

# Old News



University of Minnesota  
Center on Aging



MAGEC  
Minnesota Area Geriatric  
Education Center

## 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.

### Gerri Joseph: Two Goals and The Willingness to Say Yes

When Gerri Joseph was growing up in what she recalls fondly as a “very loving family” in St. Paul in the 1920s, she had two aspirations: to graduate from the University of Minnesota and to become a journalist. “It’s amazing how many doors were opened just by doing those two things,” she says. “That, plus a willingness to say yes to the unexpected.”

#### The Story Behind the Story

“No one else in my family had attended college,” Joseph says. “But Mom and Dad very much encouraged it. Our home had lots of books and conversation, and education was a high priority. It was tough going financially, so I worked and my dad helped some, too.”

While at the University, Joseph became one of the first two female editors of the *Minnesota Daily*. Her post-graduation goal was to write for the *New York Times*. But before she headed to Manhattan, the editors of the *Minneapolis Star Tribune* called to request interviews with Joseph and her co-editor; he was hiring staff writers. Joseph was reluctant to let go of her New York dreams, but the head of the journalism school persuaded her that going in for an interview was the “courteous” thing to do. It turned out the *Star Tribune* was interested in just the kinds of stories Joseph wanted to write, “interpretive reporting, the story behind the story.” When they offered her the job, she said yes.



Gerri Joseph, *The U.S. Ambassador to the Netherlands, 1978-1981*

Joseph wrote for the *Star Tribune* until 1953, winning several American Newspaper Guild honors along the way. She earned a Sigma Delta Chi award for her groundbreaking series on the dismal conditions of the state’s mental health hospitals. “It was the first time this men’s journalism fraternity had ever given the award to a woman,” she says. “My executive editor called them and said, ‘We want you to know this was written by a woman... but we also want you to know we’ll be annoyed if you revoke the award because of that.’ The award stood.

“It was around that stage in the game,” Joseph says, “that I married my husband, Burton Joseph.” Joseph already had a daughter, Shelley, from a previous marriage that had ended in divorce. After marrying Burton,

*Continued*

### In this Issue

#### Perspectives on Retirement

- |  |  |  |
|--|--|--|
| 1 Gerri Joseph                           | 7 Paying for Performance in Long-term Care | 13 The Long-term Care Re-think Tank      |
| 3 Jean Wood                              | 11 Care Guides                             | 15 News, Notes, and Notable Achievements |
| 5 History of Long-term Care in Minnesota | 12 The View From Here                      | 16 Happenings                            |

Joseph left the *Star Tribune*, had two sons, and encountered another unexpected plot turn. When Adlai Stevenson announced his presidential candidacy, a friend of Joseph's asked if she would run the women's section of the campaign in Minnesota. Subsequently, she was asked to stand for state chairwoman of the DFL party. "I talked to a good friend of mine, Eugenie Anderson, who was also a friend of Hubert Humphrey. She was very active in the party. I said to her, 'I've never even been to a precinct caucus.' And she said, 'Just tell them that if they can get you elected, you will serve. You'll learn fast enough.'"

Once again, Joseph said yes.

### An Era of Great Leaders

A political career had not been part of Joseph's two-point plan—University, and journalism—but when the opportunity arose, she met it gamely. "It was fun," she says. "I don't think politics is fun now, but it was fun then. Those were the years of some great leaders—Hubert Humphrey was coming along, Orville Freeman was very active in building the party and bringing in young people, and Walter Mondale, we became friends. I hesitate to go on, because I know I'll miss someone."



*Geri Joseph with her daughter, Shelley, at a National Democratic Committee meeting in 1960. Shelley enjoyed attending the meetings with her mother*

After serving as state chairwoman, Joseph was elected to the National Democratic Committee. When Humphrey ran for president in 1960, she was part of his national campaign team—and when he ran again in 1968, she headed the women's division of his campaign. After Humphrey lost that election, she became the vice chair of the Democratic National Committee, and shortly thereafter, she was elected chair of the board of the National Mental Health Association, a realm she'd "kept a hand in" ever since her series on mental hospitals. All of these endeavors were inspired by a desire to help people live better lives. "The world doesn't always work very well," she says. "You go out there and learn about people and their problems, and you learn how to be helpful, or at least how to try. That is the reason to do it."

In 1972, John Cowles Senior, head of the *Star Tribune* at the time, called Joseph to ask if she'd be interested in writing a column. "I thought that having been in politics sort of marked you," she says. "That they wouldn't want a journalist who was clearly on one side. But he said, 'A column has your name on it. You're supposed to have your own opinion in a column.'" So she said yes.

And six years later, she received a phone call with another job offer, this time from her longtime friend Walter Mondale, then vice president of the United States. "He asked, 'What do you think about being an ambassador?'" Initially she felt reluctant, but her family and friends rallied. "You've been writing about the importance of women taking advantage of opportunities," they told her, "reaching out and doing things they might be afraid of, so how could you say no?" So began Joseph's time as ambassador to the Netherlands. "That was the highlight of my career years," she says. "It was valuable to see how another country looks at your country, and why. And, of course, it was an honor to serve my country."

During her tenure as ambassador, Joseph attended a fundraising luncheon in London for a memorial for Hubert Humphrey. The purpose of the donations hadn't yet been made official, but "word was they'd go toward establishing a school in Humphrey's name at the University of Minnesota." At the luncheon, Joseph met Harlan Cleveland, the man who would be the first dean of that nascent school. He asked her to come see him when her time as ambassador concluded. "It all fit," Joseph says. A year after her return from Holland, Cleveland named Joseph a senior fellow at the newly established Hubert H. Humphrey School of Public Affairs.

### A Legacy of Care

Before Joseph reached retirement age, she witnessed the needs of older people through the work of her daughter, Shelley Kordell. Joseph fondly describes her daughter's small business, which was devoted to caring for the needs of older adults, as "rent-a-daughter." Shelley took on whatever her clients' needs dictated, from making funeral arrangements when a client's daughter was too distraught to manage it, to feeding a client's beloved pet cat each day, to bringing clients to dinner with her own family.

Shelley's compassion led her to assume a caregiving role for one of her uncles, despite the misgivings of her mother and aunt; that uncle had a daughter the family suspected might be troubled, and they worried about her response. Unfortunately, those worries were tragically confirmed in 2003. Shelley was at the Hennepin County Government Center in the midst of legally stepping down from her position as caregiver for her uncle when this troubled cousin shot and killed her.

"Shelley's death," Joseph says, "was a terrible blow to our family. But it brings me to a huge issue, which is gun control. I have a granddaughter who is now very involved in gun control issues." Another way the family honors Shelley and her devotion to older adults is through a scholarship fund in her name. Joseph and Shelley's daughter, Jennifer, established the Shelley Kordell Scholarship, awarded annually by the Center on Aging to two exceptional students pursuing careers in aging. Joseph helps administer the scholarship: "I meet with the recipients. I sit and talk with them. It's a wonderful thing—but I wish we could do even more to encourage geriatricians. There is a great and growing need for competent people to work with the elderly."

*Continued*

### The Years We Don't Think About

Joseph continued her work at the Humphrey School and with a few other organizations into the early 1990s. "When exactly did I retire? It is hard to say. I guess I'd consider myself pretty much retired as of age 72." It hasn't been entirely easy. "For the most part, we don't think about those years, about how we will fill our time meaningfully. To be very honest, traveling and working in a garden are simply not enough."

Joseph stresses the importance of social ties—keeping up with old friends as well as making new ones. "Years ago, an older friend told me, 'Be sure you have some younger friends.' I understand now what she meant. I have just a few friends my age left. All my other friends are younger."

Joseph is candid, too, about the physical realities of aging. For instance, her driving is limited by macular degeneration. That condition also necessitated her recent move from downtown Minneapolis to the suburbs in order to be closer to family.

