Informal Discussion Transcript
Concurrent Session 6B: The Changing Face of Elder Care

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ANNA M. RAPPAPORT: Phyllis Mitzen is founding President of Skyline Village Chicago, Inc., a village in Chicago. She has a social-service perspective, and she can add a lot to what we are doing. We hope that this session will add to what you've heard about long-term care throughout the conference. We'll start with a presentation from Phyllis, followed by discussion.

PHYLLIS MITZEN: Thank you, Anna for inviting me to participate in Living to 100. I've learned a lot over these past three days, applying the interface between my social-work/public-health perspective to the data you work with.

I will start my presentation with a brief YouTube video, "The Big Idea in Four Minutes."[1]

My Visions for Aging, Circa 1972

I started my career in the field of aging in 1972, just a few years after the passage in 1965 of Medicare, Medicaid and the Older Americans Act. These three pieces of legislation formed and along with Social Security, continue to provide the framework for aging policy in the U.S.

However, the world has changed over the past 50-plus years. Since the early 2000s, we've seen the emergence of major initiatives to improve communities' responses to an aging population. Examples include the World Health Organization initiative Age-Friendly Cities, the AARP Livable Communities initiative, and in the U.S., the grassroots Village Movement. Each of these movements reflects recognition that social determinants of health impact the health and well-being of the population in general, and on people as they age. For example, people who have low levels of education, lack of social supports and are socially isolated risk poor self-management and inability to benefit from care plans designed to help them. Poor, unaffordable or unsafe housing and transportation result in increased health care costs and excessive or inappropriate utilization of health care. Health disparities and psychosocial issues result in preventable hospitalizations and mortality.

The medical community is coming to realize that an individual's health relies on more than just the medical or health care system. From a public-health perspective, health depends on the air we breathe, the water we drink, the availability of affordable housing, the safety of our

[1] "The Big Idea in Four Minutes: Coming of Age in Aging America," Vital Pictures, April 30, 2012, www.youtube.com/watch?v=ZOA1v4-2Fos.

neighborhoods, transportation to shopping and services, access to healthy food and to medical and behavioral health care, presence or absence of stress. Health and mortality can be predicted by the zip code in which you live.

Medicare, Medicaid and the Older Americans Act: What Do They Do?

Medicare, Medicaid and the Older Americans Act were part of Lyndon Johnson's Great Society and passed into law in 1965. These three pieces of legislation form the policy bedrock for eldercare in the U.S.

Medicare is a single-payer national insurance program for people aged 65 and over, and for people with some categories of disabilities. Part A pays for institutional care: hospitalization, rehabilitation in a nursing home, hospice that can be both institutional and home care. Part B is a private supplement, and that pays for outpatient physician services, home health and durable medical equipment (DME). Part D subsidizes prescription drug coverage. Medicare covers acute care and rehabilitation until an acute episode is stabilized. *It does not pay for long-term care.*

What lies ahead in Medicare? I have a friend named Tom Cornwall. He is a physician, geriatrician, working for DuPage Hospital in Illinois. Tom has a black bag and a smartwatch. When I see Tom, I think back to my childhood, when Dr. Dale, the general practitioner, came to my house with a black bag to take care of us. Tom does that. He takes his black bag, he drives his car up in front of his patients' homes, and with his smartwatch and technology, he can provide care in that person's home, no matter where it is, as effectively as he could in the hospital. Home care docs are now paid under Medicare. I believe that the future of elder care, including medical care, will increasingly be provided in the home and community.

Another issue receiving attention is the coordination of care across settings. Since the 1980s, hospitals have been releasing people back home sicker and quicker. This resulted in significant numbers of rehospitalizations. Hospitals had no incentive to change, since they were paid for each hospitalization, significantly increasing the cost of health care, not to mention the consequences for people, particularly older adults. The Affordable Care Act of 2010 changed that. The act penalized hospitals for what they deemed as unnecessary rehospitalizations. This put

pressure on hospitals to not only keep people until they were stabilized, but also to assure that there was a reliable plan in place for people when they left the hospital. Transitions from hospital to home or to a nursing home can be traumatic, and the success of a transition relies not only on the stabilization of the person's medical condition, but on the social determinants of health: Is there food in the house? Do they have transportation to their physician's appointment? Is there someone who is able and willing to help? Do they have access to the medications they need, and do they understand how to take them? Medicare now pays for transitional care management to assure that these and many more issues are resolved, and to reduce unnecessary rehospitalizations.

