

**Consumers for Quality Care, No Matter Where Initiative
National Advisory Council Meeting Notes
August 4, 2011 2:00pm**

On the Call:

- Gail MacInnes, National Policy Analyst, PHI National
- Kelly Buckland, Executive Director, National Council on Independent Living (NCIL), Consumer
- Robert Espinoza, Senior Director, Policy and Communications, SAGE
- Charlene Harrington, Professor Emeritus of Sociology and Nursing, University of California, San Francisco
- Eric Carlson, Directing Attorney, National Senior Citizens Law Center (NSCLC)
- Beverly Laubert, Past President, National Association of State LTC Ombudsman Programs (NASOP)
- Gordon Peters, Consumer
- Linda Muckway, Consumer
- Robyn Grant, Director of Advocacy & Outreach, National Consumer Voice for Quality Long-Term Care
- Jessica Brill Ortiz, Program Manager, National Consumer Voice for Quality Long-Term Care
- Alia Murphy, Program and Development Assistant, National Consumer Voice for Quality Long-Term Care

Status of work in pilot states:

- A written update was provided to council members.

National advisory council composition:

- Members discussed possible representatives from the veteran and Hispanic communities as well as consumers to invite to join the national advisory council.
 - Veterans
 - Perhaps someone from Paralyzed Veterans of America
 - Hispanic Community
 - Gordon will recommend some Hispanic organizations in New Mexico and check with the National Hispanic Museum in Albuquerque. Robert suggested reaching out to Latinos for Secure Environment.
 - Consumers
 - Members decided a good goal for the number of consumers on the advisory council would be about 40%.
 - Each advisory council member agreed to ask a consumer to join by the October meeting.

Home Care & Services Survey

- National version available online and through PDF
- Spanish version forthcoming
- Dissemination strategies and plans

- Gail will promote the survey through PHI's online newsletter
- Bev explained that in Ohio, they sent the survey link to the MFP and HCBS waiver contacts and they posted it on their consumer websites
- The Administration on Aging may want to disburse the survey nationally
- Kelly will place a link to the survey in the National Center for Independent Living's weekly newsletter
- Campaign for Better Care might have ways to promote the survey; need to follow up with Cecili since she's not on the call
- Consumer Voice will post the links to the survey

Consumer Advocacy National Training Calls

- Four calls (December 2011; April 2012; August 2012; January 2013) to focus on home care issues in key topic areas and strategies for effective advocacy
- Audience: consumers, citizen advocates and ombudsmen
- Role of advisory council is to suggest topics/speakers and to help promote the calls.
 - Initial ideas for topics and speakers
 - Informational call on current HCBS training requirements i.e. overview of national demonstration projects on training requirements in 6 states; practical session on how individuals can ensure they are trained as employers; how to work with caregivers
 - Overview of state programs and options for HCBS
 - How residents might approach assessment for HCBS; how to prepare, what level of service might be authorized, etc.
 - Information about National Partnership's Campaign

Consumer Perspective on Quality Care Report

- Consumer Voice staff presented the proposed audience and products for the report.
 - Policymakers
 - One-pager with policy recommendations (specific to each pilot state-5)
 - Advocates within the Consumer Voice network (e.g., ombudsmen, citizen advocacy groups (CAGs) and not within the Consumer Voice network (e.g., Friday Morning Collaborative)
 - Five-page or less data summary and consumer quotes and guidance on how to use the data, why it is important, etc. (specific to each pilot state-5)
 - Media and general public
 - Press release with key takeaway points that also sends people to the Consumer Voice website for more information and the Action Network (specific to each pilot state-5)
 - Consumer Voice members and network, current and potential funders and general public
 - Five-page or less summary report that shares what we found (lessons learned/similarities/differences in the data) from across the five states and makes the case for doing a national version of these reports

Comments from council members



- May be better to reach out to key reporters who are likely to do a story on the report, rather than a press release
- Perhaps we can do both a press release and outreach to specific reporters
- Conducting interviews: Where can we find volunteers to make calls? What needs to be included in training for volunteers?
- Finding consumers to interview
 - Discussion of how each advisory committee member can help to locate consumers in the 5 states

Next conference call: October 6, 2011; 2:00-3:00 p.m. Eastern