



**Consumers for Quality Care, No Matter Where Initiative
National Advisory Council Meeting Notes
April 7, 2011; 2:00-3:30 pm Eastern**

Participants

Consumer Voice Staff

- Jessica Brill Ortiz
- Tina Steier
- Robyn Grant
- Janet Wells

National Advisory Committee

- Deborah Merrill
- Cecili Thompson Williams
- John Johnson
- Gail MacInnes
- Sally for Deb Holtz
- Eric Carlson
- Beverly Laubert
- Gordon Peters
- Linda Muckway

Introductions

- Deborah Merrill, Senior Policy Director, National Association of States United for Aging and Disabilities
 - Special interest in ombudsman program and nursing home issues; worked in Kansas ombudsman program; special interest in seniors and long-term care facilities
- Cecili Thompson Williams, Outreach Director, National Partnership for Women and Families, Campaign for Better Care
 - Look at delivery system of health care, focused on engaging activists and grassroots members, working with coalition members
- Sandy Markwood, n4a
 - Members provide support to caregivers and people receiving care; Older Americans Act, Meals on Wheels, and home supportive services
- John Johnson, Director, Federal Government Relations, SAGE
 - SAGE is headquartered in New York and has 21 affiliates across the country; constituency is LGBT older adults
- Gail MacInnes, National Policy Analyst, PHI National
 - Works to improve jobs of direct care workers; worked for NCCNHR

- Sally, MN regional ombudsman in MN; sitting in for Deb Holtz, MN State Long-Term Care Ombudsman, Office of Ombudsman for Long-Term Care
- Eric Carlson, Directing Attorney, National Senior Citizens Law Center
 - Deals with all aspects of HCBS
- Gordon Peters, Consumer, New Mexico
 - Involved because he had spinal surgery and spent some time in a nursing home for rehabilitation. Is currently receiving services in his home.
- Linda Muckway, Consumer, Indiana
 - Receives home care services; has experience with mother being in a nursing home and helped a neighbor in a nursing home; she knows about issues related to nursing homes i.e. understaffing, improper care
- Beverly Laubert, Ohio State Long-Term Care Ombudsman
 - Interested in serving on this committee because she wants to develop consumer advocacy in home care
- Overview of Consumer Voice staff roles
- Request for council members to share contact information for possible additional council members (i.e. consumers, members of minority organizations and members of disability groups)

Overview of Initiative and Initiative Goals (see description of initiative on state advisory council description)

- One committee member asked how the pilot states were chosen. Robyn and Jessica stated that the criteria included geography, diversity, percentage of Medicaid long-term care dollars spent on HCBS, strength of ombudsman program, presence of a Money Follows the Person program, and presence of a citizen advocacy group.

Role of Advisory Committee (see state advisory council description)

Meeting Dates (see meeting dates summary)

- For the first six months, calls will be on the first Thursday of the month from 2:00-3:00 pm Eastern
 - Starting January 2012, meetings will be quarterly

Status of Work in Pilot States

Consumer Voice staff provided an overview

- OH is the farthest along.
- Each state will have its own advisory committee. Thus far, three states have formed their committees (OH, VT, and NM) and had their first meeting by phone.
- VA is in process of forming its committee.
- In CA, we are approaching things slightly differently; we are working to find an issue that will resonate with people and then we will see what advocates and groups would like to be part of an advisory committee. It is a big state and there are many different aging and disability organizations present.

- State advisory committees identified that to get our policy work underway it would be more helpful to have at least one in-person work day - “Learning and Planning Day”
 - First one in April in OH; invite advisory committee and other people to talk about issues and develop related policy goals and strategies
- Robyn explained that we will focus more on the quality of HCBS; the issue of access is very important but we also acknowledge that there are many excellent organizations working on the access to services issue. We feel it’s important to focus on quality since it is such an important part of long-term services and supports and because we have many years of experience working on quality in nursing homes. We’re currently talking to states about issues related to quality HCBS. No issue has been selected yet for any of the states.
- Linda asked about the impact of health reform on the delivery of home care services. Robyn noted that we don’t know yet exactly how home care services will be affected but said the Consumer Voice and other organizations like n4a are monitoring this issue. John pointed out that there is good information on implementation of health care at www.healthcare.gov. He said that we need to keep track of what’s coming next. CMS is regularly issuing regulations or changes and they often have opportunities for comments. Those are opportunities to keep an eye on. Gordon noted that he is seeing cuts in the frequency and delivery of home care services.
- The OH advisory committee talked about the ombudsman program, which covers HCBS. Said people didn’t know they could even get HCBS.
- Looking for ways to partner with the Campaign for Better Care.
- The NM advisory committee talked about training for direct care workers, and the idea of credentialing. Gail explained that there are no national standards for direct care workers. Other issues in NM include lack of affordable and accessible housing (there is a long waiting list and people who have nowhere to go are sometimes forced into assisted living).
- In Vermont, the advisory committee discussed the issue of finding staff to provide support in the home, and someone who fulfills Medicare requirements. No one knew if there was a “matching” service that links consumers and workers. The group also indicated that there are problems with consistency with hiring staff. All issues discussed related to staffing.
- All pilot states are at different stages but they are moving forward. A committee member asked if the issues being identified come solely from the advisory committee. Robyn explained that an online survey and interviews with consumers are also being used to obtain information.