Technology helps bridge the gaps these limitations present. "For heaven's sake," she says, "learn how to use a computer to stay in touch with friends and loved ones." Email and texting are the main ways Joseph stays in touch with her four grandchildren—two are in their 20s, one is 36, and one is 42. "My family has always been enormously supportive of all my doings. But it is very clear to me that I have come to depend on them more."

"You might be lucky enough to have many years ahead of you," Joseph says, "but boy, you better think about it. You might be alone." In March, it will have been three years since the death of her husband, whom she spent quite some time caring for after the onset of his dementia. "I know some couples who grow old together. My doctor for example—his parents are in their nineties and they're still together. But that doesn't happen often." Never one to sit around waiting on luck, Joseph is still living life on her own terms. "No doubt," she says, "your life gets smaller. You have to accept that fact, and learn to live with it, and do the most that you can."

### Jean Wood: A Child of Her Era, All Grown Up

"You have to know how to turn pulp into paper in order to get paper made," Jean Wood says. She is explaining why her father, who worked for a Fortune 500 company running paper mills, needed a degree in chemistry. He was also a psychiatrist. "He didn't do that professionally, but he had the degree and did a lot of volunteer forensic psychiatry in prisons and jails." Wood's mother, meanwhile, held a degree in law, which she used in her human resources work for Congress before Wood was born in 1949. Consciously or not, Wood seems to have adopted her parents' passion for learning, their humanitarianism, and their embodiment of the principle that "preparation plus opportunity equals success."

Since 2006, Wood has been the director of Aging and Adult Services for the Minnesota Department of Human Services, and, in that role, she has served as Executive Director of the Board on Aging. Last September, she received the first-ever Executive Director's Award from the National Association of States United for Aging and Disabilities (NASUAD). She was recognized for her outstanding leadership nationally and her commitment to NASUAD, first as a staff member and then as a long-standing member of its board of directors. She has served as a national expert, a peer mentor, and, according to her colleagues, "a voice of reason" on many aging-related issues. Wood has also been honored with the Dutch Kastenbaum Outstanding Gerontologist Award from the Minnesota Gerontology Society.

Wood retired last month. In anticipation of that tremendous milestone, she circled back to the credo of planning and preparation that has served her so well. "In order to retire with your mind at ease," she says, "you have to spend a couple of years planning, exploring all of the avenues, it's about starting a brand new life, and figuring out, 'What am I going to do, now that I have grown up?'"



*Jean Wood, speaking at the Age and Disabilities Odyssey in Duluth, Minnesota, June 2015*

### Where It Started

Wood believes the timing of her college education—she enrolled in 1967—informed her life path. "I was a child of my era," she says. "The air was full of ideas about justice and fairness and equality." Wood saw those ideas embodied in major legislative movements of the day. "Medicare, Medicaid, the Older Americans Act, the war on poverty," she says. "Those things all pointed to a great desire to make people's lives better, and to the government's role in doing that. It appealed to me."

During her time at Immaculate Heart College in Los Angeles, Wood studied history, government, economics, and French. She majored in history with a minor in government. After graduation, she went to work for the California Welfare Department in Santa Barbara County. "It was such a unique place," she says. "I learned the basic trade of social work. That's really where it all started."

*Continued*

## In Service of Seniors

Wood's work with aging populations came later, after she and her husband moved to Columbus, Ohio. Wood transferred her work with the county welfare program to her new location, and also earned two master's degrees—one in social work and another in public administration. Then in 1982, she took a position with the Long-term Care Ombudsman Program in Ohio. "That was my first foray into working specifically on behalf of older adults, and for the state," she says. "I had an interest in social services and health care, and there was so much happening on the national scene with regard to nursing homes. So when a position came open with the ombudsman program, I thought it would be a very good fit." Indeed, it was. Just a few years later, Wood became the state ombudsman. "The spirit of ombudsman work has stayed with me," she says.

Shortly thereafter, her husband was transferred to the East Coast, and Wood went to work for the agency now known as the National Association for States United for Aging and Disabilities. There, she dealt with federal contracts, primarily focusing on elder rights and ombudsman programs. When her husband was transferred again, this time to Minnesota, where they would settle, Wood brought her work with her. She spent about two years fulfilling contracts that had already been signed and processed before taking a position with the Minnesota Board on Aging. "At that time, they wanted to start a health insurance counseling program. That was my first challenge," she says.

That counseling program ultimately became a component of the Senior LinkAge Line, one of the Title 3 programs that Wood supervised. The LinkAge Line is the Minnesota Board on Aging's free statewide information and assistance service—and the achievement of which Wood is ultimately the most proud. "I was there in the beginning when it was put up, and I've watched it grow and have supported its growth. The name might imply it's something of a call-in service, but really it's so much more than that. It's a whole group of services intended to provide crucial information and connections to services of all kinds and from all sources—on the web, face to face, and on the phone." The LinkAge Line offers valuable data for seniors facing decisions or challenges accessing insurance or housing or needed services. The Line provides personalized help with everything from Medicare and Medicaid to reducing prescription drug costs to caregiver planning and support. "It's a powerhouse," Wood says.

As supervisor of the Title 3 programs, Wood also oversaw area agencies on aging, supportive services, and nutrition. From that position, she was promoted to deputy director of the Minnesota Board on Aging. Within a decade, she was serving as the division director for Aging and Adult Services for the Department of Human Services and as executive director of the Board on Aging. All in all, she has spent 22 years with the Board on Aging.

## A Feeling of Urgency

Wood officially retired at age 66—a decision she set in motion more than a year earlier. "It's been a good run," she says. But she feels some urgency about accomplishing certain dreams she set aside over the years. "I had foregone a lot of pursuits like travel and other things I have always wanted to do, and it just came time for me to go do these things while my health is still good."

One area Wood knows she will be happy to put more time into is her athletic endeavors; she's a serious triathlete who already spends at least an hour training five or six days out of the week. Until now, she has had to fit that training in around her job, which has often meant workouts that begin as early as 4 o'clock in the morning. Her commitment places her among the elite in her age bracket. She is member of Team USA, and competed at the National Senior Games in July of 2015. She had been competing now for over 11 years, and her times continue to get faster. "Not by much," she says, "but at least I haven't gotten slower."

In retirement, she hopes to participate in more destination events, like Vineman in Sonoma. She and her husband also have plans to hike the Scottish highlands and to complete the Coast to Coast walk in Northern England, an unofficial long-distance footpath that begins at Saint Bees on the Irish Sea, traverses three national parks (Lake District, Yorkshire Dales, and North York Moors) and ends at Robin Hood's Bay on the North Sea. "It takes a number of weeks, you do a part, take a break, then start again," Wood says. "It's quite a feat."

Her main worry? That she won't find the same level of satisfaction her work brought her. "How else can I say it?" she says. "This work is tremendously fulfilling. You can't beat it. It's a wonderful, wonderful job to have had."

## The Journey to Fulfillment

Wood's work offered the opportunity to talk with many people about retirement, an opportunity she seized. "I have asked them all for advice or observations, and I've gotten great encouragement from some really good folks." The essence of the advice she's received is to follow your passions, "don't tamp down on it at all. Go from one thing to the next until you find what it is that you want to do."

She imagines retirement will be a journey to find fulfillment in new places. "I am happy about taking the journey," she says. "But it's not easy work to find out what will make you nearly as happy as what you've been doing up until now." She has, she admits, an apprehension that she might regret retiring. "Although I've got to tell you, everyone I've talked to who has retired says, 'Oh, you'll love it. You'll be busy. There is no busier person than a retired person.' Now I have to go find out."

# History of Long-term Care in Minnesota

## Part One: The Early Years



Pamela Parker

Pamela Parker is a gifted storyteller, and the particular story she tells like none other is that of the history of long-term care in Minnesota. It's a history so tightly interwoven with the fabric of Parker's own life that at times the threads are indistinguishable.

