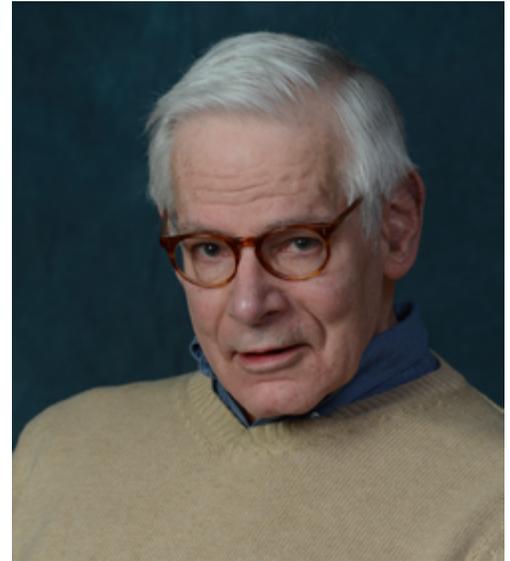


## In Memory of Robert L. Kane, MD

By now, most of you have received the sad news of the sudden death on March 6 of Dr. Robert Kane, world-renowned expert on aging and director of the University's Center on Aging as well as the Minnesota Evidence-based Practice Center. Bob's unexpected death is a staggering loss that has sent shockwaves of grief around the world. For those who worked closely with Bob day to day, the reality and scope of his absence has barely begun to feel real. On the Friday before Bob died, he was finalizing his last editorial column for this edition of *Old News*, which you can find on page 2. In that last column, Bob outlines his ambitious vision for not just improving long-term care for older adults, but completely rebuilding it from the ground up. True to his rigorous form, Bob felt there was little sense in sticking bandages on an inherently flawed product that no one rightfully wants.

Over his entire career, Bob was a tireless champion for the rights and wellbeing of older adults, and his most recent endeavor, *The Long-term Care Re-Think Tank*, is making promising inroads toward that end (*Bob's obituary* asked that in lieu of flowers, donations be made to the Re-Think Tank, among other causes). Bob's monumental intellect was widely known; that he dedicated such a mighty force to improving how we care for each other is a fact of such fundamental compassion that it will be remembered by all who knew him. Bob was so much more than an international expert, respected professor and researcher, and widely published author—though he excelled at all of those roles. He was also a fierce and heartfelt advocate for the many students and colleagues in his midst, whose aspirations he supported with a devotion parallel to none. Bob's high standards and charming toughness had a way of fostering the best in everyone around him.

"Bob had two core drives—active compassion and intellectual honesty," says Mary Butler, assistant professor in the Division of Health



Robert L. Kane, MD (1940-2017)

Policy and Management and co-director of the EPC. As one of Bob's closest colleagues, Butler observes that both Bob's compassion and intellectual honesty found a perfect home in his long-term care and aging work, but that these drives were equally applied wherever he found an opening. "He didn't advertise his compassionate acts, so it's easy to understand how someone may not have known," Butler says. "But the number of current and former students and faculty and community members he mentored is staggering and matters more than the impressive number of articles or books he wrote. And all of Bob's mentees wanted to believe we were most special to him."

**Please watch for our summer 2017 issue of *Old News*, which will be a tribute to Bob's life and work. Bob is and will forever be so dearly missed.**

### *In this Issue*

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# Old News



University of Minnesota  
Center on Aging



MAGEC  
Minnesota Area Geriatric  
Education Center

# The View From Here

## Where are We Going with Long-term Care?



Dr. Robert Kane (1940-2017)  
Director, Center on Aging

Long-term care (LTC) was never planned. It was never even consistently defined. A generally useful definition for LTC is that it is a set of services to assist people who have lost, or never acquired, basic capabilities for self-care and management. An important trust of this definition is that it is not centered on medical care, although LTC recipients typically need such care as part of a larger service package.

they are dependent on others for their intimate care. They do not want to be infantilized and over-protected. They want the right to take informed risks. It is safe to assume they also want competent medical and nursing care, but this is not at the top of their list.

If we used these common descriptors of what people want as a criteria checklist to rate how well we are doing with LTC today, we would have to give ourselves low marks. Much of this failure stems from LTC's origins in medical care. It was always the poor relation but no one ever looked to see if that was even the goal. This is why, as I've said, small steps will not suffice. This is no time for replacing roof shingles. We need to tear down the house to its foundations and rebuild according to a new set of blueprints.

The underlying drivers of LTC differ substantially between younger and older people. Younger people with disabilities typically suffer from congenital or acquired conditions that do not necessitate active and ongoing medical treatment. Their social goal is to live a full life with active participation in all aspects of society. By contrast, the need for LTC among older people typically arises from one or more medical conditions. Their goal is to preserve their accustomed lives as much as possible, but many have accepted the idea that aging is synonymous with frailty. Their efforts are devoted to avoiding being placed in institutions.

LTC was the product of unforeseen circumstances, shaped by responsive acts around regulation and payment. The centerpiece and reference point has been the nursing home, which was conceived as a miniature hospital with minimal technical capability. Modest care comes too often at the cost of personhood. Public debate about LTC policy focuses on cost. But buying something you don't want, even at half price, is no bargain.

Given the growing demographically driven demand for care at a time when we have relatively fewer people who can provide care or financing, it is essential to recognize that simply doing more of the same will not suffice. To the contrary, it will bankrupt us. This crisis should be seen as an opportunity. Small fixes will not work. It is time to start over to build a LTC system that provides what people say they want.

### What People Want

The place to start is with what people say they want in LTC. When we talk with those who give or receive LTC, we hear a common set of descriptors of what they value. They talk about choice and autonomy or control. They want to be seen as people with a life and a personality, not as some inanimate object to be tended. Ideally, they want to contribute to the world around them. They want respect and dignity, even when

Those blueprints should be drafted and the new system built around a recognition that LTC is based on three components: 1] personal services, 2] living setting, and 3] medical care (largely for chronic conditions). The nature of a person's needs for care should not dictate where or how that care is provided. No solution will fit everyone. We need options and flexibility. Personal preferences and circumstances will require adaptation as well as inevitable trade-offs. For different people, some elements will be more crucial than others. Ideally, the choices should be left to each recipient, but when public dollars are involved, some efforts at efficiency will be necessary.

### New Blueprints, New System

To identify and build LTC systems of the future we must begin by thinking creatively about alternative ways to package the three core components of personal services, living setting, and medical care. We need to emphasize what we want to buy before we start debating how to pay for it. No one can deny the importance of a financing and payment structure, but this discussion should not precede defining the product we want. While proactive medical care is a core ingredient in any system addressing persons with multiple chronic conditions, the goals of LTC transcend medical and nursing care to address what makes life meaningful, even for people with few resources.

The social transformation will require a major shift in public perceptions of LTC. To get public backing and legislative support, LTC must be viewed as a valuable service. Political candidates should campaign on improving it and investing in it. Too many people see LTC as a necessary social service, but one that fails to provide any important benefits. Contrast the public's perception of LTC and hospice care. The latter is viewed as much more effective, largely because it has defined an achievable goal of making the last phase of life as positive an experience as possible. As a result, it is much easier to recruit workers and raise support for hospice care. LTC, by comparison, is charged with keeping safe and

*Continued*

slowing the rate of the decline of those who receive it, while compensating for functional losses. Demonstrating the success of good care requires having some comparator by which the public can see the benefits of slowing decline and associated care.

