will call to let you know they plan to use a piece, but very few will contact you if they reject your submission. You should keep phone calls to editors to a minimum, and definitely not make them near the end of the day when the editor is working hard to meet his deadline.
- While inundating an editor is taboo, you can consider following up with the editor a week or so after submission to ask if the op-ed is under consideration. Think of your follow-up call as an opportunity to educate the editor about the issue -- even if your op-ed is not published. If your rapport is good, suggest a meeting or ask if there is a reporter who should get a copy as background on the issue. The result could be a relationship with the editor, which will prove helpful for the future.
- If your op-ed is published, make sure to clip it, make a copy including the name of the paper and date it was published, and send it to the policy makers you hope to influence, and professional associations.
- Submitting the same letter to the editor or op-ed piece to multiple news outlets is strongly discouraged as most news outlets want to publish exclusive, original content. If you would like to submit opinion pieces to different outlets on the same topic, it is strongly encouraged that you craft differing letters highlighting the same key points.

Resources

Advocacy 101: Getting Started in Health Education Advocacy

Regina A. Galer-Unti, Marlene K. Tappe, and Sue Lachenmayr (2004)
Health Promotion Practice (Sage Publications)

Almanac of American Politics (available for purchase online)

- This is a reference work published biennially by Columbia Books and Information Services. It provides a detailed look at the politics of the United States by profiling individual leaders and areas of the country.

American College of Health Care Administrators (ACHCA)

- Grassroots Advocacy for the Long-Term Care Administrator Profession (2014)
<http://www.achca.org/>

American Health Care Association/National Center for Assisted Living (AHCA/NCAL)

- Information for Policymakers: <https://www.ahcancal.org/Pages/Policymakers.aspx>
- Advocacy: <https://www.ahcancal.org/advocacy/Pages/default.aspx>
- Care Advocacy: <http://cqrcengage.com/ahca/home>

American Public Health Association (APHA)

<http://www.apha.org/policies-and-advocacy/advocacy-for-public-health>

Association for Supervision and Curriculum Development (ASCD)

- ASCD Advocacy Guide
http://www.ascd.org/ASCD/pdf/siteASCD/publications/advocacyguide_2009_web.pdf

C-Span: Congressional Committees/Hearings, Members, Votes, and Bills

<https://www.c-span.org/congress/>

Communicating with Members of Congress

<http://www.contactingthecongress.org/>

Congress

Search for recently-introduced and existing legislation: <http://www.congress.gov>

Finding your U.S. Representative/Senators, Committee Listings, and the Congressional schedule

<http://www.house.gov> (U.S. House of Representatives)

<http://www.senate.gov> (U.S. Senate)

GovTrack

Track pending legislation in Congress and progress in committees

<https://www.govtrack.us/>

Independent Sector

- “Beyond the Cause: The Art and Science of Advocacy” (Section I: Essentials of Successful Advocacy)
<https://www.independentsector.org/advocacy-resources>

International Council of Nurses

- Promoting Health: Advocacy Guide for Health Professionals
<http://www.whcaonline.org/uploads/publications/ICN-NEW-28.3.2010.pdf>

LeadingAge

http://www.leadingage.org/LeadingAge_Grassroots_Connector/

National Association of Long-Term Care Administrator Boards (NAB)

<http://www.nabweb.org/all-topics>

National Low Income Housing Coalition

- Advocates’ Guide (2016)
<http://nlihc.org/library/guides>

National Psoriasis Foundation

- Medicaid Advocacy Guide for Medical Professionals
<https://www.psoriasis.org/health-care-providers/medicaid-advocacy-guide>

Salsa Labs

<https://www.salsalabs.com/amazing-advocacy-guide>

State Legislatures

Please see recommendations in this Advocacy Toolkit on how to locate information on and contact information for representatives and/or senators in your state legislature.

