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People Really do Care About Long-Term Care: Or, Not Quite Present at the Creation

By John Cutler

Author's Note: Many, many years ago a woman who was involved with long-term care insurance decided that all the other people involved with LTCI should come together and talk about issues. Since she was a lobbyist for the industry and not a home office or legal sort, she decided to ignore issuing an antitrust statement at the beginning of these meetings. In fact, she opened them up to everyone. And soon they had advocates, government officials and Capitol Hill staffers as well as industry leaders in attendance. She credits the group, and its meetings, with the creation of a major LTCI initiative, namely the Long-Term Care Security Act of 2000 and the Federal Long Term Care Insurance Program.

Way back in the last century—well, barely, since it was 1999—Sandy Cook, then with Unum, started the Long Term Care Discussion Group (LTCDG). For 20 years, this group has invited speakers in on issues of all sorts, mostly (but not always) around the topic of long-term care. At first it was more insurance focused. But that tended to shift to general issues of financing. LTC involves delivery so there were sessions on that. And so on and so on.

SESSIONS OVER THE YEARS

The LTCDG and the Society of Actuaries (SOA) have a long relationship and have jointly produced a number of sessions. The SOA's Post Retirement Needs and Risk Committee worked on the topic of long-term care and retirement risk; the LTC Section on the various research efforts that lead to the Retirement Plus idea as well as a life product that turns into long-term care protection at age 65, among others.

In 1999, we hosted a one-day program on Capitol Hill with Sen. Dave Durenberger, as the keynote speaker, and Deputy Assistant to the President for Health Policy Chris Jennings. In 2002, we held the meeting at the Health and Human Services (HHS) headquarters, the Hubert H. Humphrey Building. This session revolved mainly around the new federal employees' long-term

care insurance program and related LTCI issues such as outreach and research. We also heard from Hill staffers on their congressional perspectives. Given how intense those programs were, we opted for a session every even year, after the federal elections, so that we would hear from Hill staff and/or lobbyists about legislative prospects for Congress and the administration (especially after changes in political party).

We like to keep up with various organizations and their work or research. We hosted Nora Super, then executive director of the White House Conference on Aging. Gretchen Alkema of the SCAN Foundation spoke on the framework for approaching LTC financing. AARP, LeadingAge and RTI International have hosted sessions on their work, including the redoubtable Josh Wiener from RTI on the minimum wage proposal and its impact on nursing homes and assisted living facilities.

As you might imagine, LTCI-related sessions are frequent. Some that stand out are research by Dr. Steve Holland on how long-term care insurance reduces end-of-life expenses and Nevada Insurance Commissioner Scott Kipper discussing the National Association of Insurance Commissioners regulatory efforts. We have also looked at taxation issues involving LTCI as well as combo products.

Medicare is always big. We have had topics around Altarum's MediCaring concept as well as the new (at the time) Comprehensive Assessment Reporting Evaluation (CARE) tool and another on issues around the Medicare nursing facility benefit. Minnesota's efforts to expand Medicare supplement products (both medigap and Medicare Advantage) were also highlighted in a couple sessions.

The aging network gets its due with sessions on things like the No Wrong Door program of the Administration for Community Living as well Medicaid's Balancing Incentives Program (involving HBCS).

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State reform efforts are always of interest. We hosted a session on the Massachusetts health care reform (the precursor of the Affordable Care Act) before it was adopted. We also have had sessions on the Minnesota LTC reform proposals as well as the new Washington state LTC insurance program.

Over the years, we have looked to other nations, including the Netherlands, Germany and the United Kingdom. Both the Netherlands and Germany have robust social insurance coverage of portions of the long-term care risk. The U.K. session was on the idea of adding long-term care protections to immediate annuities, an idea now being looked at in the U.S.

Other sessions of note include those on the Medical Home concept, home equity, end-of-life care, dementia care, long-term care providers, housing stock, employers, caregiving, the Programs for the All-Inclusive Care for the Elderly, or PACE, and the Department of Veterans Affairs.

MEMBER REFLECTIONS

Organizing the many sessions for the Long Term Care Discussion Group over the years took a lot of effort from the group members and chairs. Insights from some of the chairs over the years follows.

Sandy Cook, Founder and First Chair

I was with Unum, and I read in the Congressional hearing notice that the Clinton administration was considering expanding personnel benefits offered to federal employees to include long-term care insurance. I believe they were considering group life, group universal life, and accidental death and dismemberment (AD&D) products.

Separate from this, hearings were held in the House Government Affairs Committee, chaired by Joe Scarborough, on these three product lines. Unum testified on AD&D because we owned a company in New Jersey which sold that product. It is an inexpensive product that can cover a range of things such as some travel insurance (where, for example, if someone died overseas, their body would be shipped back). That product was a big hit at the hearings, particularly for federal employees,

including members of Congress who had to travel a lot. (However, Congress never did decide to offer those products.)

At any rate, after the hearings, I called George Nesterczuk, the staffer for Government Affairs, and asked him why the committee had not included long-term care insurance in the hearings and he responded that it was a “bad product” and there was not a good enough track record on it. I responded that things had changed and the product had been perfected (Ha!), and offered to bring in a team of experts to brief him and the staff. There was some push back from the Democrats (e.g., Rep. Henry Waxman), but they were amenable to listening. So, staff met with a group of experts I had invited to join in a discussion.

