



**Kansas Advocates
for
Better Care**

Kansas Advocacy in Action

Kansas Advocates for Better Care (KABC) was one of 50 or so agencies that worked in coalition to create our state's Money Follows the Person program. MFP is a federal demonstration project that moves persons who choose, from nursing homes to a home in the community. I began participating in the coalition meetings as a new staffperson for KABC. As we talked through the issues of safety, independence, autonomy, along with the practical matters of implementing this new program, I kept thinking ‘where is the access for consumers to an independent advocate with statutory authority, like we have in the ombudsman program?’ The aging advocates in the coalition indicated that such an idea would not be well received by the disabilities advocates - as too protectionist. This perception proved to be false. Disability advocates across the spectrum - developmental, physical, mental - are very supportive of such an advocate for persons receiving long-term care in-home.

KABC first broached the idea of such an advocate program to the State Long-Term Care Ombudsman. The Ombudsman was interested in and very supportive of the idea. KABC presented to him the reports we had identified that defined how several states had legislated and implemented (or not) "Community Long-Term Care Ombudsman" programs across the country. The reports were compiled and released by NASUA and by the NORC housed at NCCNHR.

The Ombudsman was in agreement with the concept, need for, and benefit of such a program. His primary concerns were about who was the correct entity to provide this service. And if it was the State Long-Term Care Ombudsman, his concern was that the legislature provide adequate funding for the positions needed to respond to consumers in the community, which could potentially be a much larger group. Jointly, KABC and the Ombudsman met with possible providers of community advocacy including the Kansas Disability Rights Center, the Adult Protective Services Unit, the Attorney General's office and others, with the goal of better defining what the needs were for such a program, and what entity might be best able to respond to those needs. We also talked with the Secretary of the Kansas Department on Aging, AARP-KS, the Kansas Guardianship Program, and others. At almost every turn, the idea was positively embraced. KABC also presented the need to the pre-legislative session of the Douglas County Legislative Delegation - a group of representatives and senators from the county where KABC's office is located.

After defining what we believed the appropriate parameters for this program ought to be, KABC took this idea to the Kansas Legislature in 2008. KABC first testified on the need in the House Social Services Budget Committee during its consideration of annual budgets for the Kansas Department on Aging and the State Long-Term Care Ombudsman, and again during the committee's oversight of the Money Follows the Person project. Repeatedly the concept received positive responses. Thanks to the foundational work done by KABC and participated in by the Ombudsman, legislation to create such a program was introduced in the Kansas House during the 2009 session. The proposed legislation redefined the role of the ombudsman to include any person

who would qualify for long-term care *regardless of the setting in which they resided* - the legislation was proposing very broad authority by using this language. Once the legislation was introduced, KABC identified a media outlet (actually two) that would report on this idea and its legislative progress. We provided stories, information, research and quotes to the reporters and identified legislators who were supportive of the legislation. The media in turn provided coverage that informed the public and a broader group of legislators about the need for such an advocacy program to serve home-based persons receiving long-term care. As the legislation wended its way through the legislative session of 2009, Kansas began to see dramatic revenue decreases, along with the rest of the country. The proposed legislation was amended to create a pilot program, with a much smaller fiscal note, that the Long-Term Care Ombudsman would implement in a specific geographic region of Kansas, and that would serve only those persons returning to the community through the Money Follows the Person demonstration project.

KABC and the Ombudsman were satisfied with this amendment as it would give us the opportunity to gather critical data before legislation and funding were determined, such as: level of utilization by community-based long-term care consumers, definition and implementation of cooperative working relationship with Adult Protective Services, level of response time and resources required by the ombudsman when serving consumer concerns in a community long-term care setting vs. facility based setting, etc.

KABC and the Ombudsman continued to advocate for the authorizing legislation in the 2009 session, but with declining revenues, the legislation was not passed for lack of funding. Again, KABC and the Ombudsman supported this, as we did not want an unfunded mandate which would hamper the ombudsman's ability to fulfill his current responsibilities to residents in facilities.

Prior to the beginning of the 2010 legislative session, KABC again met with the Douglas County Legislative Delegation to discuss the need for this program and its authorizing legislation. Again, a representative agreed to introduce the legislation that would authorize the ombudsman to serve consumers in all settings. In the interim, the State Long-Term Care Ombudsman resigned and a new SLTCO was appointed. We were only 3-4 months into a new State Long-Term Care Ombudsman when the legislature reconvened, so KABC had to get buy-in from the new ombudsman. We were successful in getting her support and the legislation was introduced in January 2010. Kansas revenues are now \$1 billion dollars less than when we originally introduced this legislation. The idea will not be advanced until there is funding for the advocacy service. We will continue to keep the concept alive and gather stories that are compelling, so that when the revenues turn around, we are ready to move forward.

The lessons learned in this advocacy effort have been:

- 1) Good ideas will advance
- 2) Having buy-in from partners (within and outside of government) makes the legislative effort much more likely to succeed
- 3) Engage the media in getting momentum behind and providing broader awareness/buy-in around the idea/concept
- 4) Collect stories that illuminate the need and which the media will pick up and legislators will grasp
- 5) Don't give up
- 6) CAGs don't have to have full-time lobbyists to advance good public policy