Medicaid is a federal-state partnership to help states provide health care for their indigent citizens. Medicaid gives states generous control over eligibility and coverage. States, in order to participate in the program, must agree to provide a basic package of services, including long-term nursing home care. Based on a states' economic position, they can receive anywhere from 50 to 60 percent back from the federal government for each $1 spent. If a person is indigent—$2,000 in assets in Illinois—and is sick and/or frail, they are entitled to these services, including nursing home care. Because of this entitlement, nursing homes began to proliferate, and the nursing home industry as we know it today was born. Within a few years, it became clear that some people living in nursing homes could live in the community if some basic services were available. To remedy this situation, states could apply to the Center for Medicare and Medicaid for a waiver from the nursing home provision, allowing the state to develop community-based long-term care services and supports that people needed to stay at home: homemaker services, including bathing and grooming, housecleaning, shopping and cooking, transportation, etc. States would pay for these services through the Medicaid program and receive a federal match.

Many states have turned to managed-care organizations [MCOs], which receives a capitated rate for people they enroll who are Medicaid eligible. In Illinois and elsewhere, these MCOs are required to include the long-term care community-based services and supports. A high percentage of older adults in Illinois who fall into this category are dual eligible. In other words, they are eligible for both Medicare and Medicaid. It is believed that MCOs can control the costs for these most vulnerable citizens who require both medical care and social services keeping them

at home and out of nursing homes.

The Older Americans Act is a federal initiative aimed at providing comprehensive services for older adults. It created the Administration on Aging at the federal level, State Units on Aging in each state, and Area Agencies on Aging at the local level. In Illinois, the State Unit on Aging is the Illinois Department on Aging. The State Units created the aging network by providing funding—based primarily on the percentage of an area's population 60 and older—for nutrition and supportive home and community-based services, disease prevention and health promotion services programs, the National Family Caregiver Support Program, and the Native American Caregiver Support Program.[2]

The Area Agency on Aging strategically locates senior centers in local areas as a place where people can go for meals, health and educational programming, and socialization. Funding for the senior centers and for all of the services provided by the Area Agencies on Aging comes from the federal government and from local and individual support, [through fund-raising]. The Area Agency on Aging also administers the State Ombudsman Program, providing a voice for older adults who live in nursing homes and, more recently, who receive state-supported home care.

The Patient Protection and Affordable Care Act—ACA or Obamacare—included several provisions to help older adults. One of them is to help make drugs more affordable in the future. Currently, when people who are enrolled in Medicare Part D reach a certain level of drug spending—insurance plus out of pocket and deductibles—they reach the so-called doughnut hole, where they are required to pay out of pocket the full amount of their drugs. This continues until they reach a "catastrophic" level, after which Medicare pays for 95 percent of the balance of the cost for the rest of the year. Under the ACA, the doughnut hole will be phased out by 2020, meaning that the government will pick up more of the cost of drugs. It remains to be seen if the Republicans will maintain this provision in their efforts to repeal and replace the ACA.

Another provision of the ACA was the establishment of the Patient Centered Outcomes Research Institute [PCORI], a nongovernmental institute charged with investigating the relative effectiveness of various medical treatments. The PCORI mission is to examine the relative health

[2] Ibid.

outcomes, clinical effectiveness, and appropriateness of different medical treatments by evaluating existing studies and conducting its own. It cannot mandate [coverage] but will inform Medicare about procedures it will cover.

Care transitions and preventing hospital readmissions, as mentioned earlier, are another focus of the ACA. In addition, the Centers for Medicare and Medicaid Services have incentivized organizations of health care practitioners that agree to be accountable for the quality, cost and overall care of Medicare beneficiaries. They are moving from fee-for-service to quality-care incentive/capitated payments based on cost and quality measures. These are called accountable-care organizations.