As word got out, more and more people (companies) and entities such as the Office of Management and Budget, began to participate. Then the trade associations kicked in (American Council of Life Insurers and Health Insurance Association of America) to offer their advice. As the group grew, dissension arose as to what “kind” of product would be offered to the federal employees: a group or an individual product. It broke along those lines, with some companies proposing an individual product because, of course, that’s the product they sold. Other companies sought to have the product be a group product, for similar reasons. Logic prevailed and the group product was selected.

So, during those months, we decided it was most worthwhile to continue the discussion on long-term care and we set up a group that met monthly.

John Cutler, Original Participant and Later Co-Chair

I was working at HHS at the time the Clinton administration came up with several long-term care proposals. Two of these were actually mine. One was what became the Federal Long Term Care Insurance Program and the other was Own Your Future, an educational campaign through the governors to



Meeting of the LTC Discussion Group at AHIP, April 26, 2018. Photo by Eileen J. Tell.

alert and educate people about long-term care risk. So, I started attending the group, which by this time was “officially” called the Long Term Care Discussion Group.

My most memorable meeting across the years was when Henry Claypool spoke; he was senior adviser to the administrator for Centers for Medicare and Medicaid Services and had us all over to the Old Executive Office Building for a session. Then there was a session where we had lined up Sen. Ron Wyden. I was sure his staffer would show up instead but it was the senator himself who came! One of the more popular meetings (over 50 in attendance and another two dozen by phone) was Mark Warschawsky, a member of the Federal Commission on Long Term Care. That was in 2013.

As an aside, for those lobbying Congress, when I was doing the initial outreach (aka marketing) to the Hill about members, family and staff being able to buy the product, I found interest as high or higher among Democratic members than Republicans. One meeting with the Democratic caucus had 20 members in attendance, which is like a gold-star moment for those of us working the Hill.

Susan Coronel, Original Participant and Later Co-Chair

One of the best attended—and most combative—Long Term Care Discussion Group gatherings was a session that focused on the Community Living Assistance Services and Supports (CLASS) Act. The CLASS Act was a facet of the Affordable Care Act. Sponsored by Sen. Ted Kennedy, the measure would have established a new federal LTC program. Connie Garner, Kennedy’s lead staffer for the act, was the featured speaker for the standing room-only session. In addition to leading efforts on the CLASS Act for the U.S. Senate, she also had her own family experience with disability issues. Her passion regarding long-term care and congressional efforts to address the issue was evident. There was some blunt talk during the session. And that was the point!

Karl Polzer, Current Co-Chair

I started participating in LTCDG meetings in 2006 just after joining the American Health Care Association’s National Center for Assisted Living. Sandy Cook was leading it then. We did a session in which I brought a couple staffers from the Hill whose bosses were sponsoring bills to make needed adjustments to Medicare Part D. The new law created a tough situation for dual eligibles in assisted living and in the community in affording medication co-pays. The LTCDG group meeting was a key part of a coordinated campaign I helped organize to address this issue, which eventually resulted in Section 3309 of the Affordable Care Act. This put these duals on equal footing with those in nursing homes by eliminating the Part D co-pays (small

but unaffordable for people receiving LTC). This revision has helped about a million people afford their medications.

I was asked to become a co-chair in 2010 and have really enjoyed making a contribution to the LTC policy community by promoting dialogue on research, policy, political and marketplace issues and developments. The group’s work on the rise and fall of the CLASS Act is a highlight. Josh Wiener’s presentation on the impact of raising the minimum wage on assisted living and continuing care retirement communities just months before his death was memorable. Debra Lipson’s talk evaluating Medicaid’s Money Follows the Person Rebalancing Demonstration Grant was sparkling. And those are only some of the many sessions where we saw key contributions to the debate on those issues.

Eileen Tell, Current Co-Chair

The group had a largely D.C.-focused membership and in-person and smaller overall event attendance. Today, we have members from all over the country (and occasionally abroad) because we have added the ability for folks to dial-in via a conference line. We now have twice as many (or more) at each meeting because we have both on-site and calling in. We’ve added a website to support the distribution of meeting materials and upcoming meeting notices for more than 500 members. While we have a core of roughly 75 to 100 who attend regularly, some topics draw a very different audience than another topic might. We have grown our membership through word of mouth and some use of LinkedIn. It is free, 100 percent volunteer supported for decades, politically neutral and very broad in scope.

FOR FURTHER INFORMATION

The Long Term Care Discussion Group is a voluntary, independent group that meets for the purpose of educating the policy community on all facets of long-term care. We convene monthly presentations exploring LTC policy, research and advocacy issues.

Signing up is free and open to all (this is not a membership organization per se). Participants span the entire spectrum of the long-term care policy community, including federal agency and congressional staff, researchers and representatives of a wide variety of stakeholder organizations. For more information or to be included on the distribution list, email LTCDiscussionGroup@gmail.com. More information can be found at <http://www.ltcdiscussiongroup.org/>. ■



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