Parker has 35 years experience in state government, Medicaid and Medicare, Managed Long-term Services and Supports (MLTSS), Medicare and

Medicaid Integration (MMI), managed care for people with dual eligibility. She was responsible for developing and implementing the nation's first integrated Medicare and Medicaid demonstration for people with dual eligibility in 1995.

Parker also served as the Minnesota's first Long-Term Care Ombudsman and has a long history of consumer advocacy at the state and national levels, founding an advocacy agency for nursing home residents and families that developed advisory councils statewide, and serving as an early board member of the National Citizens Coalition for Nursing Home Reform. In 1988 she received the Governor's Public Service Award for Excellence. In 1999, Parker was named the Dutch Kastenbaum Outstanding Gerontologist of the Year by the Minnesota Gerontological Society.

Since retiring from her management position with the State of Minnesota in August 2014, Parker continues to consult with state officials on Minnesota's unique Dual Eligible Special Needs Plan (D-SNP) administrative alignment demonstration. She also serves as MMI Consultant to the National Health Policy Group and provides MMI consultant services to health plans and states.

For the next few issues, *Old News* will be publishing a series of interviews with Parker, focusing on her own life story and its intersections with the history of long-term care in Minnesota, a history she has played an instrumental role in shaping.

### 1946-1972: Always Singing For Older People

Born in 1946 in southern Minnesota, Parker grew up near the Canadian border where her father sprayed crops and was a game warden pilot for the Department of Natural Resources. "Ours was a middle class family," she says. "Dad had been a daring P-47 Thunderbolt pilot in WWII—and mom was a lovely '40s-style singer, a diva." Early in childhood, thanks to the observations of her grandparents, Parker was found to have a

serious heart condition ("holes in my heart," she says) for which she needed a type of surgery that was simply not available at the time. In fact, there was no remedy whatsoever. "My parents were told I would die by my twenties," she says. "But Dad heard about C. Walton Lillehei, who was experimenting with the first open-heart surgeries on dogs and terminal patients, including children. This was cowboy medicine, a totally wild time, but Lillehei eventually teamed up with a guy that later helped develop the heart-lung machine, and they became successful with repairing certain conditions like mine."

Parker's dad had his daughter's condition closely watched from the early 1950s until 1960, by which time Lillehei's experimental surgery had achieved a 50 percent survival rate. "That's when my parents and the doctors decided I needed to have it done," she says. "Dad spent every vacation day in the air working in order to pay for it, even though he'd gotten offers to have it done free at the Shriner's Hospital by an associate of Lillehei's. But Dad wanted only Lillehei; so he paid cash. I had a rare blood type, O negative, and it took 13 pints of blood just to prime the heart lung machine pump. So the DNR helped with a statewide campaign to donate blood for me." Parker became one of first 500 pediatric open-heart surgeries. "Most kids in hospital at that time died from staph infections, but I was released early—so I escaped," she says. As a young adolescent, she became interested in literature, art, and music, which was the beginning of her work with older adults. "I sang for old people," she says, "in their homes or at events, because I was encouraged by my mother to do that. I was always singing for older people."

However, Parker's first foray into more organized volunteering with the elderly was a bust. "I spent one day as a Candy Stripper in the local nursing home in the very early 1960s. It was awful, I couldn't stand it!" she says. "I spent a lot of time thinking about aging, due to my very up-to-date grandmother whom I overheard talking to my mother one night about how she couldn't believe she was as old as she was, and how she didn't feel like the person she saw in the mirror."

Parker earned a scholarship to the University of Minnesota, but changed her mind at the last minute and attended Moorhead State to study English literature. "I was an antiwar activist," she says. "I hung out with the beats and hippies." She was also one of the only women in northern Minnesota to own a motorcycle, which she once drove through the sprinkler system on campus. Eventually, Parker became a single mother and dropped out of Moorhead State. She transferred to the University of Minnesota Twin Cities, worked in a racy nightclub, and moved in with a slightly older woman who also was also a single mother.

"It was a real struggle," she says. "By 1972, I still hadn't quite finished a degree in English literature and music. I needed 13

*Continued*

music credits that didn't transfer from Moorhead, and I couldn't afford it. But I had a very good welfare caseworker at the time—back then, moms getting welfare payments got caseworkers. Her name was Nancy Nelson, and she died of cancer not long after the incident I'm about to describe. It happened one day when I was in a deep depression and had no idea about what to do, and Nancy called me, and that phone call is one of two really divine moments in my life. She said I should apply to Hennepin County, because they were hiring welfare moms as eligibility technicians. Of course, I thought I would be assigned to moms and kids, but no. I was assigned to old people in nursing homes."

### 1972 – 1975: Dexter's Raiders and the Fight for Dignity

In the early 1970s, says Parker, "Nursing homes were generally stinky, crowded places, often with three or four people crammed in a room. Care was extremely regimented. People were often tied to railings or tied into their wheelchairs, and many were drugged up. Medicaid had passed in 1965 and it covered nursing home care but very little home care, so the 444 nursing homes in Minnesota were mostly full of Medicaid clients." Parker explains that counties managed Medicaid along with General Relief grants for poor, while also handling eligibility and billing through a paper system. "Nursing home facilities were often old motels or repurposed brownstones," she says, "and rarely modernized. But some of the old guys were happier in those old buildings—it really depended on the attitudes of staff and the freedoms the residents had."

Although nursing homes were created from a short-term Medicare medical model, "they were virtually the only option for people with mental health needs or disabilities. Those residents often started as private pay, then used up their money and lost their homes and were stuck there for the rest of their lives, sometimes from quite a young age." A big part of Parker's role as an eligibility technician involved driving out to the nursing homes and helping residents complete their Medicaid paperwork, which was often challenging and confusing for them. "So I got to know them. One resident who made a deep

impression on me was Joan Knowlton, a woman who was probably in her early 50s at the time, and had been in a nursing home since her 20s with severe rheumatoid arthritis. I got to see the world through her eyes. In fact, whenever I got discouraged, I would see the world through the eyes of these residents, because although their circumstances often felt tragic, they were very inspiring to me."

One of the injustices Parker learned of was the abysmally low personal allowance afforded to residents. "They got to keep either \$11 or \$13 out of their Social Security payments, depending on whether they were designated as skilled-care or intermediate-care patients. And with that tiny allowance they had to pay for everything they might need or want outside of their care—clothes, books, candy bars, anything they wanted in life." Meanwhile, Parker herself was still pinched to make life work as she balanced single motherhood of her son with her full-time job. "I was constantly running ten minutes late and in jeopardy of losing this job I was growing to love, when fortunately I was assigned to a new unit with a unique supervisor. His name was Dick Burtis, and his desk was surrounded by a forest of tall plants, which was unusual. No one else had plants! We were all crammed in there, four desks facing each other. These were generally terrible working conditions. But Dick had this elevated sandbox to play in, with figures in it—and if it was a bad day, for example, the figures might be buried upside down in the sand. He was an interesting fellow."

By now Parker had become active in the union for the county, Local 33 AFSCME, which had a social action committee, and Burtis recognized their shared social action spark. He had begun working with a group of nursing home residents, including a resident named Quentin Dexter, who wanted to start a resident's council in his nursing home. Burtis asked Parker to get involved in the effort. "We agreed I could do it through the union's social action committee, because I could get time off to go to those meetings," she says. "Dick put me in touch by phone with Dennis Wynne, an advocate for Family and Children's Services, to determine the necessary paperwork to incorporate their residents' council coalition as an advocacy organization." Working through the social action committee, Parker set a date for a public meeting with Commissioner of Human Services, Vera Likens, at the agency's St. Paul office. She then worked with other eligibility technicians to call every metro nursing home and invite residents to the meeting where they could ask for a higher personal needs allowance. Dennis Wynne got a



*Nursing Home Residents Advisory Council (NHRAC) left to right: Joan Knowlton, NHRAC Secretary and Treasurer (and often chief spokesperson), Phil Williams (NHRAC president), Pam Parker, and Iris Freeman, major activist for nursing home reform*



*A scene from Parker's early nursing home advocacy days*

*Continued*

well-known *Star Tribune* journalist, a columnist who could write whatever he wanted, to cover the meeting, which was led by Quentin Dexter and attended by more than 100 nursing home residents. "The nursing homes brought them in buses," Parker says. "They had made signs with bed sheets on which they'd written 'More Cash' in magic marker. It was such a scene, all these little old people in their wheelchairs. The social workers' heads were spinning. And the front page of the paper the next day was a story about 'Dexter's Raiders.'"