University of Kansas: Community Tool Box (Chapter 33, Sections 1 – 3, 6 – 8, and 10 – 11)

<http://ctb.ku.edu/en/table-of-contents/advocacy/direct-action/letters-to-elected-officials/main>

Voting Records

<http://www.votesmart.org>

World Health Organization (WHO)

- “Stop the Global Epidemic of Chronic Disease: A Practical Guide to Successful Advocacy”
<http://www.who.int/chp/advocacy/chp.manual.EN-webfinal.pdf>

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- American College of Health Care Administrators (ACHCA)
<http://www.achca.org>
- American Health Care Association/National Center for Assisted Living (AHCA/NCAL)
<https://www.ahcancal.org/Pages/Default.aspx>
- Golden Living
<http://www.goldenliving.com/>
- Life Care Services (LCS)
<http://www.lcsnet.com/>
- LeadingAge
<http://www.leadingage.org/>
- Health Care Administration Program, University of Wisconsin – Eau Claire
<http://www.uwec.edu/academics/college-business/departments-programs/management-marketing/academic-offerings/majors-minors/health-care-administration.cfm>
- Milken Institute School of Public Health, The George Washington University
<http://publichealth.gwu.edu/>
- National Association of Long-Term Care Administrator Boards (NAB)
<http://www.nabweb.org/>
- The Wertlieb Family

This advocacy guide is a production based upon ideas generated at the National Emerging Leadership Summit (NELS), an annual gathering of health and aging services administrators in Washington, D.C. This guide is intended to assist individuals in proactive, positive policy making on both the state and national levels as it relates to the field of health and aging services. The information contained in this toolkit will be routinely updated and is not intended to be comprehensive. If there are additional items to include, please contact Dr. Kevin Hansen (hansekev@uwec.edu) at the University of Wisconsin – Eau Claire, Health Care Administration Program, with your information to add.

Appendix A: Sample Email Communication from ACHCA



CMS Updates & News

CALL FOR TECHNICAL EXPERTS: TRANSFER OF INFORMATION AT POST-ACUTE CARE ADMISSION AND DISCHARGE QUALITY MEASURES

CMS is currently soliciting nominations for technical expert panel members for quality measures developed under the Improving Medicare Post-Acute Care Transformation Act of 2014 (IMPACT Act) to meet the domain of the transfer of health information and care preferences. The quality measures, Transfer of Information at Post-Acute Care Admission, Start, or Resumption of Care from Other Providers/Settings, and the Transfer of Information at Post-Acute Care Discharge or End of Care to Other Providers/Settings were developed for the Long-Term Care Hospital, the Inpatient Rehabilitation Facility, the Skilled Nursing Facility, and the Home Health Agency settings. CMS is seeking technical experts with expertise in care transitions and information transfer during transitions, quality improvement, and performance measurement, among other areas of knowledge.

The call for technical expert panel members is open from August 8th through August 21st, 2016. For more information, visit the [Technical Expert Panel webpage](#).

CMS BEGINS NEW 5-STAR RATING CALCULATIONS

CMS issued [new star quality ratings](#) for nursing homes around the country. The ratings are based on Medicare claims and nursing homes' own reporting. CMS has added five new measures that are being gradually factored into its nursing home star ratings intended to help consumers research and compare the quality of facilities. The new measures, primarily tied to the outcomes of short-stay residents, are based on both Medicare claims and data self-reported by nursing homes.

The five activated measures are:

1. Percentage of short-stay residents who were successfully discharged to the community (based on Medicare claims and MDS)
2. Percentage of short-stay residents who have had an outpatient emergency department visit (based on Medicare claims and MDS)
3. Percentage of short-stay residents who were rehospitalized after a nursing home admission (based on Medicare claims and MDS)
4. Percentage of short-stay residents who made improvements in function (based on MDS)
5. Percentage of long-stay residents whose ability to move independently worsened (based on MDS)

The sixth new quality measure, the antianxiety/hypnotic medication measure, has not yet been activated because the agency is still exploring appropriate nursing home benchmarks, noted a [CMS fact sheet](#). To learn more about the quality measure specifications, refer to the [CMS Quality Measures User's Manual](#).

CMS BOOSTS SKILLED NURSING PAYMENTS BY 2.4%

Skilled nursing facilities will see an estimated 2.4% payment increase - a total of \$920 million - for fiscal 2017, according to a [final payment rule](#) released by CMS. [Read more from McKnight's](#).

Appendix B: Sample Memorandum from CMS

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
7500 Security Boulevard, Mail Stop C2-21-16
Baltimore, Maryland 21244-1850



Center for Clinical Standards and Quality/Survey & Certification Group

Ref: S&C: 17-06-NH

DATE: November 4, 2016

TO: State Survey Agency Directors

FROM: Director
Survey and Certification Group

SUBJECT: Fiscal Year (FY) 2015 Minimum Data Set (MDS) Focused Survey Summary

Memorandum Summary

- The Centers for Medicare & Medicaid Services (CMS) has completed the FY 2015 MDS Focused Surveys and is providing an overview of the results.
- The FY 2015 MDS Focused Survey Summary outlines the background for the MDS Focused Surveys, the types of deficiencies and errors identified on these surveys, and provides technical resources for providers to help improve accuracy and help providers maintain compliance to enhance the safety and quality of care nursing home residents receive.