### **Risk, Technology, and Personal Preference**

A key element in these discussions is our tolerance for letting older people take risks. In the name of protecting those we define as vulnerable, we run the risk of infantilizing them. Although they may be dependent, they are not children; most are capable of making thoughtful decisions if given adequate information on the benefits and risks of alternatives. Over and over, autonomy sits at the top of the preferred attribute list for LTC, but concerns about safety threaten it.

Thinking creatively means casting aside familiar ideas and issues to identify new ways of doing things. In an era of blossoming information technology, it seems likely that information technology (IT) can and should play a central role. IT provides the means for distance monitoring (but not giving care). It allows social interaction without leaving home. It facilitates supervision, including prompting, and thus may supplement, or even supplant, some training.

Choices around living arrangements will vary with personal preferences. Some older people will want to live among younger people, including their caregivers. Others will prefer being with people more like them. With higher needs, especially for unpredictable services such as toileting, some degree of congregate living will be needed to reduce caregiver travel time. But congregate living does not mean ceding control of one's life. An older person should still control access and determine the daily schedule.

### **Rewarding Good Care**

Eventually we will have to confront some major issues around payment, regulations, and resources. Given its tawdry origins, it is not surprising that the nursing home has been heavily regulated. But regulation is, at best, useful for addressing poor performance. We need an approach that rewards good care. Many people have given their careers to implementing the extant regulations and will have problems ceding any ground, but we must. The LTC world today is different from what it was when Medicaid began. Regulations should support program goals, which, in turn, should be based on desired attributes.

Payment should reinforce regulations. Some form of quality-based payment is needed, which rewards achieving these attributes. Some efforts will need to be retained to counter abuse and neglect, but the major thrust should be positive, not negative. The larger payment question is whom to pay. The aspirations for LTC are anti-institutional. Community care will require a continuing active role from informal caregivers, who are under increasing strain as their numbers diminish and the demands on their time increase. At a minimum, people should not be penalized for receiving informal care. One way to address

that is to offer some discounted payment in lieu of covering services directly. This cashing out of benefits approach has been used in Germany and elsewhere as part of a larger effort to support consumer-directed care. It is growing in our country, as well. However, marrying a cash payment to an outcomes incentive poses challenges.

### **Reassessing and Reassigning Resources**

The related question is, who should be covered? Unfortunately, people are increasingly entering retirement with very limited financial resources, certainly not enough to weather any LTC challenge. Efforts at inducing private LTC insurance have foundered for various reasons, but primarily because a voluntary program is actuarially unsound. Some variant of universal coverage will be needed for core services, with allowance for people (or families) to top off that amount. The coverage should be limited to services and not housing. We have a long-standing tradition of allowing people with greater financial resources to live in better accommodations and providing more modest ones to those in need of support.

Another challenge is what to do with the heavy real estate investment in LTC. Both for-profit and non-profit organizations have invested a great deal in buildings in which to provide LTC. Much of that care is the institutional variety we are working to eschew. Some institutional care, for persons who have lost touch with their surroundings, may be needed still. Some can be converted to post-acute care, already an area of growth in the nursing home industry. For many good reasons, LTC and post-acute care should be more separated. However, much of the real estate infrastructure will need to be discarded. Nursing homes regularly complain that the government made them what they are today and needs to look out for them. Some form of corporate welfare may be needed.

### **Garnering Public Support**

Essential to the new world of LTC will be useful consumer information. Clients and families need better information about what works best for whom in order to make informed decisions. They also need clear information about the quality of service providers. We have made modest inroads into collecting limited amounts of information about nursing homes and home health, but not around the attributes of care deemed most salient by those receiving said care. If we hope to bring about the changes we deem urgent, we need to garner public support. The public will not likely champion a service they see as failing. We need better information that demonstrates the benefits of good care. We do not have a widely used method to compare care outcomes with what would have occurred in the absence of such care. But we know how to build such methods, and build them we must, so that we can set to work rebuilding the system itself. Ultimately, people deserve care that aligns with their priorities and preferences, care that honors their dignity and respects their autonomy as much as possible for as long as possible. Care that fails on those counts is care that no one wants.

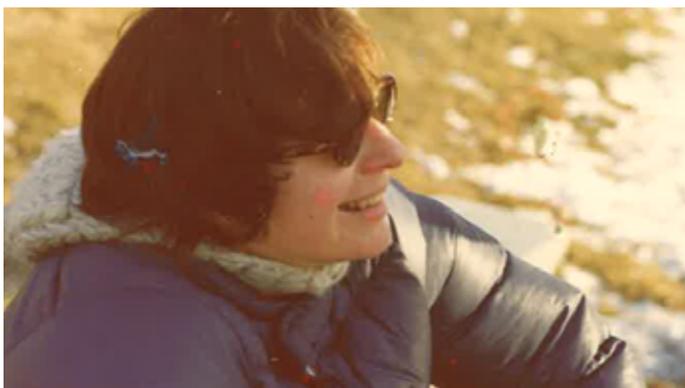
# Perspectives On Retirement

This series explores the diversity of responses and levels of enthusiasm for retirement, especially by those who have invested extraordinary effort in and devotion to their careers. We're interested in how people adapt to this next stage in their lives. Each issue of *Old News* features interviews with retirees—some early in that process or even on the cusp of it, and others who are many years or even decades into their retirement. We are trying to assemble a set of varied experiences, but ultimately we will go where the trail takes us. If you know of a story we can tell (including your own), please let us know. If you have not yet retired, but are thinking about it, share your thoughts with us as well.

## Celia Wolk Gershenson: Taking on the Next Chapter

Celia Wolk Gershenson drinks her coffee from a mug that says, *Well Behaved Women Rarely Make History*. "When I first came across this mug, I bought several as gifts for my daughters and students," she says. Fitting, for a woman who entered the field of experimental psychology at a time when it was dominated by men. "More specifically, I'm a behavioral psychologist," Gershenson clarifies. "There were very few of us in graduate school in the 1950s. It's still not overwhelmingly female. But then, I had the influence of my father, who brought me up after my mother died of colon cancer when I was 12." Gershenson's father never remarried. "So I was without traditional feminine 'training.' My father was progressive, and as long as I wanted to study, I could do anything." Gershenson suspects her experience as an only child was also influential. "I spent a great deal of time around adults—I was listening all the time. Inadvertently or unconsciously, I brought that quality forward into my life," she says. "I listen to what other people have to say."

At 81, Gershenson is now retiring gradually from her work as adjunct associate professor in the Department of Psychology at the University of Minnesota. "I have many things to do," she says. "Certainly more reading, a little travel. But the fact that I can keep intellectually and socially active—I attribute that to my cumulative experiences. I'm still on the executive board of the Center for Cognitive Sciences. And I was recently asked to write a book chapter for the third volume of *Behavioral Science: Tales of Inspiration, Discovery, and Service*, edited by Henry Pennypacker." Gershenson sees these projects as just the first of her activities during retirement, whenever it finally comes to pass. "I am pulling back," she says. "I'm slowly contemplating full retirement. Maybe this year. We'll see."