After that historic meeting, Parker helped the residents to form a coalition to meet regularly to discuss their rights. She was encouraged by experienced advocates, including Margaret Sandberg, Chair of National Association of Social Workers (NASW), to testify and provide technical information to the Minnesota State Legislature in support of increasing the personal needs allowance. A bill was authored by Senator Stephen Keefe and Representative James Rice. "I could attend these hearings under the auspices of the social action committee," she says, "so I had a cover to get in." Once in, however, the atmosphere was intimidating. "The NASW lobbyists showed me the ropes a little bit, but, really, I knew nothing about capitols except what I had learned in civics classes. And here I found myself testifying before the Senate." Those Senate hearings were open, and

many people testified, including nursing home residents like Joan Knowlton. Therefore, it was relatively easy to track what was happening with the bill in the Senate. "But from the House side, we didn't hear a word," Parker says. "Representative Rice would never return my calls. I was in despair. But it turned out he had been working his cigar-filled backroom cronies and the bill passed." Even if it hadn't, Parker says, "the allowance increase would have gone through eventually, because the new federal Supplemental Security Income (SSI) law was going to raise it to \$25 month. But with this decision, they implemented the personal allowance piece early, and that was a big victory for the residents."

And then? "Well, around this time, things changed drastically at Hennepin County, because everything was becoming more mechanized. The job became mostly a matter of endless forms we had to fill out to be read by machines that were the precursors to modern day computers. Our jobs turned into filling out those forms day in and day out with little time left to visit residents. It was awful. So I quit."

Watch for Part Two of *Pioneering Reformer Pamela Parker Reflects on the History of Long-term Care in Minnesota* in the summer edition of *Old News*.

## Paying for Performance in Long-term Care

### Four Experts Discuss the Evolution of Quality Improvement in Minnesota's Long-term Care System and the Challenges that Lie Ahead

Minnesota has been at the forefront of nursing home quality improvement initiatives and pay-for-performance policy. In 2006, the Minnesota Department of Human Services (DHS) launched the Nursing Home Performance-Based Incentive Payment Program (PIPP). PIPP supports provider-initiated projects to improve the quality and efficiency of nursing home care. The goals of this program include encouraging providers to plan and implement quality improvement projects, equipping providers with necessary organizational resources to improve quality, and significantly raising the quality of care for nursing home residents—all within the reality of state budget constraints.

"PIPP has succeeded in creating a pro-active environment for supporting quality improvement in nursing homes," says Dr. Robert Kane, director of the Center on Aging. "It's been very popular, with a high participation rate among nursing homes, and studies suggest it has had a positive effect. And now the program has been broadened so that all nursing homes can implement quality improvement plans, tying the new money to quality." Last year's legislation provides a significant increase in nursing payment linked to quality.

#### The Experts



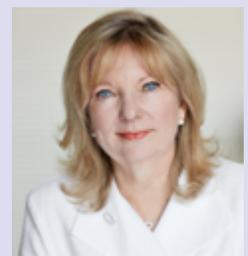
Robert Held, Nursing Facility Rates and Policy Division, Minnesota Department of Human Services (DHS)



Valerie Cooke, Manager, Quality and Research, Nursing Facility Rates and Policy Division, Minnesota Department of Human Services (DHS)



Patti Cullen, President and CEO, Care Providers of Minnesota



Gayle Kvenvold, President and CEO, LeadingAge Minnesota

*Continued*

To find out more about what may lie ahead for Minnesota's quality efforts, especially in light of the shift away from institutional care and toward home and community-based care, *Old News* asked four experts about the growing emphasis on quality improvement and how it's likely to continue changing care for older adults in Minnesota.

***Old News: Talk about the role of quality improvement efforts in changing nursing home care so far, and about where quality improvement is going as we shift toward home-and community-based services (HCBS)?***

***Robert Held and Valerie Cooke, DHS:*** Minnesota has made enormous progress moving away from institutional settings toward HCBS and assisted living. Our state's nursing home beds peaked in 1984 and since then over one third of those beds have closed, even while the number of older people and those needing long-term services has grown. Still, we're likely to need nursing homes into the foreseeable future—so we need to ensure that our nursing homes provide the best possible care—and that the care continues to improve. Increasingly, consumers view nursing homes as a bridge back to their own homes. As nursing homes evolve and serve more post-acute short-stay residents, Minnesota's quality measurement system and state-sponsored quality improvement initiatives also need to evolve to stay relevant. Efforts are underway to develop new quality indicators specific to the clinical care and consumer satisfaction of short-stay residents.

***Patti Cullen, Care Providers of Minnesota:*** Minnesota nursing facilities are now fully engaged in quality improvement activities, with the implementation of Value Based Reimbursement (VBR) on January 1, 2016, the engagement of many providers over the years in PIPP, the reliance on data from the nursing facility report card, and the nearly universal participation in Quality Improvement Incentive Payment (QIIP) program incentives. This commitment to improving quality benefits Minnesota facilities—compared to nursing facilities in many other states—as we move nationally to Medicare value-based payments and new federal requirements for quality assurance/performance improvement. While Minnesota continues to shift toward home-and community-based services, the need for nursing facilities to provide short-term rehabilitation as well as care for those with complex and/or chronic needs will remain. In addition, the need to focus on transitions and continuity of quality improvement across care settings will increase. The role of quality improvement will hopefully evolve toward a data collection and quality improvement system that crosses over the silos of care and reflects the challenges evident in transitions of care.

***Gayle Kvenvold, LeadingAge Minnesota:*** Quality improvement is more front and center in how our state pays for nursing home services than ever before. This helps us prepare for Medicare's evolution to payments based on value. Our years of experience with PIPP projects in nursing homes have absolutely furthered our understanding of quality improvement as a systems approach while teaching providers new quality improvement

skills such as root cause analysis. Data show that these new skills, combined with a culture of quality, improve outcomes not just in the specific focus areas of PIPP grants, but also in other areas as well—a sort of “raising of all boats.”

Quality improvement has also ushered in new ways for nursing home providers to collaborate. Providers now commonly work together in ways they never did before—developing care protocols, promising practices for quality improvement, benchmarking against one another to better understand what practices move the dial on quality outcomes. And provider consortia and cooperatives such as Empira and CareChoice have made quality improvement a central focus of their collaborative work. Most importantly, our attention has been drawn to the experience of care from the standpoint of consumers and their families. This focus on the customer experience and our new quality improvement process skills are absolutely transferable to community-based care—even though in a number of areas we will be creating the first generation of metrics and care pathways for the varied, diverse, and consumer-directed services that make up home-based care.

***Old News: In light of the shift from nursing home care to HCBS, how can we handle data to improve care?***

***Robert Held and Valerie Cooke, DHS:*** We have wealth of data to use in understanding the quality of nursing home care, as evidenced by the Minnesota Nursing Home Report Card, which, by the way, recently celebrated its 10th birthday. The report card displays information about all 370 facilities in Minnesota certified to participate in the Medicaid program. It has scores on input measures, such as amount of direct care staff, use of pool staff, and availability of private rooms. And it has process measures, such as direct care staff retention. But the most important measures address outcomes and include the Minnesota Quality Indicators, looking at clinical care, quality of life, and findings from certification inspections. And several new measures are under development. We are fortunate to have rich data sources from which to derive these measures, including the resident assessment instrument (the MDS), resident interviews to assess quality of life, cost report data, and so on. The result is that our quality measures support state and provider quality improvement efforts and about 2000 different users access the report card every month. So that's what Minnesota is doing and what we plan for future development.

