



State Culture Change Coalitions Networking Call Summary April 16, 2010

Topic: Involving Consumers in Coalitions

Present: Arlene Germain (Massachusetts); Amy Fletcher (Iowa); Annette Kelly (Florida); Bill Kubat (South Dakota); Bonnie Darwin (California); Heather Picotte (Michigan); Kim McRae (Georgia); Sonya Barsness (Virginia); Vickie Orcutt (Texas). Staff: Cathy Lieblich.

Cathy welcomed everyone and asked Arlene Germain to lead the discussion. Arlene described what Citizens Advocacy Groups (CAGs) are as she is the leader of the Massachusetts Advocates for Nursing Home Reform; an all volunteer organization. She explained that most CAGs have 501 C-3 nonprofit status and paid staff. The CAGs are usually either statewide or regional and their goal is to improve the quality of long-term care. CAG members usually consist of family members of residents, residents, advocates and long-term care ombudsman. Generally, less than 25% of CAG members are ombudsmen. CAGs are usually independent of providers or regulators. The CAGs around the country have recently formed the Coalition for Quality Care for such things as networking and letter writing campaigns. All CAGs are members of NCCNHR, and a list of CAGs can be found on the NCCNHR website at <http://www.nccnhr.org/advocate/advocacy-group-center>.

Arlene said that it is sometimes difficult to get consumers interested and involved in advocacy and culture change for many reasons, including not wanting to deal with long-term care issues until needed and conflicting time demands. Arlene shared that the Massachusetts coalition is starting an electronic newsletter that will include articles for providers and consumers. She said that the thrust of the Massachusetts coalition's educational program thus far has been for providers, but that they established a consumer subcommittee two years ago with Arlene representing the sole consumer advocacy group. The subcommittee developed a questionnaire regarding choosing a nursing home with a culture change perspective and a bookmark, and was instrumental in hosting and facilitating consumer discussion groups for the Picker project.

Arlene thought the best way to inform consumers about culture change would be through AARP, and hopes that AARP will become more involved now that health care reform was passed by Congress. Arlene stressed that citizen advocacy groups should be included in culture change coalitions, and she offered several suggestions for involving consumers. One idea is to invite leaders from existing consumer groups such as women's groups, Rotary, Kiwanis, AARP chapters, religious and humanistic organizations to be on a coalition consumer subcommittee to educate them about culture change, so they can mobilize their members/constituents. She suggested that if these organizations become invested in culture change, it may be possible to include culture change articles in their newsletters, and they could be a source for consumer forums. Another idea that Arlene has is to bring together residents and families that participate on nursing home culture change committees, maybe monthly or quarterly, via conference call so they can network with each other. Arlene said that consumers could become involved in the culture change movement in many different ways, such as advocating for culture change related legislation, distributing culture change articles to local newspapers, volunteering to help with fundraising, events, etc.

Annette said that the Florida coalition has restructured so that in addition to a Steering Committee, there is a Consumer Council and a Professional Council. The Steering Committee consists of the state level long-term care stakeholders plus two representatives each from the Consumer Council and the

Professional Council. The Consumer Council has some members but the Florida coalition will be recruiting additional members from those that indicated interested during the consumer discussion groups (Massachusetts, Florida, Georgia and Oregon were the pilot states). Vickie suggested that the coalitions have a presence at consumer health fairs to help get the word out. Arlene said that takes a lot of people power that a lot of coalitions might not have but would potentially have it if the consumer organizations that she mentioned are involved.

Sonya summarized the findings from the Pioneer Network's consumer education pilot, "Creating Home: Advocating for Change in How and Where We Age", funded by the Picker Institute as follows:

Background

- 2-hour meetings were held with small groups of consumers (about 9 people on average) in 4 states (FL, GA, MA, OR).
- Meeting goals were to create awareness and understanding of culture change, compare person-directed to traditional models of care, and encourage advocacy. From the pilot we (PN) wanted to better understand whether this meeting format was successful in educating consumers about LTC and culture change, and whether consumers were interested in getting involved.
- The curriculum included group exercises, discussion, and the showing of the video "Advocating for a New Old Age". Consumers were also given a 64-page guide that gave further information on long-term care, culture change, key questions to ask care settings about culture change and other information and resources.

Outcomes

- 61 meetings in 4 states with a total of 502 consumers and 45 hosts/facilitators
- Target audience was baby boomers- 54% participants in 50-65 range and 14% in 40-49 range.
- Participant experience with LTC varied, with 97% having had visited a nursing home or assisted living. For the 34% of participants currently caring for a family member, 35% indicated they lived in a long-term care community. For the 70% of participants who formerly cared for a family member, 52% lived in NH or ALF.
- Pre and post test evaluations indicated the strongest changes in knowledge/attitudes in 2 items: 1) consumers' increased understanding of the difference between traditional nursing homes and those that practice person-directed care and 2) consumers' increased understanding of what culture change in LTC means. The number of participants who rated the statement "I understand what culture change in long-term care means" as "strongly agree" or "agree" increased 100% after attending the meetings.
- 78% participants wanted to know more about culture change. In particular, there were frequent comments about wanting to know what culture change "looks like" and how it is implemented.
- Participants overwhelmingly agreed that culture change needs to happen. 97% strongly agreed or agreed that they would rather live in a culture change community than one that practices a traditional model of care.
- **63% participants expressed interest in joining coalition advocacy efforts.** They were less enthusiastic about actually visiting homes and seeing whether they were practicing culture change.

What did we learn?

- While most consumers were appreciative of this information and generally saw its importance, it was clear that this topic was not on their radar screen.

- The most common comment from consumer participants was related to financial feasibility/accessibility.
 - “Very interesting but I find it difficult to believe that the culture change talked about will come about without a high investment.”
- Some participants expressed that this topic did not apply to them. Consumers may not see the personal relevance of long-term care or culture change, perhaps because they do not see themselves ever needing long-term care or will wait until the situation occurs.
- Consumers only know what they know. Their knowledge is based on their experiences. If they have no experience with LTC, they may have a lack of awareness about institutional routines and hence wouldn't know there is a need for change. If they do have experience, they only know their experience and may be unaware of alternatives. They also found it difficult to fully understand culture change without having seen it played out. That being said, participants with personal experiences in LTC resonated with the topic and shared their experiences.
 - One of the attendees' mothers, who was in a nursing home, said of her experience “I feel like I'm in a million pieces”
 - “That's my biggest fear- they don't know who you used to be”.

Opportunities

- More education!
- Engaging consumers in advocacy efforts
 - Through state coalitions and Pioneer Network
 - Challenge is that most communities they visit will not be doing culture change. How do we prepare them for this and perhaps utilize consumers as ambassadors to provide information about culture change to providers?

Arlene commented that consumers need to know what homes near them are on their culture change journey so they can visit and see it in action and ask questions of administrators and other staff as well as residents and families. All agreed that once consumers start demanding these things, there will be a sea change.

Call participants wanted to continue the conversation about consumer involvement on the next call including going through the consumer section of the Pioneer Network website and providing feedback on it. **All are encouraged to review the consumer section before the call since there is a lot of information in it and then be on the website during the call so you can follow along.**

The date and time for the next call is May 17th at 3 p.m. ET, 2 p.m. CT, 1 p.m. MT, 12 noon PT and the call in number is 619-276-6333.