Deaf Elders Find a Home of Their Own

eniors who have been deaf all or most of their lives are a unique population, with a language and culture of their own.

Because of the language barrier, they often find themselves isolated from the hearing world. These dynamics, coupled with a scarcity of available support, make providing housing and related services for this population a tall task.

For any elder, having to leave home for a long-term care facility, or even to move into a retirement community, is a hard life transition. Add to the equation that the elder is deaf and has been so since early in life. Now the challenges multiply and become more complex. One of the most ominous obstacles is communication, say the few providers of independent housing and assisted living strictly for the deaf and deaf-blind.

Individuals who have not heard for most of their lives, and who are now aged, have often spent years in isolation. Many of them grew up in state schools in a time when there were no teletypewriters (TTYs, also known as telecommunication devices for the deaf, or TDDs) or professional interpreters.

While deaf children from nonhearing families learned to sign, those who had hearing families were not encouraged to learn to sign because it was believed that they would isolate themselves from the hearing world.

Additionally, many deaf people growing up in the early 1900s rarely learned to read or write. Although a good number of these elders still do not have these skills, most have learned to sign in order to better connect with the deaf community.

Left Behind

Those who move into a hearing retirement community, assisted living facility or nursing center are left out of activities that their peers are able to take part in.

"Imagine sitting in a dining room with someone who is talking to you. You would see their mouths moving but no communication would be taking place," says Jackie Blair, director of Chestnut Lane Assisted Living Facility for the Deaf and Deaf-Blind in Gresham, Ore. Chestnut Lane is a part of the Concepts in Community Living family of assisted living facilities in the Pacific Northwest and Northern California.

The 70-unit community just opened in 2004 and is the first of its kind in the Northwest. Both independent living and assisted living are housed in the same building so that if independent residents eventually need more support, they have another place to go without being uprooted.

Wait and See

"In the very beginning our residents sometimes feel isolated and scared," says Carole Surdyke, director of Valley View Assisted Living Community for the Deaf, Elwyn, Pa. Valley View, which falls under Elwyn's Deaf

Services division, also serves only the deaf and deaf-blind population.

Surdyke's staff have placed great emphasis on working through the communication barriers with their residents, who currently number 44. They focus on understanding and dealing with newcomers' initial hesitancy and the anxiety that stems from previous experiences.

Newcomers wonder if the staff will really sign. They have concerns about whether these strangers will understand their culture. And they worry about having restrictions that were imposed on them long ago in state schools. But the wait—and-see sentiment usually dissolves in time.

Putting the Language to Work

One means of breaking down communication barriers is hiring deaf staff. A majority of the personnel at each of the few communities for the deaf are themselves deaf, from the nurses to the beauticians to the maintenance workers.

For a good number of the employees who do not hear, these jobs in facilities for the deaf are their first jobs. Many have been on disability or simply acquired no job skills, usually because of communication difficulties. They are excited to be employed in a place where they can actually use their language to the advantage of those they serve rather than have it be a hindrance, note administrators.

The hearing, too, are required to know American Sign Language (ASL). Having an entire team that can sign helps resolve common problems. It's become easier, for instance, for residents who are sick to describe the symptoms they are having, or to explain when their discomfort began.

Learning the Ropes

Both hearing and deaf staff initially receive general training followed by ongoing instruction. At Valley View, all staff undergo a minimum of 40 hours of instruction and continue with one-on-one training as needed.

Chestnut Lane also puts a good deal of stock in educating its team and approaches training of its deaf staff a little differently in some ways.

"One of many areas that we focus on is teaching them how to maintain professional boundaries. The deaf community is very close-knit, so we teach staff how to separate work from their personal lives," says Blair.

Feeling at Home

Residents also begin to feel comfortable with their surroundings with the use of assistive devices. There are flashing door bells and fire alarms, as well as bed vibrators attached to alarms. Deaf staff wear vibrating pagers, and traditional intercoms are replaced with digital nurse call systems.

Some facilities have forged into the new millennium with a more high-tech way to converse, replacing the cumbersome process of typing into a TTY: They use video cameras with screens so that the deaf can sign "face to face." The technology also enables interpreters to relay messages back and forth between the hearing and the deaf.

As important as the accommodations are the attitudes of the staff, according to Judith Good, president and CEO of New England Homes for the Deaf. The organization's campus in Danvers, Mass., is one of only two in the country to offer a full continuum of care to the deaf—independent living, assisted living and skilled nursing.

In hiring her entire team, Good looks of course for the required professional qualifications and training. But, she says, "I also want to see a willingness and attitude that shows they are excited about working with this special population.

"Most of the staff love the culture and the language. They embrace their work. But some hearing staff get frustrated by the communication challenges," says Good. She stresses the importance of having staff who genuinely enjoy what they are doing because the residents see this.

Supply vs. Demand

Breaking through communication barriers and putting together a well-trained, good mix of employees are not the only challenges. There is the serious issue of demand for housing and special care services.

Demographic statistics about the deaf are tricky because sources disagree, and may use different definitions of deafness. The Gallaudet Research Institute, sorting through the available data, concludes that two to four people out of 1,000 are "functionally deaf," which translates to as many as 1.18 million Americans. A subset of that group, fewer than 300,000 people, were born deaf or became deaf before age 18. The rest lost their hearing later in life, most of them much later in life.

If we broaden the definition of deafness to include those with a "severe hearing impairment," the number of functionally deaf or severely impaired in the U.S. rises to as many as 6.49 million.

There are only about 11 independent living, assisted living and/or nursing centers in this country that are set up exclusively for the deaf and deaf-blind. Because of the scarcity of services, getting a placement can be very difficult.