But as Minnesota operates its measures and processes, others are getting into the act. Medicare has an evolving set of measures. Other states are doing their things. And the state and national trade associations are coming out with new products for data collection, etc. We recognize the reporting burden this can place on facilities and indeed take this into account in designing our systems. To the highest degree possible, we rely on existing data sources instead of imposing additional reporting requirements. So while we have added some items to our Annual Statistical and Cost Report, we rely predominantly on the MDS, without adding questions or assessments.

*Continued*

And when the MDS has changed, we have adapted to those changes. We hope we can all share the goal of enhanced value through combined effort. None of us can do it all by ourselves.

**Patti Cullen, Care Providers of Minnesota:** First, Minnesota has done a tremendous job in creating valid data to measure nursing facility outcomes. At the same time, the Medicare program is in the beginning stages of using data and outcomes for payments not only for nursing facilities but across most Medicare settings. The challenge for nursing facilities will be to somehow align national and state measures as well as metric expectations of various payers. We're facing a significant workforce capacity issue. The more data sources can align and automate, the more useful the data will become for quality improvement initiatives.

Second, we really don't have good comparison data or measures for assisted living, home care, and other community-based services. The settings of care and services delivered are so dramatically different from each other that it's challenging to develop measures that can be collected in a universal manner yet still reflect the fact that home- and community-based services are based on a foundation of individual choice and diverse lifestyles. We've struggled with these questions for years. And the question is not how we can handle data to improve care but what data do we need and what is the least intrusive way to get it from individuals receiving long-term services and supports.

**Gayle Kvenvold, LeadingAge Minnesota:** We need to focus more on making our metrics consistent and aligned not only across state and national pay-for-performance systems, but also across care settings. In this era of care integration and bundled payments, it's not enough to agree on which metrics we will track across settings. We must also arrive at common definitions and methodologies for measurement. Take falls—how hospitals define this metric is different than care centers and may be different again than assisted living or home care. In today's world, providers may be tracking outcomes on falls in a half dozen different ways depending upon whether for a health plan, a partner in their care network, or a state or national report card. There is promising work on common metrics, definitions and vocabulary that has been done by ACO's working with providers across the continuum in other markets, such as Boston, and there is promising preliminary alignment work that has been done by the stakeholder community here in Minnesota in the area of post-acute care.

We are also seeing a new generation of analytical tools for tracking quality outcomes that help the care team target the areas where they most need to improve. The national parent organizations of both provider associations have new suites of tools available to members that are creating opportunities not only for state benchmarking but national as well. And, of course, we know it is not enough just to have better measurement systems—we must become better and better at using that information to continuously improve the consumer experience.

**Old News: How specifically do you wish to see quality of care improved?**

**Robert Held and Valerie Cooke, DHS:** We've just started down the path of implementing Value-Based Reimbursement (VBR), a very robust pay-for-performance strategy. We have a great deal of work ahead of us to make sure that this works. Given that, we think the domain where we most need to see quality improvement, and where we fear it may be the most challenging, is in quality of life. We've seen this measure as being quite slow to move. Further, we need to eliminate racial and ethnic disparities in quality of life of nursing home residents.

**Patti Cullen, Care Providers of Minnesota:** I'm optimistic that nursing facilities are headed in the right direction with quality metrics collection, and various quality initiatives established at the state and national level. Whether the incentives are directly payment-driven (PIPP and QIIP) or indirectly payment driven via hospital referral criteria, most providers are attuned to specific metric expectations. Not all facilities have fully embraced quality improvement processes, however. Within our membership, over 100 nursing facilities and/or assisted living buildings have successfully applied for and received national Quality Awards using the Baldrige Quality criteria through the American Health Care Association/National Center for Assisted Living. Going through that intense process helps to "institutionalize" a process for performance excellence that I wish to see ingrained into the daily operations of all nursing facilities and assisted-living buildings.

Quality of care will only be consistently improved in settings with the proper processes in place, ongoing data collection/review, and leadership invested in the quality journey. With the introduction of VBR and Medicare payment reform, we need to not only keep an eye on improvement, but also acknowledge that it is the continuous focus on improving processes and care that need to be ingrained.

**Gayle Kvenvold, LeadingAge, Minnesota:** I was so struck by something that Atul Gawandi said when he was here in Minneapolis last fall. He said that what we want for our loved ones is safety, but what we want for ourselves is autonomy. I personally would like to see us address more effectively that balance between safety and autonomy. I believe that to do so will require deeper and more meaningful partnering with the consumer and their family in delivery of care—more opportunities for the consumer to define what quality means for them and have that be a key driver of care.

**Old News: What do you think is doable?**

**Robert Held and Valerie Cooke, DHS:** Implementation of VBR is imminently doable. But it will be very important to evaluate how it is working and the outcomes we are achieving over time so that we can apply the principles of quality improvement to our quality improvement system. Not only do we need to optimize the benefits of the state's investments, but we need to do this in order to best serve the people who need the care that nursing homes provide.

*Continued*

**Patti Cullen, Care Providers of Minnesota:** The potential is great—an increasing number of both nursing-facility and assisted-living providers have “bought into” the concept of performance excellence and the value proposition that quality improvement processes can offer to customers and stakeholders. Care Providers of Minnesota, with our national partners (American Health Care Association/National Center for Assisted Living) has invested in a Quality Initiative over the past few years which we are “boosting up” in 2016 with additional tools and resources for members—including a significant national database our members can access for comparisons in their quality improvement journeys. Our goal is to be certain they are ready for the upcoming federal requirements for QAPI and IMPACT Act measures in the nursing facility settings, and to be sure our home care members fully engage in the quality assurance expectations at the state level.

Aligning the education and training systems with current and future needs as well as making sure we are using technology to increase productivity will allow us to continue to improve quality of care. We are optimistic that technology in a variety of forms will help with data collection and analysis as well as prioritizing next steps. Improving quality of care can be overwhelming, especially with workforce challenges—it will be important to focus on integrating processes to keep moving forward.

**Gayle Kvenvold, LeadingAge Minnesota:** We must make it all doable. Quality is a mandate. The public will look for it, the client and their family will expect it, the payer will demand and reward it, and our care partners will build their preferred provider networks around it. The stars are beginning to align in some important ways in terms of “doability.” We have a payment system reform with quality improvement as a defining characteristic, QAPI and its focus on a systems approach to quality improvement, the Minnesota Alliance for Patient Safety embracing the continuum of care with a central focus on partnership between individuals and their care teams, and technology supports for data aggregation and exchange. We also can take a page from collective action initiatives like Act on Alzheimer’s to engage a broad stakeholder coalition in the quest for improved quality of care.

And, it is vital that we are not insular in our thinking, that we are not just talking to those engaged in work like our own, but that we seize opportunities for cross-sector learning. On an organizational level, we’re working with the Performance Excellence Network on a leadership-training program because quality begins with a strong leadership informed by quality improvement lessons from outside health care, long-term care. And, we are adding a full-time position to our Association team—a Vice President for Quality to come alongside our members to help increase their capacity to perform with excellence.

**Old News: What constraints do you see—for example, what happens when there is a single nursing home in a small town, and therefore it cannot be closed for poor quality?**

**Robert Held and Valerie Cooke, DHS:** Closing nursing homes due to poor quality has been exceedingly rare. So, while a regulatory approach to quality assurance is essential, and has brought us wonderful progress over the years, we’re interested in supplementing that regulatory approach with our data driven incentives approach. Both are needed. But this is hard work. I know we feel constrained for resources and I believe providers feel that way too. Especially human resources. But there are also data resources—we can’t have everything we might want. And financial resources—this is work done for people and by people. It takes a great deal of hands-on effort. The irony is that the better we get, the further our vision reaches, telling us how much further we need to go.