Celia Gershenson

### The Road to Scholarship

Born in Brooklyn in 1935, Gershenson lived most of her life in Manhattan. "My father was a watchmaker by profession but basically a self-taught scholar, particularly in Jewish history, Judaica, and religion, but in a lot of things, really." Both of Gershenson's parents came from Bialystok and then met and married in New York. "My father was one of a large number of young men trying not to be drafted into Soviet army—this was the 1920s. He came to New York and lived with an uncle. The uncle wanted to send him to seminary, but my father wanted to work to bring his parents over. That's why he never got a degree. Nonetheless, most of the Judaica you see on these shelves was his." Gershenson gestures toward the beautiful glass-fronted shelves that span an entire wall floor to ceiling. "In fact," she says, "he had these bookcases built specifically to hold the better part of his library. Education was extremely important to him."

Gershenson attended Jewish day schools through high school. "My high school was small and comparable to many of the very elite private schools of the time. We had a class of 19, and six of us had Regents scholarships in New York when we graduated." Gershenson was ready for such rigor thanks to her unique co-ed elementary school. "That was unusual then. According to custom and the laws of the Talmud, girls were not expected to study much and certainly not the Talmud. But this school was named for a very progressive orthodox rabbi whose son was even more contemporary and involved in the world. He decreed that girls and boys could study everything and study it together. I think my elementary school was the only Jewish day school in the city where that was the case."

After high school, Gershenson studied psychology at Barnard on scholarship. "Money was an issue. My father was a good watchmaker, but it was feast or famine." As for expectations of college women, the norm at the time was "for graduates to be engaged by senior year and married shortly thereafter," Gershenson says. Nevertheless, Barnard was academically intense. "Barnard's president said, 'Many of you will get married and have kids, but remember, you still have a brain.'" Like its sister colleges, Barnard earned a reputation for producing female graduates who went on to graduate and professional school, particularly in the sciences.

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## Breaking into a Male Dominated World

Gershenson expected to be a school psychologist—a career in the “allowable” category of education. “I definitely didn’t want to be a teacher. I was interested in math and even more so, science. I was one of the only girls in my high school class on par with the boys in science.”

But after a couple of courses in school psychology, Gershenson was bored to death. “Luckily, at Barnard, we all had to take an experimental psychology class. Those courses at Columbia were taught by two of the most serious scholars in the field of behavioral science—Fred Keller and Nat Schoenfeld. The two primary centers for behavioral psychology were Harvard and Columbia, and Columbia was the partner school to Barnard.” Still, Gershenson would not have been exposed to Keller and Schoenfeld as an undergrad at Barnard, “except that my psychology instructor, Donald Cook, who later became a mentor and friend, asked us to read one chapter of a book by Keller and Schoenfeld, *Principles of Psychology*. I still have it.” Gershenson went back to Cook and asked for a copy so she read the whole book. “That set me quickly toward an interest in a behaviorist viewpoint.”

Columbia was a natural choice for graduate school. Early on, however, Donald Cook warned Gershenson that Nat Schoenfeld didn’t like women and didn’t accept many female students. “He said, ‘He will be hard on you, but if he takes you, it will be good.’” During her first year at Columbia, Gershenson took an introductory course on learning with Fred Keller. “He was legendary—one of the best teachers ever. He didn’t think lecturing was the best way to learn and developed a method where you studied at your pace and took exams as you finished.” The culture at Columbia influenced Gershenson for the rest of her career. “It was like a family. Everyone looked out for each other. It was expected that we were not in competition. Instead, everyone was supportive, including faculty. They would come to our student parties—they’d bring a bottle of scotch, stay for a half hour and leave, or we’d all go out together. Meanwhile, they pushed us toward our best work. I learned at Columbia that being on faculty meant more than just research and teaching. It meant mentoring and fostering the next generation.”

When Gershenson was nearing completion of her PhD at Columbia, working on her dissertation with Nat Schoenfeld, an instructor position opened up at Hofstra College. “It was hard for women to get teaching jobs then,” she says. “Nat said, ‘Please apply, I think you could get it. You’ll finish your dissertation over the summer.’” Gershenson was soon commuting from Manhattan to Long Island, teaching a heavy load of undergraduate courses.



Celia, Hillel and oldest daughter Simma



Celia and Hillel

That’s when she met Hillel, the man she would eventually marry. “It was the spring of 1962,” she says. “His first cousin lived a couple of floors down from my apartment. He was visiting his cousin, and we ran into one another.” Hillel had a two-year mathematics instructorship at Princeton. “After we married, we spent that next year at Princeton,” Gershenson says. “But the commute to Hofstra became too much for me. I thought if I gave up my position I might finally finish my dissertation.”

## An Equal Marriage in an Unequal Time

After Princeton, Hillel taught mathematics at Cornell from 1963 to 1968 before being offered an associate professorship at the University of Minnesota. “I was still supposedly finishing my dissertation, but by then there were three children two years apart each—1964, 1966, and 1968,” she says. Mainly, it was simply challenging to pick the research back up after having set it aside. “Hillel was very supportive, though,” she says. “We had an equal marriage at a time when equal marriages were uncommon. Not completely equal, of course, but Hillel helped with childrearing and our schedules were such that one of us could always go to the kids’ activities. That was important. So you see, some of the feminist revolution I didn’t quite understand until later, because of my unusual upbringing and my marriage. Some of the things women really had to fight for, I did not. And I can’t say how lucky I think I am.”

Twelve years after completing her PhD coursework, Gershenson finally wrote her dissertation at the University of Minnesota based on an extension of her work at Columbia on learning and response variability. She then received a post-doctoral fellowship in the University’s physiology department. “I tested color vision in ground squirrels using behavioral methods and my minor in visual perception,” she says. From then on, Gershenson has been an active member of the University community, while also participating in several professional organizations, including the Association for Psychological Science, the American Psychological Association, and the Association for Behavioral Analysis, or ABA. “ABA is my main organizational affiliation. Through the ABA she has bonded with a small group of like-minded women. “There were about five of us—I was the youngest—and we discovered that all of us had atypical upbringings for our time, maybe even for now.”

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Despite her long academic career, Gershenson has never held a tenured position. “My work was primarily supported by research grants,” she says, an outcome tied in part to the lengthy gap between her PhD coursework and dissertation. “I tell my students to finish their PhDs before accepting a job,” she says. “It’s just too hard to do it while you’re teaching full time. And it’s too hard to go back to it after you set it aside.” Now, entering retirement, Gershenson says she’d like to catch up on some writing. “Things that are worth publication,” she says. “I had less confidence in my abilities than I should have.”

### A Mentor to Many

Gershenson feels her most important contributions have come through supporting students and championing more diversity in post-graduate education. “For about 20 years, I was active in the National Science Foundation (NSF) summer program, whose purpose was to increase the diversity—not just ethnic but also socioeconomic status—of the students going on to graduate school. We helped bring students in from underrepresented groups and also people from historically black institutions and first-generation college students.” Gershenson served for several years as director as well as co-director of that NSF program. “Throughout my career, I encouraged students at all levels to succeed and to push forward. I found fulfillment mentoring and supporting and nurturing students into their careers as scholars, researchers, and faculty members.”

