

<http://www.newsreview.com/sacramento/can-you-hear-me-now/content?oid=60673>

## Can you hear me now?

It's hard enough managing mental illness. But what if nobody speaks your language?

By [Chrisanne Beckner](#)

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**By 2003, Shane and Michelle Spurlock** were frantic for a therapist in Sacramento who was great with American Sign Language (ASL) and knew something about deaf people, deaf culture and the challenges of growing up in audio isolation. But Shane, deaf from age 5, had only a sympathetic medical doctor to rely on, said his wife, Michelle.

"Because we had no serious help, no [ASL]-certified [therapist] to consult with, we were left with a very loving, caring, primary-care physician guessing at medication," said Michelle. "[Shane] was on every different colored little pill you could give him, and it was horrible."

Flipping from medication to medication, unable to connect with a therapist, Shane developed an avalanche of side effects, including an unrelenting noise in his head, like the sound of rushing wind or badly played trumpets. On some medications, all emotions were deadened, and he would struggle even to connect with his daughter, Megan.

"His eyes were so dead," Michelle said. "He was just absolutely losing all hope."

On other medications, Michelle said, Shane couldn't sleep, grew increasingly paranoid and feared that even his own family, including Michelle, was out to get him.

What would they do when they finally caught him, Michelle teased. "Expose me for the rat I am," he told her seriously.

In real life, Shane was known as a shy, good-natured, hardworking father, but no one could break through the depression and social anxiety to help him see that.

The couple tried working with local therapists but were repeatedly disappointed.

One knew a little ASL, said Michelle, but one of the counselor's first questions was: "Do you lip-read?"



A poster of Shane Spurlock, a deaf man who killed himself in 2005, flanked by his wife, Michelle, and daughter, Megan.

PHOTO BY LARRY DALTON

"We sat through the rest of the meeting just absolutely glazed over," said Michelle. "She signed every third or fifth word she said."

Shane went completely deaf in one ear and nearly deaf in the other after a childhood bout of viral spinal meningitis. He could hear some low, loud tones, said Michelle, but he couldn't make out words.

At best, lip readers can accurately interpret a third to half of human speech, and one of the haunting elements of a deaf childhood is the emphasis on the "oral-aural method," that combination of using non-verbal cues and lip reading to participate partially in conversation while looking as normal as possible. This leaves some deaf people at a severe disadvantage, but it's the main road to assimilation.

The couple tried a second local therapist who knew a little more sign language.

"The community habits and history—she just wasn't aware," said Michelle. "[Shane] kept trying to explain to her, 'Do you see how I feel like I'm on the fence, like I'm pretending to fit into both worlds and not feeling that I fit into anything?' And she just didn't get it."

Michelle started calling every practitioner her insurance covered. Then she called those her insurer wouldn't cover. Then she called providers all over Northern California. "I would literally call maybe 20, 25 doctors on this list. Take deaf patients? Know ASL? Know anything about deaf people?" If they said no, she asked for referrals and made more calls.

Shane's anxiety and depression worsened. By mid-2003, he had moved out of the family home, away from Michelle and Megan. Eventually, he drifted into a new relationship. He e-mailed his parents saying that he was in love, but in April 2005, alone in a shed behind their mobile home, Shane used a shotgun, a gift from his father, to end his life. He was only 38 years old.

"The last thing I wanted to do was to tell Megan," Michelle recalled, wiping her eyes.

Now, Michelle said, she watches her daughter closely, reminding her how lucky she was to have such a great father for 10 years.

Since Shane's death, both Megan and Michelle have said publicly that better mental-health treatment might have saved Shane's life, at least for a little while.

"I don't know how long I would have had my dad," Megan, now 11 years old, recently told a group of county policymakers, "but I know he would have been here longer if he'd had help."



### **Advocating**

A few months before Shane Spurlock died, new legislation promised to reinvigorate Sacramento County's woefully under-funded mental-health system. The Mental Health Services Act (MHSA), approved by voters as Proposition 63 in 2004, is a 1-percent tax on annual taxable income over \$1 million. It's expected to generate \$683 million for the state of California this year alone (see ["Whatever it takes"](#) by Amy Yannello, SN&R News, January 26).

Counties get to decide how to spend the windfall, but it's challenging to rank priorities in Sacramento, where mental-health services have been under-funded for nearly 30 years.



Subgroups like the deaf and hard of hearing pleaded their case to advisory committees, then task forces and then steering committees, all to carve out a portion of the county's first \$10 million. But they were only one group out of many. The deaf competed against lesbian and gay families asking for mental-health support, small towns along the Delta pleading for mental-health-assessment services, homesick Slavic immigrants looking for county-coordinated social events, and Pacific Islanders in need of domestic-violence education.

