



State Culture Change Coalitions Networking Call Summary
March 25, 2011

Topic: How coalitions are working with other care settings beyond nursing homes

Present: Sue Crane (Florida); Annette Kelly (Florida); Kim McRae (Georgia); Monica Perry (Idaho); Nancy Wild (Iowa); Julie Ballard (Missouri); Joan Devine (Missouri); Debbie Yellseagle (Oklahoma); Belinda Gray (Oklahoma); Lynda Crandall (Oregon); Vickie Orcutt (Texas);

Lynda welcomed Annette Kelly from Florida and Kim McRae from Georgia and introduced them to the group.

Annette Kelly: The Florida coalition received a grant from Winter Park Health Foundation to repurpose Artifacts of Culture Change tool for use in ALFs. So much of ALF choice is environment rather than choice about life. Getting people to think about working within environment is hard. They brought in a culture change expert to assist in identifying the grant focus and got input from consumers re their knowledge of changing resources/options, and advocates. Their expert suggested staying with a concrete project, e.g., the Artifacts tool, rather than introducing a developed program and assisting ALF to implement it. In this way the tool can inform them what steps they wish to take making the values and direction self identified. People take ownership. In their effort to expand beyond nursing homes they felt it was helpful for them to use something that they were already comfortable with such as the Artifacts tool, and that they had already established credibility by the history of past work with it. They are working with 6 ALFs and are now in the middle of the 15 month project now.

Repurposing a tool is a research endeavor if it is to be valid. They followed a research process including review of the tool by culture change and assisted living experts suggestions for revision by experts, e.g., the tool is way too long for the ALF setting. Reduced the length of the tool first and then beta tested it with an ALF. This led to a 2nd revision. The 6 ALFs are currently using this version and likely there will need to be another revision. Karen Schoeneman and Carmen Bowman, the original authors, gave permission to the Georgia coalition to repurpose the tool.

Part of the grant work is an ALF Forum to bring together teams from ALFs around the state to share each others best practices and challenges. They will use the 6 homes to showcase some of their successes and to learn, be inspired and develop a learning community.

Another component of the project is presentations to 10 groups of consumers. So far the result has been "mixed"-- one social group that the coalition thought would be a

natural fit for one of these sessions rejected the invitation saying they “didn’t want to have anything to do with a topic as depressing as nursing homes.” Annette reflected how this demonstrates the kind of work yet to be done. They’ve had the most success with faith based groups and health based groups, e.g., YMCA.

Kim McRae: The Culture Change Network of Georgia was founded in 2008 and from the outset they were intentional to include culture change for the whole continuum of long-term care. As the Network built and developed their advisory group they invited key stakeholders from all groups from the whole continuum, e.g., adult day, affordable housing, in-home care, hospice, NH, ALF, the AAAs, Alzheimer’s Association, CMS, state survey agency, long-term care ombudsman, academics, etc. The network’s initial mission was: “To promote and foster culture change to improve the quality of life for older Georgians and those closest to them *in all settings* where aging services are delivered.” The Network recently changed the mission statement to: “To change the way Georgians *think* and *feel* about aging and disability by creating the kinds of support and services we want for our loved ones and ourselves.

The Network has worked to reframe and deinstitutionalize how they talk about culture change and LTC in Georgia. Most of what’s been done and written “out there” has been about culture change in nursing homes, so the Network has been introducing the idea of culture change and the movement more broadly and explaining how it applies to every person and every setting via every opportunity offered or found. Kim has presented at all the annual symposia and conferences for each arm of the continuum and focused on facilitating people to consider what culture change might look like in their own settings using the underlying premise of person-centered care, i.e., what would it look like in adult day, affordable housing, etc. The key is to help everyone find ways to see themselves reflected in the movement. The Network has focused a lot on language.

Kim said “it’s not fair to wait until the last minute in a person’s life or the day they have to move to a LTC setting to begin thinking about this.” CCNG wants to get all providers along the continuum and all long-term care stakeholders to focus on person-centered care as well as reach out to consumers by participating in the Pioneer Network’s consumer education project funded by the Picker Institute.

