

SUNDAY

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Another reason
to shop

Hydrotherapy
machines are
soothing weary
mall-goers.

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STOCKBYTE/ PICTUREQUEST

AT A LOSS FOR WORDS

Doctor, I can't see what you're saying

BY VICTORIA L. WILCOX
SPECIAL TO THE JOURNAL

After Alice Rodrigues, of Somerset, had shoulder surgery last year, she had to bang on the walls of the recovery room to summon a nurse. She needed medicine to relieve her pain, but without a sign-language interpreter, she could only pound and wait.

Like Rodrigues, more than 86,000 Rhode Islanders hear poorly or not at all. Yet, 12 years after passage of the Americans with Disabilities Act, they still face "tremendous barriers" to getting the accommodations they need to communicate with health-care providers, according to Jeanne Panarace, manager of Disability and Health Programs for the state Department of Health.



JOURNAL PHOTO / KRIS CRAIG

ALICE RODRIGUES

Rodrigues talks with her hands, using American Sign Language to chat with friends. Her teletype device, or TTY, lets her send and receive written messages by telephone. A relay service enables her to converse with people who lack TTYs. Their words, typed by an operator, appear on a screen.

Rodrigues reads lips, too. Yet, she feels her primary-care doctor doesn't "even try for conversation." Maria Okwara, president of the Rhode Island Association of the Deaf, says some health-care providers grow impatient with the time and effort needed to communicate.

This wall of silence deprives patients of vital information. According to Dr. Raymond Mis, a Warwick gastroenterology and liver-disease specialist, if the patient doesn't understand what the doctor says, "that whole visit is worthless."

He should know: Mis, who is legally blind and hard of hearing, wears hearing aids. He warns that when patients don't hear the questions, doctors may not get correct answers and could arrive at the wrong diagnosis.

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The author, Victoria L. Wilcox, has a doctorate in medical psychology and is on the Governor's Commission on Disabilities.



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SENIORS SIGN: The officers of Rhode Island Deaf Senior Citizens meet recently at the Silver Lake Community Center in Providence. From left are Carole Ronan, Frances Pavao, president Gilbert Desmarais and vice president Alice Rodrigues.

Deaf

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"Medically, legally, it could come back and haunt the physician," Mis says.

Beth Wilson, who served as chairwoman of the Rhode Island Commission on the Deaf and Hard of Hearing and as executive director of Self Help for Hard of Hearing People, sees barriers, too. Now working as an electrical engineer in Sudbury, Mass., Wilson, who is hard of hearing, believes people shun needed care because they dread trying to communicate. Patients have to tell what Wilson calls a "parade of people" about their hearing.

They also battle stereotypes.

When Rodrigues asks how her blood pressure is, her doctor just says "good." She wants numbers but, she says, "They think I'm stupid." The Americans with Disabilities Act tasks health-care providers with making reasonable efforts to ensure effective communication with hearing-impaired patients.

They must supply the necessary aids and services at no

charge to patients, the same way they would provide a ramp. Rodrigues says her primary-care doctor balks at securing an interpreter.

As a result, she learns about the drugs he prescribes from her pharmacist who, she says, "opens his mouth wide enough for me to read his lips." According to a Health Department study conducted from 1999 to 2001, in

which people with communication impairments were asked about their health-care access, about half of sign-language users said they never had an interpreter at doctors' appointments.

Many of those who did either brought a relative or friend to interpret, or paid a professional interpreter themselves. Another recent study, a survey of mammography facilities undertaken by the Rhode Island Breast Cancer Coalition, also found barriers. Chairwoman Marlene McCarthy says that none had a TTY, only 2 percent trained staff to use relay services, and just 18 percent had sign-language interpreters available.

Sometimes providers assume patients can read lips, will bring a hearing relative, or write notes. But many words look identical when spoken, and sign-language users may not understand written English. Relatives may be too emotionally involved to make good interpreters.

Wilson says a friend spoke of frequent doctor visits accompanied by her daughter, then pulled out a piece of paper and asked, "What does this word mean?" Wilson recalls the word: "chemotherapy."

Despite such stories, Steven DeToy, director of government and public affairs for the Rhode Island Medical Society, thinks most doctors recognize their duties under the Americans with Disabilities Act.

He says, "Physicians, of all professions, are probably the most accommodating."