Finally, the Health Resources and Services Administration [HERSA] issued grants around the country to develop curriculum and provide geriatric workforce training. Twenty years ago, Hartford Foundation did a major research to anticipate workforce needs in 2020 and 2030. They recognized the need for specialized training for health care professionals, including doctors, nurses and social workers. My work at University of Chicago is based on a Hartford grant to train more social workers in the field of aging. The HERSA grants also include paraprofessional training.

My hope for the future is best expressed by these five points outlined in a letter from California-based SCAN Foundation to the new president: (1) Name and give authority to a national leader who will build solutions for older Americans across all domestic policy areas. (2) Protect older Americans and their families from financial bankruptcy when long-term care needs strike. (3) Modernize Medicare to pay for team-based organized care to get more value for older Americans with complex care needs. (4) Accelerate federal and state efforts to integrate Medicare and Medicaid. (5) Build new ways to measure health care quality based on what older Americans want (person-centered care).[3]

Person-centered care is care informed by discussions with the older adult and people who are important to them. It focuses on an individual's strengths and interests. It takes into account

[3] Bruce A. Chernof, MD, "An Open Letter to President-Elect Trump: Five Action Items for Your Contract With Older Americans," SCAN Foundation, November 10, 2016, http://www.thescanfoundation.org/news-events/open-letter-president-elect-trump-five-action-items-your-contract-older-americans.

the person's communication styles, identifies the person's favorite things to do, and takes into account how people like to spend their time, and proposes experiences that people may enjoy, and works to mitigate barriers.

Age-Friendly Cities, Livable Communities and the Village Movement

I will now turn to a discussion of WHO Age-Friendly Cities, AARP Livable Communities and the Village Movement.

ANNA RAPPAPORT: I've been at every one of these meetings, and we've talked about the scientific aspects of aging and have had marvelous presentations. This is the first time that we've talked about the communities and the kind of social infrastructure and the fact that there's a lot going on there, too.

PHYLLIS MITZEN: And all of it has impact on health.

On December 24, 2016, the *Chicago Tribune* featured a front-page story about the plight of "elder orphans."[4] [The term] "elder orphans" was referenced in a talk earlier in the conference identifying a trend in the social determinants of health that is receiving the attention of researchers: Since 1965, we have been having fewer children,[5] which results in less family care across the life span. The issues raised by the identification of elder orphans and of loneliness as being deadly are many. I will name a few.

Caregiving is a woman's issue. Women who leave the workforce to be caregivers risk being impoverished as they age.

The sheer numbers of people with dementia have an impact on that person, on everybody who is close to them, on the immediate community. Dementia is both the public-health as well as the economic issue of this century.

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[4] Marwa Eltagouri, "Growing Old Alone: More Seniors at Risk of Becoming Elder Orphans," *Chicago Tribune*, December 24, 2016, http://www.chicagotribune.com/news/ct-elder-orphans-met-20161212-story.html.

[5] Mark Mather, *World Population Data Sheet 2014*, Population Reference Bureau, http://www.prb.org/Publications/Datasheets/2014/2014-world-population-data-sheet/us-fertility-decline-factsheet.aspx.

People tend not to plan. Much the way people have trouble planning for their future financial needs, they have difficulty imagining themselves needing help in the future or what they might need to stay in their home and community.

Loneliness and social isolation and lack of human empathy, independence as a social value—I contend that we are all interdependent, no matter who we are. Independence is not a realistic nor a preferred goal for an old person.

Successful aging is another concept that needs to be struck from our lexicon. It sets up a dyad, success/failure, that is not productive when we—. In my view, if we are alive, we are successful. Frailty, disease, dementia is not failure.