**Patti Cullen, Care Providers of Minnesota:** Minnesota can only go as far as our workforce can take us. Workforce availability is our biggest constraint, and given demographic projections, it’s not going to get any better in the future. The availability of workforce ultimately constrains our options regarding accessing services throughout the continuum and the state. There have been closures of individual nursing facilities in small towns over the course of the past decade—most of these closures have been directly connected to poor reimbursement and/or the shortage of available workforce. An additional constraint we envision, based on recent reports of the gaps in long-term services and supports, is the lack of specific community services and supports for seniors and their caregivers in the settings of their choice. These supports include homemaker services, chore services, crisis respite services, mental health services, and transportation. Where these service gaps exist, seniors are at risk for not receiving the care and services they need/want where they want to receive it.

**Gayle Kvenvold, LeadingAge Minnesota:** One of my mentors, the immediate past President of LeadingAge national, Larry Minnix, often said that a focus on quality and outcomes ought to mean there are two types of providers, “the excellent and the non-existent.” But in reality, even the best providers always have room for improvement. Quality improvement is a journey not a destination. If you asked our members what drives them in their quest for quality improvement, they are likely to say their workforce—the dedicated and talented core of experienced individuals who are the backbone of their organizations. In turn, if you asked them what constrains them, they are likely to say their workforce—in terms of open positions and turnover. Against the backdrop of these workforce pressures, we are also being called upon more and more in our residential and home-based settings to serve and support persons with a set of needs that include behavioral health issues and/or chemical dependency. This will require new service models and care protocols. And I absolutely agree that the economic models for the delivery of basic home supports like chore services and transportation and adult day are a significant challenge, not only in the rural setting but all across our state. Still, I don’t think of these so much as constraints as the challenges we must embrace of this unique time of the aging of our state and nation.

*Continued*

### **Old News: If you could design the ideal system, what would it look like?**

**Robert Held and Valerie Cooke, DHS:** If you'd asked us this question a year ago, we would have told you our ideal was VBR, but that the likelihood of its being enacted was miniscule. Now that we actually have VBR, moving forward, our ideal is to see that VBR is successful. But we answer this way because our jobs lead us to look at the world through a certain lens. We fully appreciate the need for a broad perspective. In that light, we think the ideal system is one in which, as we age, we are all encouraged to remain as engaged and active as we wish to be, regardless of our underlying conditions; where all care and support modalities prioritize each person's choices and respect their dignity and autonomy; where resources are sufficient to do what needs to be done; and where quality, efficiency, and above all, each individual are highly regarded.

**Patti Cullen, Care Providers of Minnesota:** Ideally, people should be able to live at "the place they call home" or with their families (however that's defined) as long as possible, and only

access more formalized care settings when needed. Affordable quality supportive services should be available statewide to help seniors stay at home. Seniors who choose to move to congregate-type settings should be able to access additional services as their frailty increases without additional moves, and the financing mechanisms should support that choice. Ideally, long-term care would be a respected and honored profession—individuals would want to start and end their careers working in home care/senior housing/nursing facilities settings. Quality care starts with quality professionals who choose this profession and who are inspired by excellence.

**Gayle Kvenvold, LeadingAge Minnesota:** My Norwegian Lutheran mother would be stunned by what I am about to say—but if I could design the ideal system, it would start with me. With my care team understanding me and my circle of support, then using that understanding to shape a plan that would meet my health care needs even while preserving my ability to make choices, my sense of purpose, and, as the folks from Generation Ageless would say, "a timeless and exuberant engagement with life."

## Navigating a Thunderstorm

### Volunteer Care Guides Help University of Minnesota Retirees With Long-term Care Decisions

Long-term care (LTC) decisions are frequently made in great haste while under tremendous pressure and emotional duress. Family members faced with such decisions may not know where to turn for essential information and resources. Toward this end, several members of the University of Minnesota Retirement Association (UMRA) began training last fall with Dr. Robert Kane, director of the Center on Aging, to become "care guides." These volunteer care guides are now available to confidentially assist UMRA members who need help making LTC decisions.

"People in these situations feel like they've got to figure things out in a big hurry. They are ill prepared to deal with the weighty decisions that need to be made quickly, especially in a highly emotional state," says Earl Nolting, co-chair of the UMRA Cares Committee since 2013 and former UMRA board member. "But a whole variety of things can trip you up. The health care system is quite complex and not entirely functional. Frequently, the person is just lost. The care guide's job is to help the person navigate this complicated system, so that they feel comfortable in the decision they eventually make. We help people navigate through a thunderstorm."

What might it look like to navigate a thunderstorm? Nolting gives an example. "Imagine a person who is hospitalized and is told by the hospital that they have to leave today. The person cannot return home for a variety of reasons, and the family has to figure out a plan for the next steps in what seems like in the next 10 minutes. Well, we have been trained to let people know

you can speak back to hospital, you can say, 'Hey wait a minute, we need more time.' And there is a provision under Medicare that gives you a right to ask for that." But getting some extra time is only the first step in making a good decision. You need to know your options and to be clear about what you are most anxious to maximize. Care guides can help direct families to resources and offer a structured way to make decisions.

Those who do have more time to plan LTC decisions may not need a care guide. "If you have a whole month or two to work things out, we can facilitate your thinking," Nolting says, "but we're a more important resource for the person who's faced with an immediate diagnosis that involves LTC and who needs to know right now, what are the options, costs, etc. We can help pull that together."

As the group deepens its work, longer range planning for LTC may become another focus. "We have a member of our group very committed to the idea of helping families plan ahead in case there is a crisis," says Nolting. "It's tricky, of course, because crises are all very unique—a fall is one thing and memory loss is another, so it's hard to plan. But we can certainly do more to prepare, and we are trying to figure out how to help with that moving forward."

Important to note is that care guides help facilitate decision-making, they don't actually make decisions or recommendations. "One of the resources we use is a specially designed computer

*Continued*

program in the Center on Aging," says Nolting. "It's called 'LTC You Decide,' and it has several tools that guide a person through the system, from care options to an 'ask the expert' function to a series of specific steps that work you through the information you need."

The group's goal now is to spread the word about what they have to offer in order to make sure those who need assistance will get it, as well as to recruit another training group for the future. "We're a new effort within the UMRA organization, and people don't know us well," Nolting says. "We've got to rely on various announcements and a lot of word of mouth. We want our membership to know we're here so they can pick up the phone and make a call."

### Contact a Care Guide or Learn More

To speak with a care guide, call the Center on Aging at **612-624-1185**. After hours, please leave a voice message with your name and the best phone numbers to reach you, both day and evening. A care guide will get back to you very quickly.

If you would like to learn more about what care guides are and can do or if you would like to become a care guide, please contact Earl Nolting at **651-633-4333** or [enolting@umn.edu](mailto:enolting@umn.edu).

#### UMRA Care Guides

Ron Anderson, Helen Carlson, Margaret (Maggie) Catambay, Pat Kelly Hall, Larry Johnson, Earl Nolting, Gwen Perun, Barb VanDrasek

## The View from Here

### The Ticking Time Bomb of Long-term Care ... and Two Bold Steps You Can Take Today



Dr. Robert Kane, Director,  
Center on Aging

As I listen to the presidential debates and the news in general, I am overwhelmed by the number of crises our country seems to be facing internally and externally. We have widened the gap between rich and poor. We continue a set of inequalities. We fear terrorism. Our environment is literally going to hell. Education is underperforming.

As an advocate for improving long-term care for older adults, I find myself wondering where that agenda fits in this dismal context. We have an economic challenge to find decent work at decent pay for everyone, but we have a hidden problem as well. The changes in the pension system enacted two decades ago now mean that many people will approach retirement with limited savings. Traditional pensions were effectively forced savings. The 401k approach requires workers to take some initiative and many have not because of pressing immediate needs. We have a ticking time bomb. If upcoming generations cannot afford to retire, how will they ever afford long-term care?

