

# Closing Remarks: Reflections and Future Considerations

Len Fishman, JD

Thank you to all who have shared their personal experiences, local challenges, and potential solutions for meeting the needs of informal caregivers around the world. We would like to conclude the panel with closing remarks from Len Fishman, JD, Director of the Gerontology Institute at the University of Massachusetts Boston's McCormack Graduate School of Policy and Global Studies. In this Q&A, Len reflects on last week's discussion and addresses future considerations for supporting informal caregivers.

While the Expert Panel ends today, we encourage you to share your thoughts on these closing remarks in the discussion.

## **GHDonline: How can providers and policymakers better understand the role of informal caregivers and bring them to the forefront?**

Len Fishman, JD: Let's start with the recognition that caring for elders—at the current scale and level of intensity—is a relatively new global phenomenon. And informal caregiving, like other work done mainly by women has been greatly undervalued. So this issue has been largely invisible to policymakers and a low priority. But there are signs of change. Here's one: later this summer IOM will release its Study on Family Caregiving for Older Adults, with recommendations for changes in the public and private sector to remove barriers and increase supports for informal caregivers.

The “Longevity Bonus” added nearly 30 years to the human lifespan in the historic blink of an eye. With so many people living into their 80's, 90's and beyond, the experience of informal caregiving is becoming nearly universal. What's more, people my age (I'm 64), for the first time ever, are *expecting* to live into their 80's and 90's (my kids are expecting it too), so the element of surprise (and denial) is disappearing. People are aware of the issue, recognizing its relevance to them, and are talking about it as never before. These developments are precursors to policy change.

Pressure for change will also come from the sharply declining ratio of informal caregivers to people 80 and over. In the U.S., it's 7-to-1 today but will drop to 3-to-1 by 2050. As informal caregiving increasingly interferes with men's and women's breadwinning there will be more pressure for interventions like leave time and respite care. That said, the swelling of the older population also means that public interventions will not be cheap.

## **GHDonline: A handful of states have begun cash-assistance programs for informal caregivers. What needs to be done in order for the United States to take informal caregiving seriously enough to pay for it at a national level?**

LF: Nearly all the states offer this benefit (known as “cash-and-counseling” or “consumer-directed care”) in their Medicaid programs. Eligibility requirements vary widely, and fewer than ten states permit payments to spouses. A major barrier to expansion is cost. Opponents ask, can we afford to pay millions of people to do what they’re doing already—and at no cost to the public? And, they worry that a benefit like this one could be easy to abuse. These concerns are not entirely unreasonable, even to a bleeding-heart liberal like me. But they can also be shortsighted. There is a cost to society when unsupported caregivers burn out and give up, and substitute more costly formal care for the informal care they were providing.

I work at a research and policy institute, so it won’t surprise you that I think more research is needed to better understand the extent to which publicly-funded cash-assistance programs reduce publicly-financed health care costs.

**GHDonline: What role do informal caregivers play in end-of-life care conversations, advanced care planning, and palliative care for the elderly?**

LF: They play a big role, but it could and should be bigger. End-of-life conversations usually involve the triad of patient, family and doctor, and this is especially true when frail elders are involved. But the members of this trio are not talking to each other nearly enough. While 90% of Americans say that talking to their loved ones about end-of-life care is important, only 27% have done so. Organizations like The Conversation Project are waging a public campaign to normalize conversations about end-of-life care decisions. So step #1 is getting a person to say what she wants. Step #2 is naming a healthcare proxy and explaining one’s wishes to the proxy. Step #3 is getting clinicians to record and respect the expressed wishes of their patients in every kind of setting, including hospitals and nursing homes. Step #3 is much more likely to occur when a healthcare proxy has been named and knows the patient’s wishes.

There is a special category of conversations we’re *not* having that is the responsibility of doctors, many of whom find it difficult to talk about death. Dr. Susan Mitchell has been a pioneer in reframing Alzheimer’s and other dementias as terminal illnesses. This really matters, because when doctors forewarn patients and their families about the course of the disease and likely secondary conditions, such as pneumonia, families are much more likely to elect comfort care over aggressive curative treatment. Connecting the dots makes a huge difference in these cases, and the same is true for other conditions that occur at the end of life, such as congestive heart failure.

**GHDonline: While our panel has focused on caring for the elderly, there is an entire population of younger adults with disabilities also receiving care through informal networks. What lessons from the caregivers of this population can we learn from and apply to informal caregivers of older adults?**

LF: Disabilities advocates have been way more effective at getting control of their care and using informal and paid caregivers to avoid institutional care. Long before “person-centered

care” entered the lexicon, disabilities advocates had a more pointed demand: “Nothing about me without me.” Because younger adults with disabilities, and their families, recognize early on the lifetime need for long-term services and supports (LTSS), they advocate accordingly, whereas frail elders and their families are more likely to stumble into the world of LTSS after a crisis and without much forethought. The somewhat milder demand of elders is for the right to age-in-place, which has led to the rebalancing of LTSS away from institutional care in favor of home and community-based services.

**GHDonline: Are there any additional thoughts you’d like our community to reflect on as we conclude the panel?**

LF: When we think about supporting informal caregivers we also need to consider their paid counterparts on the frontlines. I can’t think of a job where compensation is as inversely proportional to difficulty and importance as personal care aides who deliver care in people’s homes. The lives of informal and formal caregivers are intertwined. When we improve the working lives of aides (by paying them more and affording them respect and opportunities for upward mobility) we get better care. If we don’t do this we will face a severe shortfall of paid frontline caregivers and further burden the informal caregiving network.

Second, there are things that can be done at the local level to support informal caregivers. Permitting the construction of accessory dwelling units (“granny flats”) as of right; adopting “visitability ordinances” which require new dwellings to be accessible; creating robust volunteer and respite programs—these are some elements of age-friendly communities that support elders and their caregivers.

Finally, at the highest level, we need to recognize that the institutions and norms we’re accustomed to—school, marriage, childrearing, careers, and retirement—were all developed when life expectancy was *20 to 40 years shorter than it is today!* And that’s not all. Lifetime employment with one or two companies—and the paid benefits that came with it—is gone. So is the stay-at-home-parent. We need a set of basic benefits (universal health coverage; publicly-subsidized child care; affordable higher ed; and support for elder caregiving) to match the times. This is what it will take to level the playing field and ease the crushing burden so many poor and middle class Americans are feeling. If we don’t do this, the elders most at risk are those with few or no kids—but they’re the ones who subsidized my kids’ education. In the end, either we’re all in this together, or we’re all in this alone.