Gershenson also feels good about her role in shaping the careers of other women. “Part of my mentoring was talking to women who weren’t sure they could do it, even though they were exceedingly capable. When an advisor tells you that you cannot do mathematics and you are excelling in mathematics, that doesn’t help. I like to think I helped counter some of that. And likewise, I can think of at least five women who guided me along the way, all of whom were much more productive than I was.”

### A Time of Caring and Transition

In 2011, Gershenson’s husband Hillel retired. “He was ill for three or four years,” Gershenson says, “before he died in August 2016. ALS and frontal lobe dementia were diagnosed in 2014. Before that, they thought it was mild cognitive impairment. But then the ALS kicked in. There is a history in the family, we discovered.”

Gershenson received profound love and support from her daughters—Anne, a research professor in biophysics at the University of Massachusetts, and Simma, a development director for a nonprofit in England. Gershenson’s youngest child, Rebecca, died 17 years ago of non-Hodgkin’s lymphoma. “She was completing her women’s studies PhD at Rutgers,” Gershenson says. “One chapter she finished has been published.”

Gershenson says her grief over Rebecca’s death helped to prepare her for losing Hillel. “People who have lost adult children have a particular experience,” she says. “I would never diminish the grief of losing a baby, which is also particular, in that you never get to know that baby. But theoretically you may, and many people do, have another child. When your daughter is

33, well. And something like that can either make the marriage more difficult or bring people together. Hillel and I got through it together.” Gershenson points to a beautiful photograph of Rebecca. “Hillary Clinton says it takes a village to raise a child,” she says. “It also takes a village to console.”

Gershenson’s role as a caretaker shifted last year when Hillel was no longer able to be at home. “I was visiting him several times a week. He was in an incredible residence, Welcome Home. He had two aides on all day, no regimentation, meals cooked to order, incredible care. Also, because the costs were fairly modest, I didn’t have to sell the house. I have since, but not for that reason. The care wasn’t cheap, of course, but it was unbelievable in terms of quality. One of my good friends was unhappy with where her mother was when Hillel died, and she recently told me, ‘Oh by the way, my mother is moving into Hillel’s room!’”

### The Shape of Days to Come

The decision to retire has been complex, but feels right. “One, it’s time,” Gershenson says. “Although I do feel I am still functioning cognitively and intellectually. I was pleased to feel this in May as I was talking to a younger colleague.” As for adjusting, Gershenson says the hardest part for her, even now, working part time, is keeping to a schedule. “For the last six or eight months, I didn’t have to go out every day and I didn’t,” she says. “My whole schedule revolved around Hillel, as it should have. But that meant that I have not been involved in the way I once was. Of course I am still grieving. I had to learn last year that sometimes I just had to accept that yes, I have these things to do, and yet I can’t do anything. That’s the situation and I’m learning to accept it. I’m also asking myself objectively what changes I will have to make with aging.”

One such change has been Gershenson’s recent move. In May, she sold the house she and Hillel had lived in for decades and moved into The Kenwood, a senior high rise near downtown. “It’s interesting here,” she says. “Full of intellectuals and liberals, and they have activities going on all the time. In the beginning, while I was still caring for Hillel, I wasn’t very involved here, but that’s changing now. But I also still have my community of 40 odd years. That’s exciting to me, to maintain my longtime relationships and also be surrounded by interesting new people with varied histories. And, realistically, it’s nice to be somewhere that offers levels of care for aging in place. I’m independent now, but that could change in the future.”

After having found much comfort in her work with students during the last year and a half of caring for Hillel, Gershenson fears losing contact in retirement. “But I’ll find other ways to connect with students,” she says. Just recently she met with her neighbor’s granddaughter, a high school student interested in studying psychology, to talk generally about colleges and summer research programs and the kinds of things to look for. “I also have a student for whom serve as co-advisor,” she says. “And I’m active in the Center for Cognitive Science. Plus, the timing of this invitation to write the book chapter is simply perfect.”

## Within, Among, and Beyond: Hal Freshley



Hal Freshley

Throughout his life, Hal Freshley has been enthusiastically curious, a trait that led him not only to a long and influential career in gerontology, but also through a thicket of questions regarding religion and spirituality that began early, guided much of his life and work, and continue to this day. A graduate of Pepperdine University in psychology and art history, Freshley earned his PhD at

the University of Oklahoma with a focus on aging issues. "That was before aging was vogue," he says. After long serving as a researcher then principal planner for the Area Agency on Aging (then part of the Metropolitan Council of the Twin Cities), Freshley joined the Minnesota Board on Aging in 1997 as a planning and policy coordinator. He retired in 2011—one year after being honored with the Minnesota Gerontological Society's Dutch Kastenbaum Award.

"I tried to be a watch dog and a diplomat," Freshley says. "A watch dog for the best, most effective and efficient use of public funds for aging, and a diplomat with the people from whom I needed information in order to complete our studies and understand how money was spent and what the outcomes were. I relished my work. It was fascinating to me."

Freshley's guiding question was, "If I leave work today, get hit by a truck, will I regret it, regret how I spent my life? The answer was always no. I invested my life well," he says. "Not everyone is lucky enough to have a job they find fulfilling. Or to feel they can leave the campground cleaner than they found it."

### Religious Complications

Born 1946 in Santa Fe, New Mexico, Freshley was raised by missionary parents who were members of the Evangelical United Brethren. "My parents met while teaching at the McCurdy mission school," he says. "They'd been married for seven years and had moved on to teaching in the Santa Fe public schools when I was born. Dad taught biology and math and coached football. Mom taught history, English, even home economics, though she hated cooking. In a small school, you do what's necessary."

Freshley never rebelled against his parents' religion, but he became curious early on. "When I was about six, I asked Mom about the Apostles' Creed, 'What does this resurrection of the body mean?' She explained that our bodies would come up out of the ground and we would recognize each other in Heaven, which simply never made sense to me. I never wanted to believe anything that seemed unbelievable. I couldn't do it."

When it came time for college, Freshley chose Pepperdine in Los Angeles "because I had a scholarship and it was in Los Angeles. I knew nothing else about it. No one advised me." Pepperdine is a Church of Christ school, which pleased Freshley's parents because it was religious. "But Pepperdine was more than religious, it was fundamentalist," he says. "They didn't believe in pianos or organs, and we couldn't miss chapel or we'd get kicked out, that kind of thing. I did fine, but it turned me against organized religion until much later in life."

### An Accidental Path to Aging

Given that not only were Freshley's parents teachers but also his grandparents on both sides, he assumed would also teach. "My sister did become a teacher," he says. "But I took a few education classes and it was all rote, rote, rote! I was not cutout to be a memorizer." Instead, he double majored in psychology and art history. "And since I had no specific plans when I graduated from Pepperdine, one of my professors pointed me to a clinical psychology program at University of Oklahoma. Unfortunately, that year there were three suicides in that department. Even the guy who was assigned as my advisor committed suicide. It was something of a struggling program."