Beginning Discussion about Consumer Perspectives on Quality Care report

- We want to identify people in our pilot states who are receiving HCBS with the focus on services in the home. We will interview them and write a report. Project staff asked committee members for their thoughts on a number of different aspects of the consumer perspective work. The main ideas and discussion points were as follows:
 - How many consumers should we talk to?

1. Gail: Having personal stories can be so powerful. It would also be helpful to gather feedback from a larger number of people, to be combined with the personal stories. In terms of criteria, it's important to have a balance between older adults and younger people with disabilities, as their perspectives are different.
 2. Jessica: So you are suggesting we need more quantitative data that gives a broad overview and highlight areas with personal stories.
 3. Gail: Yes, if we just talk to small number of people, than there is a risk of just having their perspective and not being representative of the whole.
- Criteria for selecting consumers: Should we only interview people who receive services paid for through a Medicaid waiver? What about people receiving Medicaid home health care or people who hire their own worker and pay privately? There are many universes of HCBS.
 1. Gail: Which definition of HCBS are we using? From Older American Act?
 2. Jessica: We are not including assisted living in our definition of HCBS, for the purposes of this initiative.
 3. Gail: Are we referring to services of daily living or daily meals?
 4. Sandy: Give thought to this because it will show what types of people to survey. In looking at that consumer base, more active older adults to very frail people who are only in their homes and are not out and accessing community services. They're only getting home-delivered services. Activities of Daily Living (ADL) distinction - are you going to blend that? Are you targeting older adults or people with disabilities with extent their accessing HCBS? How are you going to frame this in the long-term?
 5. Cecili: The goal is to increase diversity of group. Given that, we need to go to groups that represent diverse communities and work with different organizations on the ground.
 6. Robyn: If anyone has anyone we could reach out to with those organizations, let us know.
 7. Cecili: Look at Campaign for Better Care coalition list and look at who to reach out to.
 - Interview questions
 1. Jessica: We are looking for information about questions that resonate with consumers and the kind of language that people respond to.
 2. Linda: The questions Robyn asked were pretty comprehensive. It covered more than one area of concern. Are you looking for narrowed down base? A starting place would be to use Robyn's interview questions.
 3. Bev: There have been satisfaction surveys with nursing home and assisted living residents and the Gerontology Center has done research and surveys. Will look at that and see if there's anything helpful in there.

4. Gail: AARP might be a good resource in terms of polling since they do a lot. You could contact Rhonda Richards.
 5. Cecili: When CBC launched, we did a poll and I can send you a link. People don't think they have a problem with the quality, so you need to avoid some phrases. I will take initial drafts to our polling people and have them look at it.
- Linda: When thinking about quality of home care services, you need to make sure to include homemaker services. I have experienced frustration with homemaker services.
 - Best way to conduct interviews given cost and geographic constraints
 1. Gordon: Where are the people we need to interview? They're coming out of nursing homes and hospitals. The obvious place to go would be organizations that are providing home healthcare, but how will they respond to a request to interview their clients about the quality of home care services?
 2. Bev: Intermediary might be AAAs or ADRCs. We would get both waiver clients as well as people who are receiving Older Americans Act services. Some of those might receive Medicare certified home health too. Those populations are more difficult to identify.
 3. Gail: What about contacting the Medicaid agency?
 4. Bev: That might be a possibility. A lot of people coming out of the nursing homes are using Money Follows the Person programs and going onto Medicaid waivers.
 5. John: Once you have a list of standard questions, it would make sense to reach out to large a number of people possible, AoA has an e-news list and we could send out a blast to these people and perhaps do a pitch with them to distribute the survey. We could also reach out to Meals on Wheels associations.

Additional Comments

- One council member said it would be helpful to quantify our goals.
- Council members suggested we provide an update to the council on what is going on in each state. Project staff agreed and will provide a monthly update on pilot state progress. Staff will also send out notes from this meeting and a list of council members with contact information.