This year will be Georgia’s 4th culture change summit. At each summit, and at all other educational events, they have asked the speakers to include all levels of the continuum in their presentations.

Other things—

- The Network has done a lot of work around dementia as this is vitally important and applicable to the entire in the continuum. 70% of persons w/ dementia live in their own home. The importance of person-centered care and life; reframing “traditional” dementia care versus person-centered dementia care; and community education is very important.
- Spoken to care coordinators in affordable housing—helping them see that even what they do can be institutional.

- Worked with affordable housing folks from 8 states to “translate” and “repurpose” the Artifacts tool for affordable housing. Also working with folks from adult day in GA. Not a formal “research” process, but using the tool as a point for discussion and creating a draft that can be piloted in both settings.
- After one consumer meeting was held as part of the Pioneer Network’s Advocating for a New Old Age project funded by the Picker Institute (Phase One), the women that participated “demanded” to start having field trips to visit and “shop” for the next level of care that they might need one day (personal care homes). This empowered them to be “in control” of their life, diminished their fear, and increased their comfort level with this possibility.
- The Network recently hosted Eden at Home in Georgia (3 day trainer certification workshop) and had people attend from all levels of care and types of organizations. If they are going to be able to do smooth transitions then everyone needs to be speaking the same language and have the same philosophy. Kim said that the Eden principles translate so beautifully to all types of folks (professionals and consumers) and people are really able to understand and “get” the concept. Most of what is out there is for the caregiver or the care receiver, but Eden at Home teaches people about care partner teams. This approach has to do with everyone participating on the team. Got feedback that the language that was used was especially helpful.
- Link to Eden at Home Article:
http://www.culturechangeqa.org/special_projects/eden%20at%20home/Creating%20Eden%20in%20Georgia%20April%201%202011.pdf
- Link to article on the continuum from Laura Beck (Eden at Home):
http://www.culturechangeqa.org/special_projects/eden%20at%20home/The%20Continuum%20of%20Care%20What%20Does%20It%20Mean%20for%20Culture%20Change%20by%20Laura%20Beck.pdf
- CCNG is also working on bringing together the aging and disability worlds.

In reviewing the call summary, Kim noticed that she failed to mention the CCNG newsletter called **CULTURE CHANGE CONNECTION™: CULTURE CHANGE THROUGHOUT THE CONTINUUM OF LIFE-LONG LIVING & LONG-TERM CARE**. It contains news, ideas, and best practices about the entire continuum so that everyone can find something that resonates. Starting in 2011 it comes out every other month (was monthly in 2010). All past issues are available at:
http://www.culturechangeqa.org/navigation_bar/in_the_news.html

Vickie Orcutt said that the Texas coalition formed in July 2010 with an initial purpose focused on the continuum of care for elders and persons with cognitive disabilities. David Seaton, co-founder of the Texas coalition, has created an Eden LifeLong Living program to incorporate person-centered care into long-term care for individuals with cognitive disabilities. He has also spoken on life long living environments at the National Guardianship Conference exposing others to the culture change concept so the Texas coalition is very much focused on bringing the aging and disability worlds together.

Sue Crane said that the Florida Pioneer Network is currently an all volunteer coalition. She wonders whether focusing on other areas of the continuum dilutes the work they can do with nursing homes. Vickie said that Texas is also an all volunteer coalition. Employers of volunteers have been supportive so meetings and work takes place both during work hours and outside work hours. They are just planning their first symposium in September and they are trying to ramp up the advisory committee by bringing in more "worker bees". Kim said that Aging Services of Georgia (LeadingAge affiliate) has donated staff time and has integrated culture change work into the activities they were already doing. They have identified opportunities to spread the word. From the Eden at Home training, they got a whole new contingent of interested people from all parts of the continuum.

The next Coalitions Networking Call is scheduled for April 22, 2011 at 3 p.m. EDT and the topic will be "How state coalitions have set up regional coalitions or groups and what they are doing, including how they are funded (if applicable)."