And if they can't pay for it, who will? The easy answer is Medicaid. We will become a nation of *de facto* old medical paupers. State governments fear this run on the treasury, and with good reason. States vary in their Medicaid generosity. Minnesota is at the upper end of this distribution. No wonder they have embraced a campaign euphemistically entitled, "Own Your Own Future," which is basically urging everyone to save in whatever way possible to pay for long-term care. But given the reality of savings in general, it may be an unreasonable exhortation.

Pressing for more individual responsibility does not seem to be the answer. We will need collective action. The big question is, how do we even get anyone's attention about this problem, especially in the context of all these other crises? How do we address tomorrow's problems when we are swamped today? The challenge is all the greater because long-term care is not a sexy topic. People do not get worked up over it. Elections are not won by platforms based on it.

The first big step then is how do we change the public dialogue about long-term care to lend it more appeal? We need to start by making sure it is seen as something positive, not just a necessary social service.

In this issue of *Old News* we describe a group that is trying to do just that. The Long-term Care Re-think Tank is a group of people from different backgrounds who are committed to getting people talking about long-term care and drastically improving its delivery. Essentially, we want long-term care to do what people say they want: maximize frail older people's dignity, autonomy, and choice, and allow them to live meaningful lives. The cost of care should not mean sacrificing these goals.

I urge you to take two steps today.

1. Consider joining the Long-term Care Re-think Tank and becoming part of the solution.
2. Send me five steps you would like to see society take to improve long-term care in the next five years. Ideally, they should be reasonably doable. Please make them as concrete as possible but be bold.

Send your proposed steps to [coa@umn.edu](mailto:coa@umn.edu). If you want to learn more about the Long-term Care Re-think Tank, contact Robert Kane at [kanex001@umn.edu](mailto:kanex001@umn.edu).

# The Time to Re-think Long-term Care is Now

## The Long-Term Care Re-think Tank

If there is one thing Dr. Robert L. Kane, director of the Center on Aging, is certain about, it's that long-term care needs a complete overhaul, starting with the way we think about what it is and what it ought to do. "We have to change how the public thinks about the effectiveness of long-term care," he says. "The debate should be about what you are buying before it focuses on how to pay for it." Society won't invest in the care that we want until we believe that good care will make a difference in the lives of frail older people. Until then, we will just keep looking for ways to make care cheaper. Therefore, reform needs to start with changing the public dialogue. Currently, no one thinks about long-term care until crisis strikes. So first, we need to talk about it. Then we need to identify what we want.

In order to engage that kind of dialogue and create an action plan around long-term care, Kane and Tracy Keibler founded a group last year called The Long-term Care Re-think Tank. Members include family care providers, professionals, and students dedicated to the idea that individuals have a right to age with dignity and choice. Members are hopeful that continued dialogue and hard work can bring about real change.

### The Necessary Conversation

Tracy Keibler is founder and executive director of ApparentPlan ([www.apparentplan.org](http://www.apparentplan.org)), a Minneapolis-based advocacy organization for older adults and their families. ApparentPlan's



Tracy Keibler

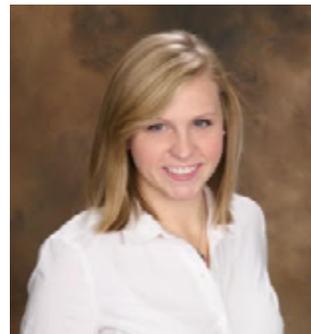
primary objective is to improve the quality of life and health outcomes for older adults through targeted health programs and hands-on support. Keibler says, "We need a whole new conversation about individual preferences in long-term care. This conversation needs to go much deeper than 'no heroic measures.' It needs to be a conversation about what makes life worth living, how much one is willing to go through in order to have a shot at being alive and what level of being alive is tolerable. The answer will be different for everyone. In Atul Gawande's book *Being Mortal: Medicine and What Matters in the End*, one patient was willing to suffer considerable pain for a shot at being alive if he could eat chocolate ice cream and watch football."

The biggest obstacle in getting this kind of conversation rolling is the simple fact that most people don't think about long-term care until they are forced to due to crisis. Amanda Horner, Re-think Tank member and co-owner of Horner Strategies, a Minneapolis-based public relations and public affairs firm with

extensive experience in health care and long-term care says, "And at that point, it largely becomes a matter of cost, because long-term care is so expensive. So for many people, effective long-term care is the care they can afford."

### Breaking Down Stereotypes and Valuing Autonomy

Long-term care stereotypes present another hurdle to engaging the kind of conversation needed for overhauling long-term



Amanda Horner

care. People tend to have pre-set notions of what long-term care is and must be, and those notions can influence their expectations of care. For example, Keibler has visited her clients in many settings and is often unsettled by what she sees, while family members are not. "I've observed residents sitting in wheelchairs and left unattended for hours, where confusion is left uncomforted

until panic sets in," she says. "When I would talk with those families I'd ask them what they thought about the care their loved one was receiving. Half of the time, they would say it was wonderful, that mom or dad was getting great care. The only thing I could conclude is that they had no idea what good care looked like. Since those scenes describe the stereotypical image of long-term care, that was their expectation. But when you see better care and you know better, you expect better. Baby Boomers don't seem to be as accepting of the stereotypical standards for long-term care and are making it pretty clear that that is an option they will not accept."

Other times, family members may restrict their complaints, and their field of vision, to only what affects their own loved one in long-term care, which presents another obstacle to systemic change. "Too often people complain about the realities of long-term care only when it affects their loved one and focus on finding a solution to a relatively small problem," Horner says. "That's important, of course, but we need to take a step back and look at the big picture. What can we do now to make long-term care better in the future?" Horner sees truly effective long-term care as something that will look different for everyone. "But it will meet each individual's needs while supporting and encouraging individuality and autonomy."

Keibler agrees, saying her clients want long-term care that tends to the needs of the whole person while offering both residents and family caregivers a reasonable amount of input. "When rigid 'protocols' don't work," she says, "the care setting should be flexible and change the protocol to meet the patient's needs."

*Continued*

She offers some real-life examples. “A 93-year-old man was in hospice,” she says, “and the family member held his hand and noticed that he was running a high fever. The daughter knew that dad wanted to be as present as possible all the way up to the end, and so requested Tylenol to provide comfort from the fever. She was told that the orders were for morphine and that it would take six hours to get an order for Tylenol.” In another instance, a mom with mild dementia was in assisted living and suffering consistent bouts of constipation due to her medications. The facility had a rigid protocol for constipation that was only implemented after four days and did not include any confirmation of effectiveness. “The daughter would see her mother with exacerbated confusion from the pain because staff would not bend the protocol, start it earlier, or follow up to determine whether the interventions had even worked. The family should be able to request Tylenol for a dying dad and get it, just as they should be able to manage a constipation problem ‘off protocol’ when the protocol is too slow and ineffective,” Keibler says.

### Elements of Truly Effective Care

Fundamentally, says Keibler, effective change and better care require environments where the nursing assistants and aides on the floor feel supported by every level of management above them. “I’m talking about environments where care uniquely supports the care recipient’s physical, emotional, and spiritual wellbeing. Where care is not about items to be marked

off on a task sheet but about the needs and dignity of the resident. Where the risk tolerance level as expressed by the resident and/or the family caregiver is understood and followed.”

Horner says she sees the integration of technology into long-term care as another part of the answer. “It’s an easy way to improve care, reduce costs in the long run, and give clients the ability to live a more independent life,” she says. “I’m hopeful that we will find creative solutions not only to the high costs associated with long-term care, but also to improve the care our loved ones, and eventually ourselves, will receive.”

### Next Steps

Keibler hopes the Re-think Tank can bring the dialogue into the public consciousness as a first key step in making changes. “The idea is that we will ask the legislature to convene a task force to identify the elements of care people really desire and that they can’t currently get,” she says. “We’ll take what the task force discovers and make a report back to the legislature a year from now. I would like to see pilot programs across the types of care settings, including residential group homes, assisted livings, and skilled nursing, where leadership is trained and the ideas that are generated from the task force can be implemented as a test. We want to see if the type of care we are seeking can be provided well—because we believe that good care matters—and affordably.”