Freshley found his way to the University of Oklahoma's medical school, which offered a program in human ecology, combining anthropology and health. He earned his master's degree in social psychology and continued with PhD coursework while employed in a number of research positions, beginning at the Oklahoma Medical Research Foundation. "Those were good years," he says. "I loved what I was studying. Outside of school, I was living on a commune, being a hippie. I was very idealistic." Freshley found his academic jobs engrossing in the best way. "At the foundation, I was a data coder, which was so interesting. Then I got into the relationship between health and culture, health and behavior, and cultural perceptions of health. I wrote my thesis on the concept of 'helping behavior' because I was working for a guy doing a cross-racial study on who helps whom. I loved it!"

By his late 20s, Freshley had completed coursework for a PhD but had yet to write the dissertation. "So I took a research assistantship in Missouri with a guy studying what happens when people grow older and lose their health and their social ties. I got totally interested in aging then. Especially how chronic illness and aging interact with one another and influence social status and roles in the community." After completing his dissertation in 1977 at age 31, Freshley took a post-doctoral position at the University of Michigan School of Public Health. "That's when I discovered I'd never be an academic. It was so competitive. People actually 'stole' each other's ideas and tried to undermine each other. I liked the culture at the other schools, even Pepperdine, but not Michigan." On completing the post-doc, Freshley looked for positions outside academia, and accepted one at the Twin Cities Metropolitan Council Area Agency on Aging.

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*Hal Freshley and his poodle Beechum*

Ironically, the projects Freshley is most proud of from his years at the Metropolitan Council are what he now calls failures. “For example, we attempted to figure out the total dollars spent on human development in the Twin Cities metropolitan area in one year—health care, education, mental health, everything related to increasing or improving human capacity. For three years this project took huge amounts of effort, but in the end, no one was interested. No single entity is in charge of all that money, so no single entity truly cared how it was spent. Counties wondered what the Council wanted with information on their health and welfare spending, their policing, etc. We couldn’t sell our data it and it was too much work to do on our own. Politically it was just stupid. But I loved it.”

Freshley’s transition from the Metropolitan Council to the Board on Aging was inspired by a friend’s life-changing experience in the Peace Corps. “She came back having learned so many new things; I decided I was ready for a new job, and there was one open in aging at the State level. I took it. I was 51, and it was kind of a midlife—well, not crisis, but challenge.” At the Board, Freshley directed many successful initiatives including oversight of the Eldercare Development Partnership Programs as they transitioned into their technical assistance roles with community service providers, the biannual report to the Legislature on Minnesota’s Long-Term Care System, and a three-year Administration on Aging planning grant focused on evidence-based health-promotion strategies. His commitment to the best interests of older adults made him a trusted member of the aging network in Minnesota.

### **Passing the Baton**

Freshley felt he couldn’t retire until someone was ready and waiting to do an even better job than he had. “In 2011, when I was 65, Kari Benson appeared. She was younger, smarter, faster,

and cared about the work as much as I did. Her heart was in it. I could leave then, because she would be there trying to make the best possible system for older adults.”

At first, Freshley tried easing out, thinking it would be easier than quitting cold turkey. “I started with a six-month partial retirement, but it was awful. I was a lame duck, working with people who knew I was no longer fully on staff. Plus, I was half-time, but most people could only meet over lunch or after work, so I was putting in full days, anyway. I even had to pay for my own parking! Basically, I felt underpaid and unappreciated. That ended up being a good way for me to disconnect from work I had loved, because I wasn’t yearning to be there anymore under those new circumstances.”

Full retirement started off busier than ever. “Right away, I joined a gym and lost 30 pounds. I read books by the bagful. I did a ton of gardening. I felt fantastic! I started traveling a lot because that’s something I hadn’t done much during my work years, because I didn’t like that feeling of relaxing only to have to rev back up. So I was making up for lost time, I think. I went to England with the Minnesota Horticultural Society and I took some long road trips—Nevada, Wyoming, Ohio, the Blue Ridge Mountains—with my standard poodle, Beechum. I had this romantic idea of John Steinbeck’s *Travels with Charlie*. But frankly, I hated it! The driving, staying alert, always remaining attentive to road. Even Beechum didn’t like it. Eventually I realized I didn’t have to do all these trips. It took me months to finally relax, to not need that perpetual stimulation.”

### **An Unlikely Pastor**

Once Freshley finally relaxed, he found an unexpected way to fill his time: pastoral care. “It surprised me,” he says, “considering my aversion to organized religion. Pastoral care was not what I would have predicted for myself.”

Yet, such work sprang quite naturally from the spiritual practice Freshley had maintained all along, including during his hippie days in Oklahoma. “Where I live now, a row house on St. Paul’s East Side, a place where pretty much everyone has lived in a commune at one time or another,” he says. “So we have these communal traditions like work days in the yard in the spring and so forth. A bunch of my neighbors are musicians, too, so we sing as we work, all the old hippie songs. Back in 2001, one of the guys invited me to come sing in his choir at the Unitarian Universalist Church.” Freshley agreed to go once—and loved it. “There’s something about singing, 60 people all breathing together and listening and seeing how you fit into the sound of the whole thing. It’s a meditation. I’d go after work on Thursday nights tense and exhausted, and by the end of choir practice I’d be in tune and relaxed.” Freshley never planned to join the church, but over time discovered that the Unitarian Universalists don’t ask anyone to believe anything, but rather to explore their own beliefs. “That was interesting to me. I discovered I was part of community without realizing it. So after a few years, I joined officially.”

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Then as soon as Freshley retired, one of the ministers asked him to join the pastoral care team, which involves reaching out to parishioners, often older adults, who can't attend church for various reasons. "I thought she was nuts. I'm a researcher, not a one-to-one person! But I started visiting people anyway."

### Long-term Care from the Other Side

One important relationship Freshley formed through pastoral care was with Mary, an older woman with dementia who was living independently. "She was an artist, no children, two brothers both dead, and she couldn't remember the names of her sisters-in-law. I got to know her banker, became power of attorney, and through that experience I learned that the health care system for people with dementia is just awful."

Despite years of striving to create the best, most accountable long-term care system possible for older adults, Freshley found the system didn't work as he expected. "Once you get on the other side, trying to get the services to work for a person? Oh my god, what a fiasco! In so many ways, what's offered is not aligned to what people want. And home care was a huge challenge. The companies we tried to hire had multiple employees that only worked specific shifts, etc. So in any given week Mary might have three or four different caregivers. She couldn't form relationships with them, and her condo building wouldn't give security cards to all these people. I had to keep the security card and go back and forth letting caregivers in." With home care, Mary could have lived in her own home longer, but instead she was placed in a memory care unit against her will. "I was even threatened by one of the condo people that if I didn't get her moved out of there they would call adult protective services and accuse me of keeping a vulnerable person in an unsafe environment," Freshley says. Mary's neighbors had known her for years, but because she had dementia, they no longer wanted her in the building. "Mary has passed away now. I was with her till the end."

As he witnesses the aging journey through pastoral care, Freshley feels more prepared for his own aging journey. "It's sometimes painful, but it seems real instead of unreal," he says. "It's not unknown to me anymore. It's going to be known."

### Aging as Spiritual Journey

"Aging is really a series of losses," Freshley says. "Loss of spouse, loss of job, loss of mobility, just zillions of losses you go through sequentially. Of course it's good to stay active, but eventually, there will come a time when you no longer can. The question is, how do you meet that spiritually? Or emotionally, or psychologically, or however you prefer to think of it. For me it's spiritual."