In spite of the competition, Lois Diamond, a deaf woman and one of the community's hardest-working advocates, saw the MHSA as a possible boon for her community, not just because of stories like Shane's, but also because so many deaf adults grew up in isolation and suffer serious untreated anger issues. Most of their families never learn to sign, said Diamond.

Diamond sits on Sacramento's Disability Advisory Committee (DAC), which advises the Sacramento County Board of Supervisors, and the DAC quickly threw its support behind Diamond's proposal. The deaf community asked the county for three things: a mental-health-care provider who speaks ASL and is culturally sensitive, a private location with a private line so that the deaf can manage direct communication with that provider, and some mechanism for "outreach, prevention, education and intervention services."



"Parents have no communication with their children," said Lois Diamond, of Sacramento County's Disability Advisory Committee. "They don't sign with them. ... They have an internal, built-in frustration, and they grow up with anger." PHOTO BY LARRY DALTON

Sacramento's not alone in making these requests. In 2003, the National Association of the Deaf called for a nationwide commitment to the same exact goal: direct, private access to therapists who possess an "intensive and extensive awareness of the cultural and linguistic differences, and psychosocial impact associated with hearing loss."

"It starts when children are little," said Diamond. "Parents have no communication with their children. They don't sign with them. ... They have an internal, built-in frustration, and they grow up with anger. I have a friend who was molested twice, a dear friend, and she couldn't tell anyone. She couldn't tell her parents."

Shane also grew up in a family that didn't learn to sign. "He tricked his family," said Shane's mother, Patricia Spurlock, who said she never realized how little he could hear. "We thought he was understanding what we were saying," she said.

"Most hard-of-hearing people have learned to 'pretend' to understand what is being communicated," warned local advocate Sheila Conlon Mentkowski in a letter of support for Diamond's proposal.

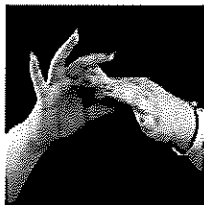
Through conversations with Shane's early teachers and audiologists, the Spurlocks were convinced their son would learn more in a normal classroom than in a deaf program, and Shane did excel as a student at times, but Patricia Spurlock now feels that Shane was always angry at her and her husband for keeping him away from other deaf students.

"We thought he could function in the world where we live," she said.

Shane was in his early 20s before he started teaching himself ASL and finally entered into a world of other deaf adults where he could socialize freely in a commonly understood language. That's when he met Michelle, a hearing ASL tutor at Sacramento City College.

"He was kind of on a high when I met him," said Michelle. But as he got older, his moods got blacker, and Michelle remembered how the fear of interacting with insensitive people in the hearing world would keep him at home fuming and disappointed with himself.

His physician couldn't help, and his family couldn't help, and there was no qualified therapist in the area.



### **Collaborating**

To show policymakers how serious the need was, Diamond packed meeting after meeting throughout the winter and spring with private, somewhat insular deaf people who rarely come out to share their stories with the hearing world.

Ellen Thielman, who's been deaf since infancy, recently lost her 17-year-old son and his best friend in an auto accident. "We went to the Compassionate Friends group," signed Thielman. "We went, but they couldn't provide an interpreter, so I had to grab an interpreter to volunteer for me. ... Every meeting, I felt so alone. The other boy's parents got a lot of support from other parents who experienced the same kind of grief. But where was my support? There was nothing there for me."

Members of the deaf community, like Linda Cook, a spirited retiree who went deaf at age 36, remembers how the community shared news about Thielman, watching her go month after month without one-on-one therapy. "We knew she was trying online counseling," said Cook.



Like Shane, Thielman never did receive the help she needed.

Because she went deaf as an adult, Cook still speaks clearly, but, like Shane, she's completely integrated into neither the deaf community nor the hearing community.

"Once you go deaf, the fight is on," she said, remembering how she struggled for acceptance and job duties at her old workplace. Now Cook's become what she calls "a hurdle jumper." She's sometimes criticized because she "doesn't act deaf," or she's "not deaf enough."

"I called suicide prevention on Thursday last week," Cook said during one of Diamond's meetings, complete with interpreters. "I called to see why they didn't have a TDD [telecommunications device for the deaf]."

A TDD is a machine that allows the deaf to call on a regular phone line and hold typed conversations with someone on a receiving TDD—kind of like real-time e-mail.