## The Long-term Care Re-Think Tank’s Long-term Care Tenets and Aims

### Background

- The population is aging; maintaining the status quo is unaffordable.
- The status quo is not what people want. We are in danger of inflicting on our parents care we would never want for ourselves.
- LTC was never planned; it evolved in response to financial and regulatory incentives. It responded to a need to supplement (but not supplant) family care.
- LTC consists of three basic building blocks: room and board, personal care services, and medical care (largely addressing chronic illness); it can be delivered in a variety of settings.
- Medical model settings minimize the potential to improve client quality of life and overall wellbeing.
- A great deal of innovation is occurring; technology will play a key role.
- Minnesota has been rated as a national leader in LTC rebalancing, but that should not be a basis for complacency. If we are to retain our edge, we need to think creatively.
- Minnesota leadership has been working actively to confront the issues around paying for LTC. We need to give equal attention to what we propose buying.

### Challenges

- How do we create the proper mix of incentives (payment and regulation) to encourage innovation and to create the sort of care people would want?
- What do we do with the extant infrastructure (i.e., institutions and current staffing)? How do we mobilize a workforce with a new mindset of LTC when many are highly invested in current models of LTC?
- Can we harness the business concept of disruptive innovation, which suggests that cheaper, more convenient products may drive existing ones out of the market, even if the new products are of lower quality?
- Will society accept less formally trained care providers who are better supervised through technology?
- How can we offer a positive model of LTC that will make funders willing to spend money on it?
- How can LTC models channel the power of human connection and engage individuals to live with purpose and as vibrantly as they are able, or choose to live?

*Continued*

## The Long-term Care Re-Think Tank's Long-term Care Tenets and Aims (cont.)

### New Approach

- Care is provided in livable environments (ambience depends on personal financial resources). A variety of housing options would be available; most would be small individualized living units.
- Clients live in the setting of their choosing; may need to move into more congregate settings but retain tenant status. They control access to their living quarters.
- Care given largely by aide level workers supervised by clinical professionals through smart phones or other information technology.
  - Check reliability and time spent (GPS).
  - Monitor conditions (clinical tracking forms).
  - Report changes in client status. Caregivers are trained and competent to provide care in a way that minimizes discomfort and provides the greatest consideration and respect for the individual.
- Clients hire/select workers, but with some method of oversight from professionals.
- Primary care is proactive—track client's status and intervene when there is early evidence of a change.
- Medical care, social care, and the client coordinate to develop and focus on shared goals.
- Personal care workers make "clinical" observations and collect data.
- Coordinated care would address the potential for improvement in independence and quality of life.
- Care would emphasize nonpharmacologic interventions.
- Assistance with decision making.
- Clients are allowed to take informed risks.
- Payment reflects/rewards outcomes (quality of life and quality of care) as well as services provided.
- Payment and provision of subacute care (post-hospital) should be separate from LTC. Subacute care can be given in rehabilitative units or at home, but the same institution or operating unit should not deliver subacute care and LTC.
- Communities are engaged with and connected by regular, ongoing interaction with LTC clients to benefit both groups.

### Help us Re-think Long-term Care

To learn more or to become a member of the Long-term Care Re-think Tank, contact Robert Kane at [kanex001@umn.edu](mailto:kanex001@umn.edu).

## News, Notes, and Notable Achievements



Jessica Finlay

### U of M Grad Student's Work in Aging is Featured

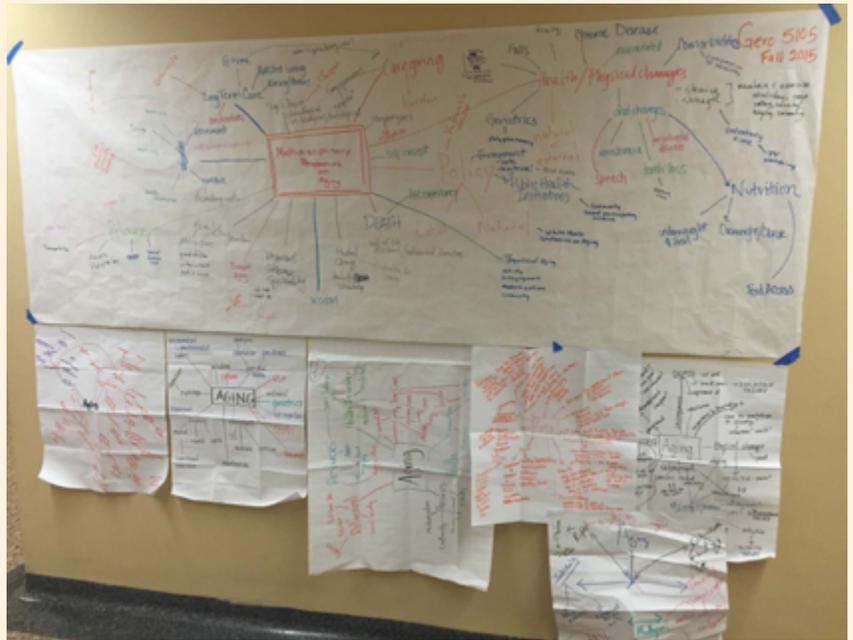
Jessica Finlay, an Interdisciplinary Doctoral Fellow at the University of Minnesota, is working on a dissertation about the intersection between living environments and aging. Her work, which falls within the discipline of "geographic gerontology," was recently highlighted in a feature article, "Aging in the Right Place," published by the newsletter of the University of Minnesota Graduate School.

The article explains: "Although most people have never heard of geographical gerontology, it emerged in the 1970s and 1980s in academia. It has since largely faded as a field of inquiry—which is unfortunate in light of the unprecedented growth in aging populations and broad concerns in health care, social security, public policy, and civic planning in the U.S surrounding this expanding demographic." Finlay's work examines how we can facilitate safety, comfort, and independence, and how we can deliver some of these staples of everyday life through more accessible home and neighborhood design.

The full article can be accessed here: <https://www.grad.umn.edu/news/aging>

## Students Create MindMaps of Aging

The students in the fall 2015 Multidisciplinary Perspectives on Aging (Gero 5105) displayed their learning and perspectives on the topic of aging (see the photo). As part of the mid-term course review, students created "MindMaps." Then, as part of the final course review, students collaborated on one comprehensive MindMap, documenting the interrelatedness and complexity of the field of aging studies. Gero 5105 is offered each fall and serves as a core course for the Graduate Minor in Gerontology and the Certificate in Aging Studies. Coursework focuses on issues and trends affecting the lives of older adults and those who serve and care for them. Students from a wide range of disciplines participate.



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.

### Letters, opinions, and news items may be sent to:

Jeannine Ouellette, Editor, *Old News*, Center on Aging  
D351 Mayo (MMC 197)  
420 Delaware Street SE  
Minneapolis, MN 55455  
Tel: 612-624-1185  
Fax: 612-624-8448  
Email: [coa@umn.edu](mailto:coa@umn.edu)  
Website: [www.aging.umn.edu](http://www.aging.umn.edu)

*The University of Minnesota is committed to the policy that all persons shall have equal access to programs, facilities, and employment without regard to race, color, creed, religion, national origin, sex, age, marital status, disability, public assistance status, veteran status, or sexual orientation.*



## Happenings

### Minnesota Gerontological Society Annual Conference

#### "As We Age: Trends - Triumphs - Transitions"

Friday, April 22, 2016,

Earle Brown Heritage Center, Brooklyn Center, MN

Registration details will be available at [www.mngero.org](http://www.mngero.org).

*The University of Minnesota's Center on Aging is a University-wide center for research and education focused on aging. Our mission is to foster basic and applied gerontology research and education that will inform public policy, prepare students at the undergraduate and graduate level for work within an aging society, and provide information and outreach to help address the health and well-being of older adults.*