Freshley takes comfort in his belief that we become what we practice. "If you have a particular mindset about something, it becomes real," he says. "And if you change your mindset, your changed mindset becomes real. About five years ago I was asked to pray for people at my church who were going into surgery, and I freaked out. Prayer was some superstitious goofy thing I didn't believe in. I asked the minister what to do, and he said we have to develop our own spiritual self. So every morning before I take the dog out I have a ritual, which is to think about three prepositions, within, among, and beyond. I do it while inhaling exhaling, each preposition three times with one breath each. Within is who I am within. Among is who I am among the people I am with. And beyond—that refers to everything that is beyond the current situation, the current life, current time. I do this meditation every day and it's never the same. I've gotten insights into myself, and I'm much clearer about how I interact with other people, and I'm more comfortable with myself in the 'beyond,' beyond string theory, relativity when you go way beyond, beyond and come back to where you started. Now, when people ask me if I can pray with them, I can. So it opened me up to a whole new level of awareness."

### Reflections of Ourselves

Freshley, who is gay, has no children and never married. "I do, however, have a wonderful community of emotional support. I don't need to be with them all the time, but I know they're there. When I had back surgery, my neighbors set up a bed in my dining room before I even got home from the hospital. That kind of support is essential. Staff, no matter how caring and kind, are not the same as the people who know and love you. Without those people, you lose that sense of people reflecting back who you truly are—not just as you are now, but as you have been. This is especially important as you age."

Preserving this kind of reflection of self is also a central aspect of retirement. "If someone is afraid of retirement, they might be afraid that no one will reflect back who they are or have been, or who they think they are," Freshley says. "We all need to have our worth reflected in some way." Ideally, one will already have built and nurtured a strong community of support long before retirement. "But then it still requires investment and maintenance," Freshley says. "You have to water your garden. Don't assume it will grow without some effort."

## Reflections of an Unprepared Caregiver: Pamela Parker

*In our March 2016 issue, Old News began publishing a series of interviews with long-term care reformer Pamela Parker, focusing on her own life story and its intersections with the history of long-term care in Minnesota. That history is so tightly interwoven with the fabric of Parker's life that at times the threads are indistinguishable. In this issue, we conclude our series with an intimate conversation with Pam about her transition to caregiver for her husband Dennis, who suffered from a serious stroke last summer. While the couple have four sons from each of their previous marriages, only one son lives locally, leaving Parker responsible for the vast majority of Dennis's caregiving needs.*

At age 69, Pam Parker was still in the process of retiring from the Department of Human Services—after an accomplished and sometimes frenzied career in long-term care and aging—when her husband, Dennis, age 82, suffered a massive stroke last June. Overnight, caregiving became Parker's new full-time job. The shift was abrupt, but not unexpected. In fact, Parker had worried about just such an event for twelve long years—since Dennis's first stroke at age 70. "That one started out minor," she says. "But a severe medical misstep led to a brain bleed, and basically everything that could go wrong did." Dennis spent 40 days in the hospital with relentless complications, and long-term recovery was slow. "Dennis was a practicing clinical social worker," Parker says, "and after the stroke, he gave up his license. But he did regain the ability to lead guided imagery and discussion groups at the Psychosynthesis Institute of Minnesota, which he co-founded in the 1980s. His deep wisdom was enhanced too, as can happen with near-death experiences. And he was able to go on with his life, with his warm, generous, loving spirit. We traveled and enjoyed season tickets to the theatre and opera. But he lost some of his executive function and eye sight. And I lived in constant fear of another stroke."

Then it happened.

Parker described Dennis's most recent stroke and its aftermath, including her new role as his caregiver, over a gourmet brunch in her home in South Minneapolis, a splendid Victorian furnished in period style with Persian rugs, ornate tile and columns, mirrored buffets, and stained glass. Brunch was equally opulent, with quiche and stuffed tomatoes, fruit and cheese, warm bread, salad with pear and blue cheese, and even flourless chocolate torte. "Cooking is something I have to do a lot of now," Parker says, "but it can be a creative outlet. I have company coming for dinner tonight and tomorrow. Tasks like shopping and cooking calm my mind, which is good, because I've always been active and busy. I'm not used to spending so much time at home."

### A Series of Unfortunate Events

Parker says Dennis's recent stroke was caused by an incident a week earlier, on Memorial Day weekend. "My mother—she's 92 and lives in Warroad—was here with us, so I thought, hey,

it's a beautiful day, let's do something patriotic. Let's go to the service at Lakewood Cemetery." Parker wanted to enjoy the outdoor events at Lakewood and even show her mother the plots that she and Dennis had reserved there. "After the service, the three of us headed toward the reflecting pool for a concert," Parker says. "That's when the most bizarre thing happened. Mother and Dennis were side by side—and I was walking ahead—when they both put their canes down on what they thought was the step, but the steps were unusually wide and shallow, so their canes dropped down to the step below. They both went down at the same time. Everyone was gasping and I saw Dennis's head jerk back and then hit the ground—there was blood everywhere. People were running toward him. Mother was getting up, but given she is 92, I worried she'd broken a bone and headed to help her. Everyone was yelling for medical professionals, frantically calling 911. People were wonderful."



Pamela Parker

Parker's mother had only a small scratch on her knee. Otherwise, she was perfect. Her pants weren't even smudged. Dennis, however, was injured. "Volunteer medical personnel cradled his head until the ambulance arrived. I raced to the hospital after him while a good Samaritan sat with my mother until my brother could get there. We caused quite the scene. The band had to postpone their concert until after the ambulance left."

Hospital staff decided that in addition to a gash on his head, Dennis also had a small bleed between his skull and brain, and should therefore temporarily stop taking Coumadin (a blood thinner he'd been taking since his first stroke). "But I didn't want him taken off Coumadin," Parker says. "I was afraid he'd have another stroke." Medical staff said the odds of another stroke during a short break from the medication were tiny. They also admitted there were no guarantees. "We didn't feel comfortable," Parker says. "But in the end I capitulated. I feel now we made the wrong decision."

Within a week of stopping Coumadin, misfortune struck. "I was still working part-time then," she says, "and I always called to check on Dennis during the day. That morning, I had taken my mother to the airport before work—Dennis had even helped her into the car—and when I called him on my way to work, I couldn't reach him." Parker began to panic. When she finally got through, it turned out that on his way back into the house after Parker left with her mother, Dennis had given a dollar to a woman panhandling on the street, and the woman then tried to

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*Dennis, June 5, 2016, two days before his second stroke*

rob him by coming through the back door. "Dennis had called the police and was just starting to calm down when I came bursting in. Once the police left and the dust settled, I thought, 'Well, she's not coming back to rob him again today.' So I finally left for work. When I called again on my way home, the phone picked up and I heard breathing and the sound of the TV. Dennis was trying to talk and couldn't. I thought, here it is, it's finally happened, exactly what I dreaded all these years."

