

Alzheimer's Disease on the Frontier

By

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Background:

In late June, care providers from seven frontier states, including state officials, Alzheimer's Association chapter members, and other community organizations, gathered in Cheyenne, Wyoming, at a meeting organized by the Technical Assistance Center for the Administration on Aging's Alzheimer's Disease Demonstration Grants to States National Resource Center. At this first-ever meeting of its type, the people who are in charge of directing Alzheimer's care and education could talk about what makes their job in frontier communities different and share ideas on how to provide both indirect and direct services to clients and families in an environment in which resources are stretching thinner. This article summarizes the meeting's key findings.

Care Giving on the Frontier

In 1893, historian Frederick Jackson Turner declared the American frontier closed.

More than a century later, a number of people would debate that point.

One of them is Carol Miller, executive director of the Frontier Education Center, whose mission it is to be a national clearinghouse, conduct research, educate and offer leadership roles on issues that are important to frontier communities.

"A whole movement has been born from frontier health care issues," Miller said. "So many times, we're dealing with one-size-fits-none programs." Frontier regions – defined by vast areas and low population – lack access to programs and resources that city dwellers and others in more settled areas take for granted.

People who live in frontier areas take different things for granted, such as clean air, a willingness and the time to help someone in need, self-reliance and living their lives at an unhurried pace. They take for granted that driving to the grocery store may be a 250-mile round trip, and a doctor's appointment may take most of the day.

Those very factors can pose dilemmas for the agencies that deliver care to people who need it most, like those with Alzheimer's disease.

Susan Raymond, who now works at U.S. Health and Human Services Administration on Aging Region VIII office in Denver, shows just how hard care giving on the frontier can be.

Outside of Grouse Creek in northwestern Utah several years ago, a rancher struggled to care for his wife, who had Alzheimer's. They lived five miles from town, which boasted a single store. Family members were able to help out a bit, and the Church of Jesus Christ of Latter-day Saints – another possible source of help – had a stakehouse (church), but it was miles away. The rancher was mostly on his own in caring for his wife while he was still running the ranch.

Raymond tried to do what she could to help. "I called the home health agency to see if we could find someone they could hire to help out," she said. Raymond also called around to arrange for area restaurants to prepare meals for the rancher and his wife.

"By the time we got that in place," Raymond said, "the husband had decided he couldn't do it anymore. In her wanderings, his wife almost stepped on a rattler."

She had reached the stage in her Alzheimer's where she could not recognize the danger a rattlesnake posed. The rancher decided his wife had to go to a nursing home, which was a four-hour drive from the ranch.

This scenario is familiar to people in the frontier whose business is providing care; the shortage of resources available in cities and towns drives creative solutions and a different way of thinking, and sometimes sad decisions. But even as frontier areas share traits like these, they are by no means the same. Cultural differences, immigration patterns and geography are factors that differentiate one area from another.

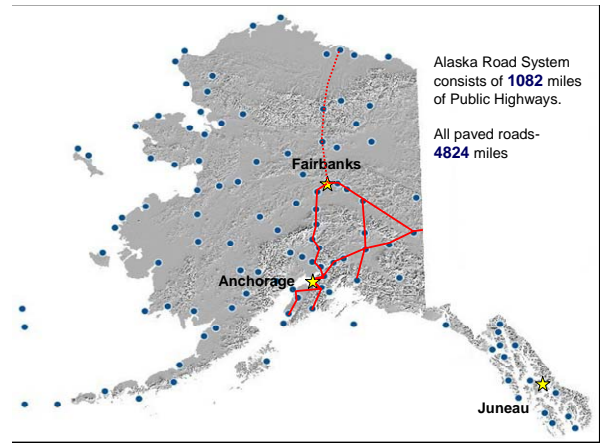
What is the Frontier?

In describing the frontier, people use terms like “beyond God’s backyard,” or “rural on steroids.” While no commonly agreed-to definition exists, the Western Governors Association and the National Rural Health Association have adopted a consensus definition based on a matrix developed by Miller’s agency, the Frontier Education Center, that includes population density and distance in miles and travel time from a market service area that might include a store, gas stations and a health clinic, for example. This matrix is flexible enough to include areas isolated by barriers like mountains, or road-less areas, which can make access much harder.

The seven states represented at the meeting – Alaska, Arizona, Idaho, New Mexico, North Dakota, South Dakota and Wyoming – each had its own distinguishing frontier factor. For instance, most travel in Alaska takes place by airplane because most of the state is road-less; the telephone becomes very important for communication and training. But parts of New Mexico don’t have access to basic telephone service.