Age-Friendly Cities: World Health Organization

Early in the 2000s, the World Health Organization brought people together from hundreds of cities. The gatherings included stakeholders, policy makers, people who are providing services, old people and caregivers to discuss aligning health care systems with the needs of an aging population. The conversations focused on four priority areas: aligning health systems with the needs of the older population; developing systems for providing long-term care; creating age-friendly environments; improving measurement.[6]

Through hundreds of conversations around the globe, eight domains of urban life were identified. Four of the domains are an umbrella for how the built environment accommodates the needs of people of all ages. These are access to community and health care; effective, affordable and accessible transportation; affordable, accessible and safe housing; safe, inviting, welcoming and accessible outdoor spaces and buildings. Four domains represent the community's ability to engage people and forge relationships. These include social participation—how connected are people with each other?; respect and social inclusion—are people respectful of older adults and include them in neighborhood organizations, sectarian and nonsectarian institutions?; civic participation and employment—are older adults included or discriminated against in governance and in the workplace?; and communication and information—are the means of communicating

[6] World Health Organization, *Global Age-Friendly Cities: A Guide*, 2007, http://www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf.

varied to include people who are visually impaired, have hearing loss, are technologically challenged?

To date, 332 cities in 36 countries have applied to the World Health Organization to become Age-Friendly. In order for the WHO to confer the Age-Friendly designation on a city, the city leadership—the mayor or city manager, the legislators—must commit to the effort. At the same time, older people must be involved as full partners in all stages of developing, implementing and evaluating the plan. They are to provide suggestions for change, implement improvement projects and monitor the city's progress, and act as age-friendly advocates and advisers.

Madrid, Spain, is an example of a city that conducted a thorough analysis of environmental, social and economic factors that lead to active aging.[7] Madrid prides itself on its history of commitment to its older citizens. As an example of Madrid's openness to new ideas, early in the 2000s, a group of people approached the municipality to provide land so they could develop communal housing. The result is the cohousing program in Trabensol, Spain. A TEDx Talk describes how a planning committee met with architects to design both indoor and outdoor living space that is both communal and offers privacy to residents.[8] It includes a communal dining room, living room, meeting rooms, and private apartments. It also includes a communal garden and playground designed for older adults. Eighty people currently live there. It will be important to follow this movement to watch how they evolve as the needs of the participants change over time. In the U.S., a Nevada architectural firm specializes in cohousing and identifies 60 projects that they have developed around the U.S. and one in New Zealand.[9]

Speaking of adult playgrounds, this has become somewhat of a passion of mine. When I visited Shanghai in 2015, my colleagues and I found adult playgrounds. When I came home and started to talk about how effective they were in getting people out and "playing," I learned that these can be found all over Europe, South America and Asia. There are some in the U.S. but not

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[7] World Health Organization, *Madrid: An Age-Friendly City*, November 25, 2016, https://extranet.who.int/agefriendlyworld/wp-content/uploads/2016/10/MADRID-AGE-FRIENDLY-CITY-DIAGNOSIS.pdf.

[8] Jaime Moreno-Monjas, *The Elderly Design Their Own Future*, TEDx Talks, October 22, 2014, https://www.youtube.com/watch?v=r4z4OExOXRw.

[9] McCamant & Durrett Architects, "Complete Projects List," http://www.cohousingco.com/complete-projects-list/.

many. I'm hoping we can bring them to Chicago in the near future. These are natural spaces where people of all ages and abilities can participate and engage with each other.

In the U.S., [The AARP Network of Age-Friendly Communities is an affiliate of the World Health Organization's Age-Friendly Cities and Communities Program.] AARP has rebranded the concept and refers to its initiative as livable communities. AARP is putting a lot of effort into designing tools to share best practices and to developing helpful tools for communities to use to evaluate [their] livability and to advocate for changes.

The city of St. Petersburg, Florida, recently signed on to become a WHO Age-Friendly City. With a population of about a quarter million, 18 percent of them are 60 and over. They joined the global network just last year. They convened stakeholders, listening posts and sessions all around the city to gauge community interests and needs, and they identified three priority areas to start: cheaper parking, better access to public transportation and more green space. They will go on to develop a five-year plan with short-, mid- and long-term goals.

New York City is also an official WHO Age-Friendly City. With five boroughs, they refer to themselves as a City of Neighborhoods. As part of their commitment to [the] Age-Friendly [initiative], there is a person in city government who works with each of the boroughs to identify their short-, mid- and long-term goals. For example, Manhattan created a multilingual neighborhood resource guide as a short-term goal. The Bronx decided as a midterm goal to create a plan to better inform older adults of all the neighborhood resources. Both Manhattan and the Bronx plan to improve street crossings and sidewalk access, adding countdown clocks. And both identified as a long-term plan to develop and implement age-friendly training for bus drivers.