Background

Federal regulations for the Resident Assessment Instrument (RAI), including the MDS 3.0 and the Care Area Assessments (CAAs), are found at 42 CFR 483.20, and the guidance is found in Appendix PP of the State Operations Manual (SOM). These requirements apply to all Long Term Care (LTC) facilities participating in Medicare and Medicaid.

The primary purpose of the resident assessment and MDS 3.0 is to serve as the clinical basis for individualized care planning and delivery of person-centered care. The MDS 3.0 also impacts resource utilization group (RUG) scores and associated Medicare, Medicaid payment rates (in some cases), quality monitoring such as the Skilled Nursing Facility (SNF) Quality Reporting Program (QRP), and more. In addition to being used for quality monitoring through survey activities and facility quality assurance, MDS 3.0 data forms the basis for the facility's quality measures (QMs), including the subset of the publicly-reported measures used in the *Five-Star Quality Rating System* on the *CMS Nursing Home Compare* website. Assessment accuracy has a critical role in all of the aforementioned outputs. The assessments are paramount to optimizing person-centered care planning and to ensuring each resident is able to attain or maintain the highest practicable physical, mental, and psychosocial well-being. Over the last few years, several activities related to assessing the accuracy of MDS 3.0 assessments have occurred.

In 2012, the Office of Inspector General (OIG) performed a review of nursing facility records and found that one-third of the records reviewed did not contain evidence of compliance with Federal requirements regarding resident assessments.¹ Also in 2012, the OIG reported that SNFs misreported information on the MDS for 47% of claims reviewed.²

In 2014, CMS, together with five volunteer States, piloted a short-term focused survey to assess MDS 3.0 coding practices and its relationship to resident care in nursing homes. After completing the pilot, CMS announced we would expand these surveys to be conducted nationwide in 2015. The surveys were also conducted in conjunction with CMS' efforts to strengthen the *Nursing Home Five-Star Quality Rating System* (see press release at <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2014-Press-releases-items/2014-10-06.html>).

In October 2015, the Government Accountability Office (GAO) reviewed QMs that are calculated using MDS 3.0 assessments, and recommended CMS establish and implement a clear plan for ongoing auditing to ensure reliability of data self-reported by nursing homes, including payroll based staffing data and data used to calculate clinical quality measures based on the MDS 3.0.³

Based on the above activities, the MDS 3.0 Focused Surveys will continue to be conducted through FY 2016 and FY 2017. Additionally, we are providing information on the results of the surveys conducted in FY 2015 and technical advice so that facilities can learn from the findings and improve the accuracy of the MDS 3.0 assessments they conduct.

FY 2015 Results

Below is a summary of the results from the MDS 3.0 Focused Surveys conducted in FY 2015. These surveys also included a review of facility compliance with the requirements for nurse staffing posting.

Scope and Severity:

The majority (56%) of deficiencies were cited at a scope and severity level of "D", followed by an S/S of "E" (25%). This translates to a severity level of no actual harm with potential for more than minimal harm that is not immediate jeopardy, and a scope of isolated and pattern, respectively. Below is the percentage of deficiencies found at each level of S/S.

Scope and Severity Level	Percentage of Deficiencies
B	5%
C	11%
D	56%
E	25%
F	3%
G	1%

¹ OIG, *Nursing Facility Assessments and Care Plans for Residents Receiving Atypical Antipsychotic Drugs*, OEI-07-08-00151, July 2012

² OIG, *Inappropriate Payments to Skilled Nursing Facilities Cost Medicare More Than a Billion Dollars in 2009*, OEI-02-09-00200, November, 2012

³ GAO, *Nursing Home Quality*, GAO-16-33, October 2015

Top Cited Deficiencies:

Across the scope and severity levels, there were 56 different deficiencies (F-tags) cited. The more frequently cited deficiencies are listed below.