After cycling through a couple of staff people, Cook finally spoke with someone who confirmed that the crisis center did have a TDD. The number just wasn't listed in the phone book—a fact that shocked Cook and sent her deaf friends into shrieks of ironic laughter.

"She said, 'We never thought about listing it in the phonebook,'" Cook recalled. "I said, 'How would you expect a deaf person to know you have a TDD so we can call if it's not listed in the phone book?'"

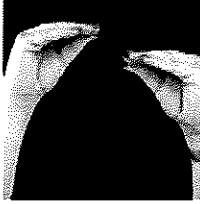
If you're wondering how Cook, a deaf woman, managed to call a suicide hotline without knowing the TDD number, it's because the deaf have access to the California Relay Service, which attaches a deaf person's TDD to an operator with a TDD. The operator reads messages to the hearing person on the receiving end of the call.

This is a great innovation and a sign that the deaf are getting more and more connected to the hearing world. It does have its limitations, however. A deaf person clearly might avoid such three-way conversations if he or she is contemplating suicide and needs counseling.



"[My mom] was following what the audiologist said. Very biased," recalled Leslie Birchell, program manager for the NorCal Center on Deafness. "They say, 'Oh, sign language will cause you to be an aural failure.'"

PHOTO BY LARRY DALTON



## Educating

Approximately 8.6 percent of the U.S. population is deaf or hard of hearing—28 million people at last count, most of them over the age of 65. But very little information is available about the number of deaf people living in Sacramento County, let alone how many of those struggle with mental illness.

Ninety percent of deaf babies are born to hearing parents, and those hearing families traditionally have consulted with hearing physicians and speech therapists who warned them to discourage sign language. This leaves deaf adults fuming.

"Unfortunately, there's a huge gap between the real-life world for deaf adults and these people who view deafness as a pathology, something that needs to be fixed," said Michelle.

ASL, with its unique syntax and grammar, is the preferred language of deaf adults but long has been considered a crutch by doctors and educators. This is changing now that studies suggest that deaf children taught ASL as their native language find it easier to learn English as a second language. Still, many of today's deaf adults grew up with experts who recommended they try to master English, even if they were born deaf and had no idea what language sounded like.

"Yeah," said Diamond, "we're talking about how lucky kids are nowadays. We talk about that, but people forget about us. It's like we were born in the wrong years. We still have a long way to go in our life, and there are many of us who still need help."

"I don't know how it's still allowed that you don't have to provide communication for a child," said Michelle. "You couldn't have a kid who needs a wheelchair to get to school and have a parent say, 'No, you will learn to walk. I will give you knee pads and elbow pads, and you will commando your ass to school, and one day you will learn to walk just like the other kids.' ... But you can have a deaf child and not communicate with them, not bond with them, not understand them."

In conversation, a bitter, mirthless laugh bursts out whenever the topic turns to education and childhood, like when Michelle reminded her friends that hearing babies and even chimps are taught to sign, but many experts still don't want to teach the deaf kids, or when Thielman and Diamond recalled teachers whacking deaf students on the knuckles for signing in class or had them sit on their hands to keep them from relying on their "secret language."

Currently, the average deaf person reads and writes at about a fourth-grade level, said Leslie Birchell, program manager with the NorCal Center on Deafness. NorCal provides interpreting services and job counseling for the deaf but does not provide mental-health counseling. It would love to, said Birchell, but it's a matter of money.

Birchell herself grew up deaf with parents who never learned to sign. "[My mom] was following what the audiologist said. Very biased. They say, 'Oh, sign language will cause you to be an aural failure. If you want them to succeed in the world, you don't use sign language.'"

Like many deaf people, Birchell is a powerhouse when she communicates. Not only does she sign, but she also voices, her face and hands extravagantly busy. But even when she vocalizes, a hearing person can't understand everything she says. She still needs an interpreter. It's sign language that connects her to an interpreter and to the hearing world.



Angelene Fowler, co-owner of A Show of Hands, a sign-language-interpreting agency, is a certified interpreter and the guardian of a deaf girl who uses ASL. Fowler is facing some of the questions that parents like Birchell's faced generations ago but with more information. She could send the child to one of California's two residential schools for the deaf, or the girl could attend one of the deaf programs at local schools, but Fowler has chosen a third option. She sends the girl to second grade with an interpreter who stays with her all day, helping her learn at the pace of her classmates.

And Fowler's still pressured to teach the girl to speak. At every meeting, said Fowler, the message is the same: "Please put her in speech therapy."

Fowler says her agency gets calls about twice a week from someone who needs an interpreter to help handle mental-health issues, but often the calls come once the deaf person has reached a crisis point or has already been institutionalized.