The state representatives also worked up a list of attributes that they said describe the frontier:

- Challenged by distance from and the availability of basic necessities
- Unique geography and seasonal access
- Often lack adequate tax base (federally owned land)
- Many transportation issues and challenges
- Can be areas of multi-governmental jurisdiction
- The frontier is flexible as is its definition



Alzheimer’s Resource Agency of Alaska

As they have for more than 200 years, Americans are looking westward. They come for clean air, unspoiled vistas, the chance to experience nature outside city and state parks.

Sometimes the broad expanses of unspoiled nature are the result of ranches, which keep vast tracts undeveloped. In other cases, the federal government ensures the view, because it owns so much of the West and makes a lot of its land available for a variety of uses, including recreation.

Although they may not think in specific terms, people are looking for high amenity communities on the frontier; areas with scenic beauty, few people, recreation opportunities and a small-town feel. That’s why some frontier states in the Rocky Mountain region have the fastest growing populations, including retirees and the soon-to-retire.

Hidden behind these high amenity communities are a far larger number of towns and settlements that have been overlooked by real estate developers because they lack access to cultural activities or ski slopes. These hardscrabble communities are marked by declining populations, as people continue to leave to find opportunities and jobs elsewhere. But those with strong ties to the land and to the frontier culture stay, and they require services, too.

Providing even the most basic health care can be a challenge in certain instances; providing more complicated care can be much harder.

“When we surveyed the states, we’d hear about Sturgis, S.D., and Yuma, Ariz.,” Miller said. Special events like the annual Sturgis

Motorcycle Rally, or the influx of snowbirds who migrate south in the winter for warmer weather, can overwhelm volunteer health services for a day, a week, or several months at a time, she said.

Scarce resources can be used taking care of people who visit frontier areas for a day or two and do risky things, like climb mountains. If they need a costly helicopter evacuation, that means less money is available for other locally provided services. “We count on volunteers,” she said.

In high amenity communities, residents may want more services, but they may also vote down tax increases that would pay for them. What’s more, Miller said, the problems of caregiving on the frontier are made more complicated by economic factors. Wages are low, which drives away people who could serve as volunteer emergency medical technicians or who could be hired as respite care workers.

Community Strengths and Weaknesses

A key characteristic of the frontier is independence; you can’t live there and not be able to fend for yourself and your family. Raymond’s story of the Utah rancher illustrates a culture that teaches people to take care of their own because there’s no one else to do it. The cost for home health care workers to travel to remote homes can eat into small budgets, for example, making that kind of care scarce.

But Alzheimer’s, with its progressive nature, challenges that independence and self-sufficiency.

As vice president of programs for the Alzheimer’s Association Colorado Chapter, Cheryl Dunaway oversees seven regional chapter offices, as well as developing and putting in place new programs to meet the needs of clients, including those who live in frontier areas.

While a disease like Alzheimer’s affects people the same way no matter where they live, caring for the person and the person’s family is a far different proposition on the frontier.

The first stage is marked by progressive forgetfulness and confusion, Dunaway said. Mood, personality and judgment can change and everyday skills such as balancing a checkbook

are lost. The second and generally longest stage brings a shortened attention span, interrupted sleep cycles and restlessness, inappropriate behavior or loss of impulse control. People in this stage need full-time supervision. The third stage requires constant care as the person with Alzheimer’s won’t recognize family members or friends, be able to speak clearly or swallow.

Understanding what the disease means, how it will have an impact on the person who has it and how to prepare for the future depends on having access to health professionals who can give a good diagnosis, she said, and not someone who will say that memory loss is just a part of getting older and nothing to worry about.

Deciding when a person with Alzheimer’s should no longer drive is a consideration, Dunaway said. “Driving is dangerous in the early stages,” she said, “because the person knows how to operate the vehicle, but once out on the road can become confused and disoriented and feeling anxious. We don’t know at what point someone is unable to drive a car unless there has been a comprehensive assessment, and they are not available everywhere.”

Often a diagnosis comes only after some kind of crisis. Dunaway said raising awareness about Alzheimer’s as a disease rather than as a natural part of aging will help, but that’s not always easy to do in frontier areas.

Identifying the challenges the frontier presents is one way to establish how and what kind of care can be provided. One way to do that is through the system devised by John McKnight at the Asset-Based Community Development Institute at Northwestern University, which can catalog what a community has to offer. In contrast, a needs-based approach generally focuses only on what’s lacking rather than what’s available.

Some of the key characteristics of frontier people identified at the workshop were adaptability, pride, independence, a willingness to pitch in and help and the ability to match expectations to the resources available. While they value their privacy, frontier people also know everyone else’s business.