- F278 – MDS Accuracy
- F356 – Posted Nursing Staffing Information
- F279 – Develop Comprehensive Care Plans
- F329 – Free from Unnecessary Drugs
- F314 – Treatment/Services to Prevent/Heal PUs
- F315 – No catheter/Prevent UTI/Restore Bladder
- F274 – Comprehensive Assessment after Significant Change

Common Errors:

For deficiencies cited for MDS Accuracy (F-278), surveyors found trends in the types of coding errors that occurred. Below is a short summary of the most common errors found during the investigations.

- Antipsychotics:
 - Coding inconsistent for residents with and w/o antipsychotics
 - Incorrect number of days administered
- Restraints: Residents w/restraints not coded as having a restraint
- Falls: Residents not coded to reflect a fall when a fall had occurred
- Urinary Tract Infections (UTI)
 - Incorrect coding based on UTI criteria in RAI Manual
- Continence/Catheters:
 - Coding inconsistent with residents with and w/o a catheter
 - Residents coded as having a catheter with no diagnosis
 - Coding inconsistent with residents' actual state of continence
- Pressure Ulcers:
 - Coding inconsistent with residents with and w/o pressure ulcers
 - Pressure Ulcers not coded at the correct stages
 - Coded as healed when not healed
 - Incorrect number of pressure ulcers coded
- MDS Quarterly, Comprehensive (annual), and Significant Change in Status Assessment (SCSA):
 - Not completed timely or not completed at all

For deficiencies related to posted staffing (F-356), surveyors found that the most common reasons for noncompliance were that the staffing posted was not up to date, and staffing records were not retained for 18 months, per regulation (42 CFR 483.30(e)).

Resources for Improved MDS Accuracy and Compliance

In addition to assessing compliance with federal regulations, CMS aims to help providers maintain compliance to improve the safety and quality of care nursing home residents receive. Therefore, based on the findings of the MDS focused surveys, we are providing several resources nursing homes may access to help improve compliance:

Appendix C: Sample Comment on Proposed Rule from Federal Agency



State of Minnesota
Office of the Ombudsman for Mental Health and Developmental Disabilities

121 Seventh Place East, Suite 420 ■ Saint Paul, Minnesota 55101-2117

Voice: (651) 757-1800 ■ Toll Free: (800) 657-3506 ■ Fax: (651) 296-1021 ■ TTY/Voice – Minnesota Relay Service 711

November 15, 2010

Social Security Administration
Office of Regulations
137 Altmeyer Building
6401 Security Boulevard
Baltimore, MD 21235-6401

To whom it may concern,

The Minnesota Office of the Ombudsman for Mental Health and Developmental Disabilities is charged under Minnesota Statutes §§ 245.91 – 245.97 with promoting the highest attainable standards of treatment, competence, efficiency, and justice for persons receiving services or treatment for mental illness, developmental disabilities, chemical dependency, or emotional disturbance.

This agency is writing to the Social Security Administration (SSA) to comment on the Revised Medical Criteria for Evaluating Mental Disorders; Proposed Rule (Docket No. SSA-2007-0101). The agency would like to commend the SSA on its work to modernize the terminology and approach used in the evaluations of those with either a mental illness or an intellectual or developmental disability.

The clientele this Office serves benefits greatly from Federal monetary assistance through social security funds, and the process by which the eligibility for those funds is determined is essential for the continued success of agency clients in remaining out of facility-based settings. This agency is appreciative of the new approach to determining a client's eligibility based upon a functional test of his or her abilities. This is essential, as many clients have abilities that extend beyond their labeled diagnosis, and some that function below what the standard may be for their illness or disability. In addition, the included signs and symptoms that are written in for the examiners' usage are fair, useful, and accurately reflect the current approaches with mental illness and developmental or intellectual disabilities.

Again, this Office commends the SSA on the beneficial approach to the evaluation of a client's need for assistance. However, there are concerns regarding the standardization of test results and the scores a client must have on those tests to receive assistance. These concerns are largely based upon the set minimum scores a client must have, which appear to be largely unattainable for the vast majority of clients this agency serves. There are few tests which can reliably measure a client's ability to work. The proposed changes require examiners to determine a client's degree of mental functioning and subsequently determine his or her ability to work based upon that level of mental functioning. It has been the experience of staff members in this Office that a client's ability to function in a work setting largely depends on the environment in which he or she works, the persons who are providing support services, and the nature and thoughtfulness put into the design of the support services or accommodations.



