**Capitol Hill Plenary**

**Lori Smetanka Remarks**

**November 8, 2017**

As you have heard from the presentations this morning, the Nursing Home Reform Act was a monumental and life changing piece of legislation. The hallmark principles that the law espouses – individualized care, person-centered care, consumer engagement, informed consent, and taking into account preferences in care and treatment – have made a tremendous difference in the lives of nursing home residents.

These standards should be universal – they should apply to all people receiving care and services regardless of the setting. We are beginning to see these principles being incorporated into rules developed for other settings – for example, in the Home and Community Based Settings Rule, issued by CMS and which applies to settings that are not institutional in nature. For the first time, these rules define person-centered care and require that it be incorporated into care planning and implementation. These HCBS rules are just starting to be implemented and we still have a long way to go until these principles are universally applied to all care recipients.

Implementation of care standards has not been without challenges. We know there are still many residents who are not benefiting from the nursing home standards that were issued 30 years ago. Standards are only so good on their own. In order for them to be meaningful, they need to be implemented and enforced. And we know the system is lacking in this area.

This causes great concern with what will happen with the new emergency preparedness regulations that are about to go into effect. Twelve years after being collectively horrified by the deaths of residents as a result of Hurricane Katrina, we are about to have comprehensive, stringent regulations go into effect. But will they be enforced? How? Just two short months before these regulations went into effect, 14 residents died in Florida as a result of a facility not being appropriately prepared for the contingencies that might arise from the hurricane. And when the Governor’s office issued emergency rules requiring all nursing homes to have generators in place within 60 days, the nursing home industry sued to prevent them from implementing those rules.

We are also facing real threats to the current, newly released nursing home regulations. With an eye on providing flexibility to providers and reducing provider burden, a push by the industry and by CMS is ongoing to revise or roll back provisions in the regulations. Less than one year after the rules went into effect, efforts began to roll back provisions.

We, as consumer advocates, need to step up and make our voices, and those of the people we are working for, heard. Not only reactively, in response to policies that we don’t like, but proactively – having recommendations for what we want to see and how to get there.

What do we want to see?

**We want quality standards implemented and enforced in a timely way.**

* Current efforts to delay implementation and enforcement of regulations are harmful to residents. The vast majority of these regulations have been longstanding requirements. In fact, in the preamble to the rules, CMS noted that it was surprised at some of the comments which reflected lack of provider understanding about the rules and reiterated that most requirements had been in place for almost 25 years. Development of these revised rules was a multi-year process covering multiple opportunities for all stakeholders – providers, professionals, consumers – to give input into areas that should or could be revised. When the proposed rules were released, CMS received more than 10,000 comments that were carefully considered and justification provided for all provisions that were accepted or rejected.
* Requirements relating to mandatory reporting of suspicions of crimes, despite being passed as part of the Affordable Care Act and effective in 2012 are still not being implemented in nursing facilities. Language requiring this reporting was included in Phase 2 of the nursing facility regulations, but it is at risk of further delayed implementation by CMS.

**We want full implementation of all provisions of these rules with no delay.**

**We also want effective oversight and enforcement that takes into account the true impact on residents.**

* The vast majority of complaint investigations result in no citation of noncompliance, and only 5% of deficiencies that are cited reflect actual harm to residents. Yet deficiency statements themselves reveal a different story. The under-coding of deficiencies is a documented, long-standing problem that serves to minimize the effect of poor care on residents.
* Noncompliance needs to be called and coded for what it is – including when actual harm exists – and appropriate enforcement actions put into place.
* CMS and state survey agencies need to stop tolerating poor performing facilities. Research continues to show that many nursing homes are not adequately meeting the needs of residents; and that a significant percentage of residents are likely to experience some form of adverse event after entering a nursing home. Ombudsmen, citizen advocates, and consumers regularly report facilities that, year-after-year, come in and out of compliance for the same issues. Yet providers continue to complain about burdensome regulations, about their inability to absorb the cost of increasing numbers of staff or installing generators that could prevent significant harm or death to residents. **At some point we need to stop accepting excuses and begin holding providers who voluntarily get into this multi-billion dollar, taxpayer funded business accountable for the care and services provided to a vulnerable, susceptible population.**

**We want the principles of person-centered, individualized care applicable in all settings – including assisted living, home care, and other community based services.**

* Standards and quality in assisted living and other community based services vary widely, in part due to a lack of national standards. We need to raise the bar in demanding quality, individualized care in each setting, as deserved by each person receiving services.

There are Immediate challenges to implementation of the regulations supported by a powerful interest group: Provider associations calling for delays and revisions to specific sections of the rules. And letters were sent to CMS from 120+ members of the House and 30 Senators.

* Challenge to retain the regulations may seem daunting. We advocates have been in this position before. Once in strong advocacy to develop and implement the Nursing Home Reform Law. And also years later, launching another major advocacy effort to preserve the federal law when it was targeted for elimination.
* How did we prevail during those times?
  + Strong Consumer advocacy, grounded in real experiences buoyed by stories from actual residents about their experiences,
  + Relentlessly contacting members of Congress and CMS, and keeping the pressure on to do what’s right for residents;
  + Engaging in public awareness activities, including media attention, and focusing on the impact on individuals and caregivers,
  + And also by highlighting examples of good providers that are already doing what was required.

**We need to do the same today!**

Consumer Voice is working hard using each of those steps to defend the regulations and fight for better care in nursing homes. Urgent action is needed here. Your being here on Capitol Hill, talking to your members of Congress today is an important step in protecting the regulations.

**When you go home:**

* keep the pressure on your survey agencies, and on CMS regional offices to fully implement the requirements.
* Use every opportunity to insert as many of the federal regulations into your state regulations as possible or talk about the need to incorporate specific federal provisions into your state regulations every time there is an opening to mention the need.

**In addition,** we as advocates need to ramp up our efforts in other settings. Be involved and vigilant in applying individualized, person-centered care in HCBS. Become or stay involved in the dialogue in your state, educate consumers, identify issues and propose recommendations/solutions to policy makers and providers. Consumer Voice is doing the same and has resources to assist you.

**We appreciate the hard work each of you has undertaken to do the same. As we’ve been reiterating throughout this conference – We Will Move Forward Together!**