"At Pilgrim Tower, we have a waiting list of about 100 people," says Barbara Schwerdt, director of training for CARING Housing Ministries, which is an affiliate of Front Porch and manages Pilgrim Tower.



New England Homes for the Deaf resident Lois Finocchairo shares a moment with Activity Director Melissa Dickerson. New England Homes is one of only two providers who offer the full continuum of care to the deaf.



New England Homes for the Deaf looks for staff, like Director of Nursing Lauren Grenier, who are excited about working with this special population.

Open since 1968, this Los Angeles community living facility provides 100 affordable housing apartments. Applicants may be as young as 18, but priority is given to those who are at least 62 years old and deaf. Residents who are elderly and/or deaf must be independent. They bring in their own special services if needed. However, a full-time resident services coordinator is available.

Already, many deaf seniors find that they have few options when they can no longer remain in their homes. A large number are forced to move into assisted living and skilled nursing centers for the hearing.

Lassoing Funding

The trek to find funding can also lead down a rocky road. What is known today as Valley View Assisted Living Community for the Deaf, Elwyn, Pa., has been a chameleon of sorts over the years, having become quite proactive when put to the test as times and circumstances have changed.

This provider, which first opened as a retirement community for the deaf in 1902, had difficulties when it moved from its Philadelphia location in 1971. The building was in need of major renovations in order to meet code. The management, Pennsylvania Association of the Deaf, approached the Nevil Foundation for a grant.

"At the same time, Elwyn went to Nevil asking for funding. So the foundation kind of married the two organizations," says Surdyke.

By 1983 the trust that was set up by the foundation was exhausted, and the retirement community was converted to a nursing center in order to receive government reimbursement.

"Then in the early '90s, nursing home regulations changed, and case mix became a part of our lives," says Surdyke. "We couldn't keep serving the deaf with the reimbursement we were receiving. The state agreed to help us out with the understanding that we would close the facility, move again and reopen as an assisted living facility with a nursing home waiver."

Chestnut Lane has also been proactive and creative in seeking financial support and keeping costs down. Through community outreach, Blair has lassoed donations for costly equipment and assistive devices. Communication Services for the Deaf, Sprint and SignOn Oregon have donated video camera technology for residents to call family or friends or even to order pizza. The Helen Keller National Center has donated a low-vision TTY.

Savings come from looking to volunteers for support. Interns from Western Oregon University's rehabilitation program come to Chestnut Lane to help residents adjust to moving into an assisted living facility or to support them, should they go through the grieving process for varied reasons.

Because of state funding cuts, a nearby deaf services organization has had to eliminate some of its offerings, and now Chestnut Lane seems be where most referrals are directed, from as far as 100 miles away, according to Blair.

The financial support available to residents varies, depending on the state. Independent housing may be subsidized by HUD funds and in some cases, such state agencies as departments of health and human services will subsidize a portion of the cost. Many facilities offer a sliding scale to those who still fall short financially.

The Deaf Connection

Because the deaf community is small and has a language and culture of its own, newcomers almost immediately meld with the other residents. In fact, it is quite common for them to move in and see at least one familiar face from day one.

"I have yet to see one person move into Chestnut Lane who did not already know someone who was living here," says Blair.

Recently, a woman's daughter brought her to the facility from Seattle, where she was living in a hearing facility. The elder woman came with great reservations, but that changed quickly.

"She was walking up the sidewalk when a resident saw her from a window and came down to the lobby because she recognized [the visitor's] face from when they were roommates as young girls in Idaho. It had been about 60 years since they had last seen each other," says Blair. This was all it took before the newcomer was ready to pack her bags and move in.

A 96-year-old woman living in the same facility is no stranger in her home. She had been a dorm parent at Washington State School for the Deaf where many residents of Chestnut Lane had lived much earlier in their lives.

The deaf connection is powerful, and so relationships are also easily formed outside in the community. Students from deaf schools hear about the facilities from each other. They ask if they can come in to do activities with the residents. They crochet, make ornaments with the deaf "I love you" sign, and have made gifts for soldiers in Iraq. New England Homes for the Deaf has an on-site community center where the nonhearing come from around the region for social functions. The organization also sponsors five regional senior citizen centers in Massachusetts.

"Some of the people who eventually move here have come through those senior centers," says Good, who has also brought in a board of directors that is nearly 50 percent deaf. Prominent members include the director of the regional center of Gallaudet University and the director of the state's association for the deaf.

"They are a liaison that helps us stay current on what is appropriate in caring for the deaf and deaf-blind," Good adds.

Reaping Rewards

Good's experience as the mother of a deaf daughter (Lauren, now 34) is part of what drew her to her profession of over 20 years. Having learned to sign as a young adult, Good says, "It's a beautiful language. It just flows from the hands, and you can see such expression on a person's face."

She believes that she couldn't have found a better occupation than working to meet the needs of a people with a language, perspective and culture of their own.

"I could be running any nursing home. But working with the deaf adds another dimension to what I do. It's so much more."

Arlene Karidis is a freelance writer living in Mt. Airy, Md.

Resources

Chestnut Lane Assisted Living, Gresham, Ore. Contact: Jackie Blair, director, (503) 674-0364.

Valley View Assisted Living Community, Elwyn, Pa. Contact: Carole Surdyke, director, csurdyke@elwyn.org or (610) 891-2000.

New England Homes for the Deaf, Danvers, Mass. Contact: Judith Good, CEO,

judith.good@nehomesdeaf.org or (978) 774-0445.

Pilgrim Tower for the Deaf, Los Angeles, Calif. Contact: Barbara Schwerdt, director of training, CARING Housing Ministries, (626) 300-2440.

Gallaudet Research Institute, Washington, D.C. http://gri.gallaudet.edu/index.php.