### A Difficult Recovery

After nearly 60 days of hospitalization and many medical complications during which Parker slept in the hospital almost every night, Dennis transferred to a transitional care facility for seven more weeks before finally coming home in late September. The first months at home were a blur of medical home visits, at least 13 a week for various therapies including speech, physical, occupational, plus nurses and home health aides. Then came the repeated middle of the night trips to the emergency room for pneumonia. "The problem was damage to his lungs from a severe pneumonia in the hospital," Parker explains. Treatment is nebulizers twice a day, which Dennis can administer himself if Parker sets them up. "I actually administer his 13 meds twice a day. He doesn't have much eyesight due to macular degeneration. His right hand was nearly immobile immediately post-stroke and still lacks fine motor skills. He has trouble holding a spoon or pen, and his left hand was damaged in the first stroke. So I fix his smoothies and his meals. He does the treadmill every morning for 13 minutes—we started with five and are working toward 15. He was a strong guy, a lumberjack in his younger days, but he has lost much of his muscle strength. He is now able to take his own showers and, if I lay out his clothes, dress himself. But it takes him about a half an hour because he's all thumbs."

Communication is slowly improving, but can go downhill rapidly. The stroke left Dennis with severe language and speech impairments, including aphasia, apraxia and dysarthria, though his memory and mind are mostly intact. Parker says it's painful to see someone who was revered for his wisdom unable to speak simple words when he clearly knows what he wants to say. She feels least capable when she loses her patience. "Sometimes he tries to say something and keeps mumbling without words, and I've had to melt down a little bit. I've had to just say I can't understand you, you have to find a word. I've had to just stop for a while. But sometimes he gets mad that I can't read his mind. And then I think if this is the way you are going to be, I can't do this for you."

Ultimately, however, such moments of frustration are rare exceptions against a backdrop of gratitude. First all, Parker is grateful for the extensive care Dennis has received—from inpatient hospital to in-patient hospital rehab to transitional care to in-home care to and now outpatient services. She is grateful for the skill and devotion of the nurses, doctors, social workers, aides, and therapists, a large proportion of whom were immigrants. "Without immigrants, the health care system could not function," she says. She's also immensely grateful simply for the opportunity to care for her own husband. "Caregiving is hard," Parker says, "but its way better than widowhood. You still have the person you love with you. I don't know how long this will last, but for now we can still share camaraderie and enjoyment. We are political junkies and watch the news together. A few weeks ago we saw *La La Land* and *Hidden Figures* back to back in one afternoon. We've always liked doing things like that." Dennis, always a good dancer, has also been able to resume attending the monthly swing dances where Parker's band performs. Recently while on stage, Parker was alarmed to see Dennis's seat empty. Then she spotted him—on the dance floor with a friend! On Valentine's Day, Parker gave Dennis a card, saying there was no place she would rather be than with him. Dennis got teary and was able to express his sorrow over not having a card to give in return. But when Parker left for an outing and later returned, Dennis had spent the entire time she was gone scrawling a misspelled note with an unmistakable message, "Pam, I luvue you all, Dennis." These signs of recovery make her hopeful, but also more conscious of what could be lost.

### An Unprepared Caregiver

Despite decades working in long-term care, Parker never thought she was capable of caregiving herself. "I had done nothing to prepare. Well, no, I did one very important thing: I invested in very good insurance including long-term care policies for both of us. But we don't have advanced directives, a will, asset protection, or prepaid burials," she says. "Yet, there's nothing special about what I'm doing. Think of all the women who go through this. Almost every woman, eventually. It's like joining a universal club." Still, Parker admits she had misgivings about her caregiving abilities. "I hated being a Candy Stripper," she says. "I don't have a lot of patience. I hate bodily fluids—I remember in a restaurant once seeing an older man with something dangling out of his nose, and I thought I could never, ever deal with that. Now I'm helping Dennis with that every day. I guess I'm lucky to have seen my mother care so patiently for my dad with Alzheimer's when there was no glimmer of hope anywhere. Her example helps. And the fact is, I don't have time to feel sorry for myself. But I do sometimes feel depleted."

Officially retired now, Parker maintains consulting contracts for about ten hours a week. "Even though I am not working much, I don't always like the pressure of consulting while caregiving—I was taking meetings in hallways in the hospital! It's a balancing act, literally. One recent morning I had a full urinal in one hand and the phone in the other with a congressional committee

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staff on the other end! But I also don't want to give up work completely. What if something happens to Dennis and I find myself with nothing to do? I don't want to be disconnected from my ability to make money, or from doing what I love professionally. So I'm trying to hold on to some of it, but not too much."

Overall, Parker feels good about how she's coping. "With help from Dennis's close friend Dave and his son Mike, and from our dear friends and my brother Joel who lives in our attic apartment, plus some creativity, I have been able to do most of what I need to do, including attending some meetings in Washington, D.C. and going out socially once in a while."

### The Power of Connecting

A great caregiving challenge is trying to live two lives packed into one schedule. "This is exacerbated when the patient has cognitive or communication difficulties and medical instabilities, as Dennis does," Parker says. "Even when your loved one is in a hospital or rehab setting, which Dennis was for almost four months, you still have to work around the schedules of the institution and its caregivers, which differ in every setting. These schedules take precedence over yours and you must fit all of your own basic needs within them. It can be hard to find time to go to the bathroom!"

Communication demands are also daunting. "Everyone wants to know what's going on, when they can visit, etc. Some visitors are comforting and helpful, and others add to stress. Certain people who hadn't seen Dennis for nearly 30 years wanted to visit! But he had so many therapies and appointments, there just wasn't time for them all and I didn't have the emotional energy to be the arranger for all of that. My advice would be, don't be afraid to tell people it's not a good time to visit."

One strategy Parker found valuable was a dedicated Facebook Messenger group of family, close friends, and second tier friends, including those far away. "I wrote an update on his condition nearly every day," she says. "It was a good outlet for me to keep track of what was going on and to vent and share about the struggle. People followed it closely and responded with messages and prayers. It was a huge support." CaringBridge is a popular option for the kind of communication Parker describes, but she found the Facebook Messenger group to be simpler

and more direct. "We used texting and calls for more personal communication or for special advice from our close friend, LaJeanne Runnels, a psychic and healer, who would delve into the medical puzzlements with me at length and helped me stay hopeful," Parker says. Finally, for people not on the internet, Parker designated a nearby family member to share updates in person. "That saved a lot of energy. And many of those friends and relatives had church groups who prayed for Dennis, too. That was so comforting and created a sense of community."

### Becoming the Other

Since June, Parker has needed to be constantly available for bedside care, doctor visits, therapy appointments (to communicate for Dennis and observe his progress), and meals (to see how he was eating and swallowing, etc.). "I had to make sure he didn't do something unsafe or not allowed. I had to monitor toileting issues—less of an issue now but still happens—and observe his condition in order to communicate and advocate changes to the medical staff. I also feel my role is to simply be him in a way, to figure out what he needs or is trying to say, since he can't speak for himself."

Mostly, these immediate demands have kept larger questions at bay. Yet, sometimes Parker wonders what comes next. "What would it be like to be alone?" she asks. "Would I keep this house? Those are hard questions. I am a locational person. I go back to the same places, the same restaurants. I didn't like it when the Guthrie moved. I am in a big fight with them about accessibility, in fact. I've got a relationship with their member services now." In quiet moments, Parker sometimes thinks about what she might take on if she were by herself—but mostly, she grapples with what she might lose.