Other assets – economic, personal and institutional – were also listed. They ranged from ability to share what’s available, access to

state-funded special programs and local philanthropy to roles that local lawmakers, churches and associations like the Rural Electric Association and co-ops can play.

FRONTIER STRENGTHS

Adaptability
Independence
Flexibility
Collaboration
Take Care of Own
Resourcefulness
Mind Your Own Business / Privacy
Stubbornness
Know your business (gossip line)
Match expectations to resources

PERSONAL SKILL STRENGTHS

Inventiveness
“There’s Only Us”
Community Knowledge
Making Time for One Another

The flip side of this assessment is the barriers that exist because of the nature of the frontier, with its sparse population and wide-open spaces. For some federal programs, small populations aren’t statistically large enough to qualify for aid. Those small populations spread out as they are in regions with federal land ownership, live in and around communities where the tax base is narrow and so they don’t have access to matching funds needed to access federal programs. Alzheimer’s Disease Demonstration Grants to States require matching funds. Administrative costs are higher in the frontier because economies of scale aren’t available.

With a lack of care providers comes a lack of expertise to train respite care workers. At the same time, people with Alzheimer’s and their families don’t know much about the disease and they don’t always have access to information or help. Even if it were available, some cultures discourage seeking outside help.

Having access to few apparent resources is not enough to halt progress.

While an Area Agency on Aging director in a rural area of California Dennis Dudley, now

an aging services program specialist at the Administration on Aging’s Region IX office in San Francisco, witnessed what a community can do if it’s motivated.

“I was asked to work with a local hospice board. About all the hospice had was a thrift shop and a couple of nurses. It wrote grants and got some funding,” Dudley said.

The board was content with what the hospice was doing. But the hospice director saw the need for growth and groomed the hospice board of directors to take action. In a town of 7,000, the board raised \$2.5 million in 17 months to launch an expansion.

Drilling down to the details At the personal level

The aging Baby Boom will bring with it a host of challenges; one of them is expected to be the rise in the occurrence of Alzheimer’s disease, which some say could reach epidemic levels.

Under the current federal funding structure, direct in-home services provided to a person with Alzheimer’s disease by an agency provided, paid direct care worker, are required, while indirect services such as telephone support to caregivers is not. However in frontier areas, indirect services are more commonly available and used.

In frontier areas, care for people with Alzheimer’s rests mostly with family members; they need education, and they also need support and resources that may not be typically allowed under the requirements of some programs.

The Colorado Alzheimer’s Association is among the chapters that participate in the Alzheimer’s Contact Center, a round-the-clock helpline that’s available to answer questions and provide guidance on a number of issues like understanding memory loss to developing a long-term care plan.

“Last January in Colorado we had a span of storms,” Dunaway said. “A man who was caring for his wife was stranded for days. He just wanted to talk to somebody, so we were able to give some quick, friendly support.”

Through collaboration with the Administration on Aging, the helpline has grown rapidly, and in a year or so, it’s expected

to reach the entire country, highlighting the value in using something as common as a telephone line to deliver help.

Beyond that, Miller said the Frontier Education Center, with its focus on sparsely settled areas, sees neighbors helping neighbors. “There are community coalitions, but they don’t know what to do,” she said.

“Are we experiencing the last generation where family care is a given?” she said. Youth flight to better opportunity is robbing the frontier of the age group that will become caregivers in coming generations.

That shift has drained many frontier communities of people who could work as caregivers, provide respite services or even volunteer support. Because ranching – a common occupation on the frontier – is not generally lucrative, there’s little money to pay for help, even if it were available.

At the Government Level

State government has a role to play in advancing the care that can be given.

New Mexico has launched a Medicaid Self-Directed Waiver program called “Mi Via,” which loosely translated means “my way.” The program, administered jointly by the state Aging and Long Term Services Department, the Department of Health and the Human Services, created a community-based alternative that gives participants more choice and control over what services they want within a certain agreed-upon budget. The program also frees the state to reach the greatest number of people possible.

Doyle Smith, deputy division director of the New Mexico Elderly and Disability Services Division, said the program took three years to get off the ground. “Serving between 200 and 2,500 people at \$12 million to \$16 million a year was our goal. Now we have more than 9,000 people in the program at \$180 million a year.”

Self-direction, he said, is about thinking outside the box. Pets can make a big difference to someone who needs care. In the Medicaid budget for self-direction, \$10 a month can be budgeted to pay a grandchild to care for the pet.