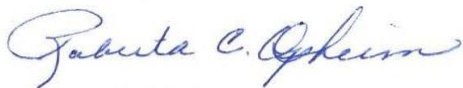
Serving Minnesotans receiving services for:
Mental Illness Developmental Disabilities Chemical Dependency Emotional Disturbance

The test under the proposed rule requires that the client's score be two standard deviations below the mean for the level of functioning to be determined as "marked" and three standard deviations below the mean to be determined as "extreme." This increase in the qualification to receive services would ultimately result in many clients of this agency not being eligible for the necessary supports and services that allow them to function as independently as possible in high-independence, community-based settings. This ability to remain as independent as possible, in the most non-supervised setting as possible, is extremely important to the mental well-being of these individuals and contributes to the success in staying out of facility-based settings, saving both the state and Federal governments in taxpayer funds. These changes not only affect adults with illnesses or disabilities, but also children who are in the developing stages and need additional assistance to ensure proper growth and support services to grow up healthy and prevent further illness or declination of health in the future.

Again, there are many good things included in the proposed changes, but there are substantial concerns regarding the proposed testing requirements as well as the standards which are proposed for eligibility within those tests. Under this proposed rule, there would be many individuals in Minnesota, as well as across the United States, who would not be able to work or have the necessary supports and services through Federal disability benefits, causing some to rely more heavily on state-provided services and causing some to do without services they need to be independent and successful. This agency hopes you will take these concerns seriously and work with those who have raised this issue to determine an amenable solution to the standardized testing methodology.

If you have any questions about the clients we serve or if you need any further information, please don't hesitate to contact this Office. Contact information is below in the signature block for your use. Thank you.

Respectfully submitted,



Roberta C. Opheim
State Ombudsman
Office of the Ombudsman for Mental Health and Developmental Disabilities
121 Seventh Place East, Suite 420
Saint Paul, Minnesota 55101-2117
(651) 757-1800 or (800) 657-3506
roberta.opheim@state.mn.us

Appendix D: Sample Press Release from Hospice Action Network

FOR IMMEDIATE RELEASE:
April 21, 2010

CONTACT: Dawn Teachey
Ph: (803) 555-4444
Email: dteachey@hsc.org

SOUTH CAROLINA HOSPICE CEO ADVOCATES ON CAPITOL HILL FOR PATIENTS & FAMILIES FACING END-OF-LIFE

Dawn Teachey asks Congress to Protect Access to Compassionate and High-Quality End-of-Life Care

Spartanburg, S.C. – Dawn Teachey, CEO of Hospice Care of South Carolina and over 400 other Hospice Advocates from across the nation this week urged Congress to protect access to compassionate and high-quality end-of-life care for all Americans. Teachey joined her fellow advocates in Washington, D.C. as part of the National Hospice and Palliative Care Organization's (NHPCO) Capitol Hill Day 2010.

Teachey met with Senator Jim DeMint (R-SC) to discuss the value of hospice care to patients and their families in South Carolina. During the meeting, she encouraged Congress to support efforts to stop cuts to hospice programs nationwide especially smaller programs in more rural areas.

"Following health care reform and the cuts the hospice community are slated to sustain as a result of Medicare payment reform, Hill Day was a great opportunity to educate our Members of Congress about the value that we as hospice providers bring to [Insert state] patients and families facing the end-of-life," Teachey said.

Over the past two years, the hospice community has been facing rate cuts on two fronts — regulatory cuts enacted in October 2009 that eliminated a key component of the Medicare hospice reimbursement known as the Budget Neutrality Adjustment Factor (BNAF) and more recently, cuts slated to be enacted in 2013 as a result of the health care reform bill passed last month. This year, they are working together to educate policy makers on how the hospice community will be impacted by the combined 14.3% reductions.

"In the aftermath of health care reform, NHPCO's Capitol Hill Day 2010 was just the beginning of our efforts this year to educate Members of Congress on the hospice community's value and uniqueness as compared with other health care provider groups. Over 1.4 million patients and their families depend on compassionate end-of-life care from hospice programs in communities throughout the country," said J. Donald Schumacher, NHPCO president and CEO. "It is important that Congress know the importance of hospice to their constituents so they can take an active role in preserving compassionate end-of-life care for generations to come."

