Building a Social Movement to Improve Long-Term Care in California

Margaret Mead, the pioneering anthropologist, once said, “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has.” Last month, Washington, D.C. hosted the 2012 American Society on Aging Conference, and The SCAN Foundation brought together one such group of inspired individuals.

Panelists from a variety of backgrounds and fields gathered to share their experiences on organizing California’s older adults, people with disabilities, and caregivers to improve home- and community-based services through social action.

At stake is the ability to age with dignity, choice, and independence for two key groups: today’s seniors and people with disabilities who depend upon a system of long-term services and supports, and baby boomers who will likely need care in the future. In the last five years, California has made approximately $15 billion in cuts to services for these individuals, often losing federal matching dollars in the process. In the face of such drastic circumstances, these motivated leaders see the state’s budget predicament as a genuine opportunity to bring about change in how the Golden State provides support to those with daily needs.

Their vision – one that could be achieved by creating a more accessible, person-centered system of care – is to provide services that enable Californians to live in their homes and
communities whenever possible. Making this a reality will take a groundswell of support from seniors and baby boomers themselves, whose collective power cannot be denied if they act as a unified body and speak as one voice, insisting upon a better system of care for all.

The first step to creating a social movement is to humanize the issue. Presenters stressed the importance of talking directly with people living in the community who rely upon services to stay independent. Collecting one-on-one feedback through personal stories provides organizers with information straight from the source, and can bring their voice to the table on key policy issues. Social media, such as issue pages on Facebook, is another effective way to get broad audiences to tell their stories, especially boomers caring for their parents who have a large Web presence. This human face to the issue also needs to reflect the range of cultures and ethnicities in the community. When reaching out to diverse senior populations in cosmopolitan cities such as Los Angeles or San Francisco, it is important to establish trust with immigrant groups who may not at first be inclined to speak out and increase their working knowledge of the issues at hand.

Bringing a variety of stakeholders together with different political and financial interests all looking to hang on to their piece of the pie can also present significant challenges for social activists—especially in a state like California facing such severe cuts. This economic reality makes it difficult to build a coalition of hospitals, advocates for people with disabilities, home-and community-based service providers and others. But the fact of the matter is that, when done right, a better organized, person-centered system of care that bridges medical care and supportive services is ideal for consumers, providers, and health systems.

Efforts to mobilize these diverse groups also need to use language that resonates. The SCAN Foundation’s national polling and focus group work has helped shed light on how people think, feel, and talk about aging. Boomers and seniors respond to aspirational messaging that focuses on what people want life to be like at older ages rather than fear tactics of aging or focusing on a broken system of care. People also respond to reality checks based upon quantitative research, such as the fact that 70 percent of people over 65 will need some form of long-term services and supports, on average for three years. Messaging about growing older and creating a world that honors an aging America needs to be succinct and clear, and not laden with insider language oriented to policy wonks.

To grow this social movement beyond California and throughout the country, it will take elevating the issue of improved home- and community-based services and better coordination with medical care to a national priority, with hundreds of thousands of seniors and boomers demanding a better system of care. Only then will aging with independence, dignity and choice go from being a lofty ideal to a reality that is within reach.