When the program started at the end of 1999, Smith said most funding was going to

institutions that provide direct care, like long-term care facilities. Now, 73 percent of the funding goes to communities to help people where they live, and the balance goes to institutions.

Many of the households that now use Mi Via were on food stamps or other support before they joined; and now the program has created livable wages in rural communities. “The impact is phenomenal. It’s changed how people in these households live their lives,” Smith said.

The challenge in a program like this is that getting away from the traditional Western model of health care delivery takes a long time, he said.

State legislatures have the power to drive other changes to make the delivery of care smoother in frontier areas. One key area is in nurse practice acts.

Susan Reinhard, co-director of the Center for State Health Policy at the Rutgers University, said professionals often are the ones standing in the way of consumer-directed health decisions.

“Social workers don’t want to let go of case management, and nurses don’t want to let go of medication administration,” Reinhard said. “There are two issues. One is if we let this happen in consumer-directed care, it will be the beginning of the end of nursing. The other centers around dementia – would a nurse trust a non-relative to give medication?”

Every state has its own nurse practice act and each is different, she said. Some states say nurses shall never delegate giving medication, but other tasks can be assigned. Nurses in Oregon can delegate or teach care in community settings. Wyoming’s act is quite restricted.

The basic question is how a state can arrive at a new model of cooperation between people who need the care and the people who give the care. One of the key concepts is that money follows the person. That might mean paying family members to provide care, which will help support community living.

Reinhard said supporting independence means changing professional models, supporting cooperation with consumers and their families and changing programs, policies and laws that stand in the way.

What's next?

More creativity will give more flexibility. One of the goals of the workshop was to put ideas in the hands of the people who attended to take home with them.

Three themes emerged. One was the importance of educating – lawmakers, who can fund programs and provide matching funds for federal programs; family and community members to identify the early signs of Alzheimer's and related dementia disorders; and tribal communities, whose cultures may have limited the access to information. Second was cultivating other sources of funding, such as corporate philanthropy and community foundations. And third was building collaborations with groups that have similar interests and concerns. A likely result is leveraging what local resources are available to get the greatest benefit, and recognizing that families need as much support as possible to help them care for their own.

It was more than an academic exercise, as requirements in federal funding are changing to stress consumer-directed care, streamline the programs available and reduce duplication

Two programs – one at the local level, another at the state level – stood out among the others in meeting the needs of people who need information and care in innovative ways.

The first is a program developed in Tompkins County, New York. To reach people in rural upstate New York with indirect services, information kiosks were set up in 24 area gas stations with brochures and information from a variety of health interest groups on issues including breast cancer, aging, Alzheimer's disease and child protection. Each brochure is coded to track where the information is being picked up. Restocking the kiosks by one of the collaborating agencies takes about four hours, but the information is available around the clock.

The second was the innovative approach that the Alzheimer's Resource Agency of Alaska uses to cope with the challenges of the nation's largest state.

Melissa Mitchell, the agency's In-Home Services manager, developed the program that includes respite care, consumer-directed

personal care assistance and chore services. The challenge is that only 4 percent of the state is accessible by road.

To recruit respite care workers, agency staff asks the family for suggestions and advertises with posters and brochures in clinics. Staff members specifically search out people who have served as caregivers to their own family members. To train workers in remote areas, the agency has a handbook and video program, and the monthly newsletter has training express modules that workers fill out and return to help meet education goals. Quarterly teleconferences also provide access to training for respite workers who must have 10 hours of annual training.

Recruits are required to be tuberculosis-free, undergo criminal background checks and know first aid and CPR. Sometimes the agency grants a waiver on the background checks until they can be done.

Because the agency relies on grants, it cuts expenses whenever it can; Mitchell has found that phone cards are a better deal than traditional long-distance service that's used for intake interviews.

"We wanted to know how long caregivers would keep a person with Alzheimer's in the home," she said. "About 67 percent felt the respite care was great, and 67 percent said that without it they would have placed the family member outside the home a year earlier."

Key Findings

To better serve frontier people with Alzheimer's disease and their caregivers, participants concluded that it's necessary to:

- *Recognize that indirect services such as telephone support services, rather than direct in home services provided by paid direct care workers, are often the only support available to family caregivers;*

- *Implement new state policies such as:*
 - *New Mexico's Medicaid consumer directed personal care option which enables families to hire family members or neighbors to help provide care;*
or
 - *Changes to state nurse practice act to allow family members or caregiver neighbors to dispense medications; and*

- *Create new care options like Alaska's dementia training program, that draw upon the care giving experiences of neighbors to assist families in crisis.*

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