One source of solace has been a book Parker received from a friend going through similar issues: *Many Lives, Many Masters*, by Brian Weiss, M.D., the true story of a prominent psychiatrist, his young patient, and the past-life therapy that changed both their lives. "Dennis and I have been reading it together," she says. "The whole point of the book is that the lessons the patient was learning through the therapy were in some ways more important for the psychiatrist than for the patient. I think Dennis's stroke is a lesson for me, too, about patience, about unselfish love. That's how I am trying to look at it."

## Following the Minnesota Long-term Care Pioneer Trail

In the 1970s, Minnesota had one of the highest rates of nursing-home beds in the country. Now, Minnesota stands out nationally for having achieved one of the best balances of long-term care (LTC) options of any state. In recognition of this achievement, Minnesota has been rated number one in long-term care in the first two AARP national LTC report cards. Clearly, Minnesota has come a long way and blazed some trails for others to follow. How has this come to be? What has changed over the last 50 years?

This is the first installment of a new *Old News* series exploring a half century of improvement in Minnesota's LTC system. We intend to highlight the challenges and the achievements as well as the dedicated individuals who have worked and sometimes fought hard for a better care system for older adults. In upcoming issues of *Old News*, we will explore various aspects of transforming Minnesota's long-term care, including meeting future challenges; for now, we offer a broad overview of where we are and how we got here.

### Shifting the Focus of Care

The last half-century has brought substantial improvements to the way in which we care for older Americans. Much LTC has shifted away from institutions toward home- and community-based services (HCBS). Nursing homes are much less the touchstone. The desirability of HCBS is widely acknowledged and incorporated into Medicaid waiver programs. Federal programs actively divert older adults from entering nursing homes and get them out as quickly as possible. In addition, assisted living in various forms (e.g., apartment style, small group homes) has displaced much of nursing home care for privately paying clientele, and it has made inroads into Medicaid. We see this shift to assisted living as a major step forward, but others see it as simply another variant of institutional care.

Hard numbers help to quantify the magnitude of Minnesota's shift away from nursing home care toward other more community-based options. "In 1984, of all Minnesotans age 85 years and older, 36% were in nursing homes," says Bob Held, who worked in LTC for 43 years including 18 years at Minnesota Department of Human Services before retiring in 2016 from his role as Director of the Nursing Facility Rates and Policy Division. "And given that nursing home occupancy rates are lower than at any time in the past, this has not been accomplished through denial of access, but rather through concerted efforts to shift the locus of long-term care."

Held points to a number of efforts between 2000 and 2005 that helped shift LTC in Minnesota away from a bias toward institutions. "Minnesota was a highly bedded state and found several mechanisms—enactment of bed closure incentives, including layaway, planned closures, single bed incentives—that, in combination with funding for HCBS and pre-admission screening, furthered our progress. Since the peak number of

beds, over a third have been closed and this has occurred while the number of elderly has been growing." Held also points out that more recently, the Return to Community and the Moving Home Minnesota Programs have helped to continue shifting the locus of LTC.

### Improving Care Within Nursing Homes

Older adults who do reside in nursing homes have also seen improvements. "A major factor leading to improved care came in 1976, when the Minnesota legislature enacted the nursing home rate equalization law," says Patti Cullen, president and CEO of Care Providers of Minnesota. "This law required that private pay rates not exceed the daily rates of Medicaid residents for comparable services." Minnesota is virtually unique in having such a law.

Quality care requires well-trained and supported caregivers, and toward that end, the Nursing Home Scholarship Program, enacted in 2001, provided accessible funding for nursing home employees to advance careers in their facilities or in long-term care. "Several thousand people have benefited from this program, receiving comprehensive funding to cover the costs of training, primarily to become nurses," Held says. Also in 2001 came an extensive report from the Long-term Care Task Force, a group composed of Minnesota legislators and state agency commissioners that met to address the state's LTC issues and develop strategies for dealing with them. Kari Benson, director of the Aging and Adult Services Division at the Minnesota Department of Human Services (DHS) and executive director of the Minnesota Board on Aging, cites the work of the taskforce as instrumental in shaping the state's system of care.

An important consumer-centered initiative toward better quality care has been the Minnesota Nursing Home Report Card, which went online in January 2006. "This report card allows facilities and consumers to look at empirically valid comparisons of nursing home quality along several domains," says Held. "Over 2000 people access this resource monthly." Furthering the focus on quality, the 2008 Health Reform Law called for the establishment of a statewide system of quality-based incentive payments to health care providers. These payments are sometimes also called "pay-for-performance" incentives. This more coordinated approach to measuring, reporting, and paying for health care quality sought to create stronger incentives for nursing homes to improve quality. It was also seen as a means of providing Minnesota LTC consumers with more useful and understandable information. Data collected through the Statewide Quality Reporting and Measurement System have been used to develop the system of quality incentive payments to nursing homes, based upon achieving target levels of performance or based on improvement over time. The incentive payment system was implemented in 2010 for participants in the state employee health plan and enrollees in state public insurance programs.

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LTC has become more person-centered and occasionally even person-directed. The Nursing Home Pioneers, a national group formed in 1995, has pressed for culture change toward empowered residents and frontline staff. The vital role of family and friends as unpaid caregivers has been better recognized; there have been some programmatic efforts such as respite programs to support such caregivers and even to pay them. Additionally, most states now have programs allowing market-rate payment to family members (other than spouses or parents of children with disabilities) for services to relatives with disability. "But the market rate is not adequate," says Dr. Robert Kane, director of the University of Minnesota's Center on Aging.

### Challenges Remain

We have done a lot to improve the system, but more drastic steps are needed. As described in the editorial in this issue of *Old News*, we need to re-think LTC and move even further from the current nursing home paradigm. Too many nursing home residents still live in meager, often shared rooms, isolated from the larger community, according to Kane, who also cites the labor force as an area of concern. "These workers, especially those providing HCBS, are still paid minimum wage or little better. They never see the fruits of their labor." In his editorial, Kane outlines a number of other areas needing further attention, including better quality control measures for HCBS, where he says quality problems are emerging not unlike nursing home concerns of past generations.

Perhaps the most urgent challenges will be finding and training enough caregivers to tend to a growing population of older people. Currently, shortages exist across all strata of eldercare, from geriatricians to certified nursing assistants. "The average medical student at the University of Minnesota gets about four hours of training on dementia and maybe four days on all of geriatrics. They never see a positive model of care, unless by accident," says Kane, who notes that the outlook for nursing is equally grim. Recent Bureau of Labor Statistics employment projections have called for dramatic growth in the need for personal care aides, home health aides, and nursing assistants, predicting that more than 1.3 million new paid caregivers will be necessary to meet demand over the next decade. But the decreasing worker-to-old-person ratio means that too few people will be available to care for those who need it.

These challenges, and the passion, skill, and inventiveness with which Minnesota's leaders in long-term care plan for and address them, will shape the quality of the next many decades of long-term care in our state. In our next installments of this series, we'll examine our state's most important milestones and achievements in greater detail, while gathering insights about what should come next.

The purpose of *Old News* is to provide timely information about events, education, and research in aging to the professional and public constituencies of the University's Center on Aging and the Minnesota Area Geriatric Education Center.

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