



**Consumers for Quality Care, No Matter Where initiative
National advisory council meeting**

**January 3, 2013
2:00 pm Eastern
Agenda**

Dial-in number: 1.866.490.1502

Code: 7909949987

On the call:

- Deb Merrill, National Association of States United for Aging and Disabilities
 - Eric Carlson, National Senior Citizens Law Center
 - Sherri Culp, Bluegrass/Nursing Home Ombudsman Agency
 - Consumer Voice Staff: Robyn, Sara
1. Initiative update
 - a. 3rd national conference call: November 14, 2012 – From Consumer Voices to Advocacy Action
 1. The purpose of this call was two-fold: 1) we informed participants about how consumers assess quality and the policy implications of what consumers believe is needed to achieve quality long-term services and supports at home; and 2) we also taught participants key skills for turning policy recommendations into advocacy action. Two hundred and thirty-nine people registered for the call.
 - b. Consumer Input Council: December 11, 2012
 1. We held the first meeting of our newly formed Consumer Input Council. The purpose of this council is to give participants an opportunity to regularly provide Consumer Voice staff members with feedback about their experiences with home care. That information will help guide the Consumer Voice in its policy work. In addition, participants will receive regular policy and advocacy updates and opportunities to take action themselves. During our call in December we asked consumers questions regarding their workers. Twenty-nine consumers registered for the call.
 - c. Pilot state update
 1. New Mexico: The New Mexico Advisory Council is seeking a sponsor for a legislative resolution to establish a state study committee to examine the need for expansion of the long-term care ombudsman program to home care consumers. A t set of talking points to use when speaking with a possible sponsor has been created.
 2. Ohio: The Ohio Advisory Council is in the process of determining how it might conduct advocacy related to Ohio’s dual eligibles demonstration project and a

conference call/webinar to educate consumers about home care and build the advocacy network.

3. Vermont: The Vermont advisory council has prepared draft legislation that would create a state task force charged with developing recommended requirements for training/competency skills of personal care attendants. The legislation would identify the members of the task force and specifically lay out their responsibilities. The task force would also be required to make recommendations to the legislature and provide the legislature with interim reports as it does its work. The advisory council met with the Commissioner of the Vermont Department of Disabilities, Aging, and Independent Living to see if the agency would consider sponsoring this task force and will hear back in February, 2013. In the meantime, the advisory council members will approach state legislators about sponsoring the legislation.
4. Virginia: The Virginia advisory council is currently evaluating whether to focus its advocacy efforts on ensuring that appropriate consumer protections are in place if CMS approves Virginia's application for the dual eligibles demonstration program. The council is also discussing advocacy work that could be done during their current legislative session.
5. California: We surveyed the California Advisory Council to determine their level of interest and involvement in the council and evaluated the issues that are currently the focus of the group. With regard to our nursing home transition work, we are working on finalizing a draft of the report with the interview summaries and policy recommendations to the council in the next quarter, and then finalize it after receiving feedback. If the council decides to proceed with work on nursing home transitions, we will then develop an implementation plan by the end of the next quarter.

2. Pilot states & Duals Integration Demonstrations

- a. Is there a role that CV/state councils can play nationally or in VA, OH or CA?

Council members expressed two ideas:

- The way to have impact at this stage is to pick one or two issues that seem to have some general applicability and build them up and make enough noise that CMS may pay attention. Advocacy has to be in coordination with DC people who are having conversations with CMS. Down the road there can be advocacy on education and roll out issues which are going to be state-specific. From a Consumer Voice perspective, it depends on how deep our connection is with people on the ground. We need to pick a niche that works for us because there are so many groups already advocating on this issue, we want to make sure we're spending our efforts wisely.
- Advocacy efforts are fairly state-specific at this point in terms of exactly what they're going to do. There could be a way that the council could work on the broad picture. Education will be the key for consumers. The power is with many organizations working together.

3. Discussion of ideas for consumer resources at the national level

- a. Are there any resources or materials related to home and community based services that you think would be good for us to develop at the national level?

Council member ideas:

- Regarding services, it could be beneficial to develop a checklist of how to start the process of obtaining entry level care. This resource could identify the services that were available in their state, where do you go to apply, where to find out if you're eligible, etc.
- It would be helpful to have a resource explaining activities of daily living and inform consumers of the language used to describe what kind of services they might need. For example, getting into the tub vs. total bathing assistance.

- b. We'll work on a draft outline of these resources and ask for the National Advisory Council to provide us with feedback.

4. Council survey

- a. We thanked Council members for their involvement and informed them that we are conducting a short, 10 minute survey to help assess how they feel about the advisory council and the initiative and are hoping to send that out next week.

5. Upcoming events:

- a. Plan 4th national conference call for early 2013 – any ideas for topics?

Council member ideas:

So many states are adding managed care to their process. For consumers, this will be a significant change. It could be beneficial to have a call where we hear from states who have had managed care for a while. During this call, we could pull out all of the common elements of managed care - what does it look like, what are some basic ways you can advocate for yourself, how do you find out what your rights are. The key is the timing – is March the time, or would it be better to do it a little later in the year?

We could have a discussion about self-direction. We could get examples from different states, which could be eye-opening to hear what other people are doing. One issue is to the extent to which managed care and self-direction can co-exist. During this call we could talk about best practices, lessons learned, what worked, what didn't work, what you'd do differently, what you liked, what you didn't like, etc.

Next call: April 4, 2013 at 2:00 pm Eastern