For more information on Hospice Care of South Carolina, visit www.hospicecare.net, and to learn more about NHPCO's Hospice Action Network and the hospice community's advocacy efforts nationwide, visit www.hospiceactionnetwork.org.

Appendix E: Sample Letter to the Editor from Hospice Action Network

November 18, 2009

RE: Health Care Reform and Hospice, National Hospice Month

Dear Editor:

November starts the season of reuniting and celebrating with loved ones. As an employee of hospice I have learned and studies have shown that, when faced with a life-limiting illness, most people are more concerned about the impact it will have on their family, not themselves. Hospice care, like that provided by Hospice of Central Iowa, allows patients to live their last days completely and without pain while helping their families treasure final moments. Thus, hospice plays a critical role in the lives of millions of people nationwide.

November is also National Hospice Month, a time to raise awareness of quality end-of-life care. With the hospice system currently facing two big cuts—a regulatory cut proposed last year and enacted last month as well as the projected health care reform reductions—this is more important than ever. If passed, many Iowa hospices will be forced to close our operations or severely limit service areas. This is particularly concerning for those living in rural areas, where hospice care is often the most expensive to deliver. Therefore, I urge everyone in our state to contact Senator Charles Grassley and Senator Tom Harkin to tell them that “Two Cuts are Too Much for Hospice!”

As a community, we need to fight for those who cannot fight for themselves and ensure that hospice is available now and for generations to come. Everyone can do this easily by following the link from www.hospiceofcentraliowa.org. Less than five minutes of time can make a difference.

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Appendix F: Sample Op-Ed from Hospice Action Network

DON'T CUT HOSPICE TO FINANCE HEALTH CARE REFORM

Insurance companies and drug companies make billions of dollars in profits. But when Congress has gone looking to cut "waste, fraud, and abuse" in the health care sector, why have they focused instead on programs that operate on a tiny budgets, such as hospice programs? Could it perhaps be because these programs lack the millions of dollars that lobbyists are spending daily to protect big corporate profits?

As a hospice patient diagnosed with end stage COPD (chronic obstructive pulmonary disease), I have a unique view as to the value of these services, both in saving money and improving quality of life. Unfortunately, because of the taboos around open and frank discussions about death and dying (exactly the kind of counseling that became demonized as "death panels" during the whipped up hysteria of last summer) many families don't get the opportunity for a realistic discussion of their options as a person nears death. Because of the slow and unpredictable course of my disease, I have now been in hospice care for nearly a year; most people enter hospice programs within only the last few weeks of life, and therefore are less able to advocate for these programs.

I have benefited enormously from being a hospice patient. Before hospice, I had a series of frequent, short-term hospitalizations, followed by periods of being at home with no support services. Now, with in-home hospice care, I have intensive support from a nurse, social worker, physical therapist, chaplain, and volunteers, with family members providing ongoing care, and a hospice doctor providing overall supervision in consultation with my primary care doctor. Hospice staff is available on call 24 hours a day, seven days a week. My medicines and durable medical equipment are provided with no out of pocket costs, through the Medicare "hospice option." The hospice philosophy is focused on quality of life—as defined by the patient—which helps me achieve my self-defined goals. Hospice staff has provided support that has enabled my partner and I to go away for weekends, to attend social and cultural events in the community, and to fulfill as many of my wishes as possible during my final months of life. The guiding philosophy of hospice staff is "what can we do to help you achieve your goals?"

Hospice care is not only cheaper than my frequent hospitalizations, it is also better for dying people who have chosen to focus on quality of life rather than pursuing an elusive "cure." (Of course, patients who wish to continue receiving intensive medical and surgical interventions, rather than hospice care, should continue to receive the services they choose.) Why, then, when Congress is looking to find "extra" money to fund health care reform has it zeroed in on home care and hospice programs, which would appear to promote exactly the values embodied by reform? Helping people to access the care best suited to their needs, and which are cost-effective, are the kinds of programs we need more of, not less! Every dollar that is saved keeping people out of expensive hospitals and nursing homes when they can get the care they prefer should be used to enlarge these programs so they can meet demand. Indeed, surveys show that most people would prefer to die at home while in fact the majority of deaths take place in hospitals. Instead, small agencies are forced to struggle to serve the patients they now have, and may not be able to meet current need, let alone expand to reach all the people who can benefit from their services.

Judi Chamberlin is a hospice patient. She blogs about her experiences at <http://judi-lifeasahospicepatient.blogspot.com>