The Village Movement

The Village Movement is another example of how people are reorganizing and restructuring society in response to the aging of the population. The Village Movement started with people like me sitting around a table in the Beacon Hill neighborhood of Boston. They wanted to stay in their homes as they aged. To achieve this, they recognized that they could anticipate needing help, both for themselves and to maintain their homes, and that they needed stronger social connections. They

formed Beacon Hill Village as a 501(c)(3) nonprofit organization. They conducted research in the community on what people felt they needed, formed a board of directors, developed a membership structure with dues, and designed programming. They also set up a vetting system for service providers, much like an Angie's List, so that members could trust the providers that BHV referred them to. They developed a manual and guidelines to help other villages get started, and sold it as a fund-raiser for BHV. They worked with a capital investment firm that underwrote and helped them form the Village to Village Network (VtoVNetwork).[10] VtoV is an association of member villages focused on helping communities establish and effectively manage villages. There are 200 villages currently in operation, with another 185 in formation, primarily in the U.S. Villages are small businesses, membership and volunteer driven, most with minimal staffing. Most villages collaborate with Area Agencies on Aging and with community partners and offer vetted and discounted providers. Membership numbers range from under 100 to the highest at 450.

Villages tend to reflect their geography. Most are in middle-class and upper-middle-class urban or suburban neighborhoods. There are a few rural villages, most of which cover a much greater geographic area. The average number of members is approximately 150. The highest numbers are Beacon Hill Village and Lincoln Park Village, both at approximately 450 members.

Research on the Village Movement is being conducted by Andy Schearlach and his team at Berkeley, and by Roscoe Nicholson with the Mather LifeWays research institute. Most recently, Scharlach published an article on the predicted sustainability of Villages.[11]

As Anna points out, the villages are a way to recreate a sense of family and belonging. It can be a creation of an extended family in the midst of strangers, people who share common interests and are able to help each other out when the need arises.

Villages are not structured financially like a CCRC [continuing-care retirement community], but act more like a neighborhood membership organization. They might link people to services but do not typically provide anything other than services provided by volunteers and

[10] See the network's website at http//www.vtovnetwork.org.
[11] A. E. Scharlach, A. J. Lehning, J. K. Davitt, E. A. Greenfield and C. L. Graham, "Organizational Characteristics Associated With the Predicted Sustainability of Villages," *Journal of Applied Gerontology* (February 2017): 1–23.

perhaps social-work coordination of services.

Technology and Older Adults

I want to start with a caution about the leap to using technology to replace human contact when it comes to solutions for older adults. Louise Hockley and John Cascioppo are researchers at the University of Chicago who have done much of the research on the impact of loneliness. We need to consider this: The moment we can eliminate a task, we downgrade the relevant skill involved to one of mere mechanization. We need to weigh future interventions against our evolutionary design as social animals. For example, driverless cars may be in our future, but how will this innovation benefit someone who needs help getting to the car, getting into and out of it?

I believe that economies of scale for service delivery will force expanded urbanization and communalization. Universal design and smart homes raise the issue of privacy and confidentiality, but our notions of privacy have evolved rapidly, even over the past decade, with the introduction of smartphones, apps and instant communication.

Data, logistics and crowdsourcing are driving our future. Men like Jeff Bezos (Amazon), Mark Zuckerberg (Facebook), Garrett Camp and Travis Kalanick (Uber), Peter Theil and Elon Musk (PayPal), and Brian Chesky, Joe Gebbia and Nathan Biecharczyk (Airbnb) are reshaping how we shop, communicate, travel, bank and even where we live. As start-up companies turn their attention on applying innovations to the needs of older adults, we need a seat at the table.

Where is all of this going? My first position out of graduate school in 1980 was to start a home-sharing program. It was a hard sell then, but now we have Airbnb, and a growing cohousing movement, and a sharing economy, and evolving ideas of privacy. Will all of these companies be around 20, 30, 40 years from now? I don't know, but today they are changing our way of thinking about how we live and how we all will grow old.

PHYLLIS MITZEN: And by the way, I do have all the answers: the Magic 8 Ball.

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