"Every call is an emergency," she said.

The Americans with Disabilities Act obligates doctors' offices and mental-health practitioners to provide ASL-certified therapists to their deaf and hearing-impaired clients, but Fowler's office also receives numerous calls from health-care providers wondering if they really have to comply with that law. They do, Fowler tells them.

But this is tricky when it comes to mental health. Though interpreters enjoy a high level of respect within the community and smooth over many transactions with the hearing world, they're not always wanted in highly personal, sensitive conversations, especially with mental-health professionals. It's difficult enough to share suicidal thoughts with a licensed therapist. It's even harder if you're also sharing them with your interpreter, who may be part of your social group.



### **Evolving**

The numerous deaf people who shared their stories with the DAC made a huge impression, but they were only a drop in the bucket for the county, which reached out to thousands of local people in the process of allocating MHSA money. Interested groups like the DAC pleaded their cases to decision makers who ranked them in order of need. It looked to Michelle like dueling sob stories. Groups that had been ignored for years were trying to prove they were the most

miserable.



"How would you expect a deaf person to know you have a [telecommunications device for the deaf] so we can call it if it's not listed in the phone book?" said Linda Cook, an advocate for the deaf and hard of hearing.

PHOTO BY LARRY DALTON

Though the deaf community's proposal started the process ranked at No. 3, once its specific task force, along with all the other task forces, took recommendations to the final decision makers, that ranking plummeted. The deaf community's proposal dropped to No. 14—too low to be funded in the first year. But the final list of 31 recommendations included a lot of other worthy programs even further down the list, including suicide-prevention programs, caregiver-training programs and services to older residents of single-room-occupancy hotels.

Psychiatric Emergency Response Teams—the pairing of mental-health professionals with law-enforcement officers—were ranked high, as was a trans-cultural wellness center for Asian and Pacific Islander communities, and permanent, supportive housing for homeless families.

The county sent its list of recommendations to the state, and deaf advocates waited for any change in priorities before the county's 400-page plan was set in stone. So far, the state has opposed none of the county's rankings but called the plan "truly a job well done."

While Diamond was losing hope that \$10 million would be enough to add any services for the deaf, the county's Division of Mental Health (DMH) was asking whether it could do better by this community, even if money wasn't available from MHSA.

"The community had come to us before the Mental Health Services Act process," said Jo Ann Johnson, who works with distinct cultural groups as the ethnic-services manager for the county.

During a recent interview at DMH headquarters, Johnson pulled a status report from a stack of reference materials and walked through the county's new strategy for helping the deaf community find that ASL-proficient, culturally sensitive counselor it's been looking for.

First, the division mailed out multiple recruitment letters around California, asking for qualified candidates. To its surprise, only one candidate responded.

"No one local meets the requirements," said Johnson.

The county is now in the process of meeting and interviewing its single candidate. If she's qualified, the deaf will be referred to her when they call the county for mental-health services.

Johnson is also working on the community's request for TDD access. The county has ordered new TDDs for mental-health-service centers, said Johnson, and they're training their staffs to use them. The phone numbers will be published in future phone books and brochures.

The next step is to reach out to the deaf community and let it know services are available. But, Johnson warned, the situation is the same for many non-English-speaking people in Sacramento, including the area's large Hmong and Ukrainian populations.

Impatient for services to flow to her community, Diamond sees the county's efforts as a first step.

"There is absolutely no way this counselor can handle all the deaf needs," said Diamond in an e-mail. "This includes our deaf children whose parents don't sign and deal with communication frustrations. We will seek a clinical psychologist to help expand the program."

"We recognize that there's a gap, and we're trying to do the best we can to correct that," said Johnson. "We never want anything to happen like what [the Spurlocks] went through."



In her Land Park home, Michelle keeps a blown-up poster of Shane hugging their young daughter. While the baby-faced man looks happy to be near Megan, his face has a sad, taut look about the eyes that still haunts Michelle. She looks at it while she speaks, wiping at her eyes with tissues that pile up next to her.

"[Shane] was of the percentage of deaf who have the typical childhood, the anxiety and the chemical propensity for depression and wasn't able to overcome it," Michelle recently said at a public meeting. "For those people who can't overcome it, this is just a death sentence."

Michelle and Megan have been telling Shane's story for months, hoping to jump-start services that will help generations of deaf adults. Now, Michelle's thinking about returning to school to study deaf education.

"Making us No. 14 is what got us all motivated," said Michelle. "Supposedly, there's a reason for everything," she added.

