

No sight, no sound, nowhere to turn

By AMY COUÉ, The Virginian-Pilot
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Five-year-old Alex, smiles as he feels his mother, Noel Gilman's touch while cuddling each other. Across the room is father, Paul, holding the youngest child, Kayleigh, at their home in Chesapeake early this month. Hyunsoo Leo Kim photos/The Virginian-Pilot

Alex speaks to his mom with his whole body, sitting in her lap and rocking his small frame forward and back so hard his head crashes into her breastbone with each swing.

When he is happiest, when they sit with their legs tangled up on the carpet in the living room, he opens his eyes and stops moving his bony frame just long enough to smash a sloppy, wet kiss onto his mother's lips.

Then the violent rocking begins again.

The 5-year-old Chesapeake boy, who doctors said was unlikely to live past infancy, is deaf and blind. Unlike his 8-year-old brother Cameron, he can't ask for a snack. Unlike his sister Kayleigh, who is 1 year old, he doesn't know to come when Mom calls.

His parents, Noel and Paul Gilman, have learned to interpret Alex's babbles and screams to decipher if he's hungry or hurt. But they have tried for years to find someone who can teach them what Alex is trying to tell them with his motions.

On Thursday, a regional conference in Hampton will help local families find out about resources such as interveners, specialists trained in how deaf-blind children best communicate with others.

The conference, at the Virginia Air & Space Center in Hampton, will address the legal issues surrounding deaf-blindness, advocacy and schools. It also will give parents a chance to network.

In the Gilmans' home, communication is mostly about touch. Alex explores his home's textured surfaces, repeatedly rubbing his face against the sharp grates of the air vents and banging things hard against the glassy surface of the wooden coffee table to create vibrations he can feel.

One agency's census shows that Alex is one of 133 deaf-blind children in the state, but an official with the group, the Virginia Project for Children and Youth with Dual Sensory Impairments/Deaf-Blindness, thinks the number is closer to 400. A handful lives in Hampton Roads.

Decades ago, services for the deaf and blind were concentrated in state-run institutions. Today, deaf-blind children live at home and attend public school programs alongside their peers. Their parents look to community and state agencies to help them find specialists who can answer questions about schools and health care.

Such resources have been difficult to find.

In a 2004 national ranking, the most recent available, Virginia stood 47th in the amount of money it spends on community services for people who are developmentally disabled, which includes services for the deaf-blind. For 25 years, Virginia has consistently lagged behind most of the country.

"If a child is just deaf, they can still take in a huge part of the environment; the same with a child who is blind," said Deborah Nickerson, whose 11-year-old daughter, Ashley, is deaf-blind. "When you take away both of those things, you are taking away a huge chunk of how they learn."

Siblings don't completely understand but quickly learn the power of touch and motion, and parents are forced to find new ways to get through to children who often hurt themselves, banging their heads into walls, for example, or biting themselves, in an attempt to communicate.

Many attending Thursday's conference are health-care providers, teachers and administrators who have not had the chance to work with the deaf and blind.

"They throw their hands up. They don't know where to begin," said Mark Campano, project director for the Virginia Project for Children and Youth with Dual Sensory Impairments/Deaf-Blindness.

Hands-on experience with this disability is hard to come by, he said, even for those in fields such as special education.

Lori Cooper, a special education teacher at G.A. Treacle Elementary School in Chesapeake, has worked with deaf students for 10 years but has never had a deaf and blind student.

If such a student were to walk into her class today, "it'd be a huge challenge," said Cooper, who has never been trained in this area but knows to use her sense of touch to try to communicate with them.

The likelihood of a parent having a deaf-blind child is unknown, even by experts. That's partly because there are hundreds of causes, from prenatal rubella to too much oxygen after birth, and also because deaf-blindness typically comes with other complications.

In addition, those who are deaf-blind often are lumped into a broad category called disabled or severely and profoundly disabled.

Those in the field say deaf-blind children are fully capable of learning once someone figures out how each child communicates. Some, such as Alex, use violent rocking to communicate; others

use another activity such as jumping. Children can learn to communicate by using sign language, done in the palm of their hand.

Because some deaf-blind children are not completely deaf or completely blind - but legally meet that definition - parents hold out hope that one day, with enough surgeries or technological aids, their child will one day see or hear.

Nickerson has become one of the loudest advocates for Virginia's deaf-blind community and is campaigning for more services from the Virginia Department of Education. Nickerson, who lives in Henrico County where Ashley attends school, is one of the few parents in the state with a specialist trained to aid in communication between Ashley and others. The intervener is with Ashley much of the day to explain what's happening in the world around her.

Texas, North Carolina and Utah are among the few states that recognize interveners. Nickerson wants Virginia to do the same.

Some schools, dumbfounded by the children and untrained to teach them, set them aside in chairs and pull them around by the arm when it's time for the next activity. Most teachers, including those in special education, don't know the techniques these children count on to communicate because the training required to work with the deaf-blind is so specialized.

"I think they have a lot more going on in there than we've been able to get out and understand," said Andrea Borum, mother of two deaf-blind daughters in Virginia Beach.

For 25 years, according to the National Coalition of Deaf-Blindness, the federal government has allotted the same amount of money annually to deaf-blind services - \$12.8 million - even as the number of deaf-blind children has doubled and care has moved from institutions to communities.

"It's like not getting a raise for 20 years," said Betsy L. McGinnity, the coalition's campaign coordinator, who is asking the federal government to increase funding in fiscal 2008 by \$2 million, to \$14.8 million, even though she knows it isn't enough.

The Gilmans understand what it means to not have enough money. They're stuck in the middle, making too much money for certain assistance programs and too little to buy technical aids Alex needs.

So they keep calling Children's Miracle Network, going to conferences and seeking out other parents who understand what life with Alex is like.

Meanwhile, Noel and Paul Gilman anticipate the day they might be able to talk with Alex, if only through sign language tapped into the palm of his hand.

"I talk to him completely," his mother said. "I don't want to stop talking to him just in case he might hear me. I hope that one day he'll hear something. We know there's something in there waiting to come out."

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Alex Gilman, 5, plays by rubbing toys against each other and his face. His parents, Noel and Paul Gilman, hope that one day they can talk with Alex.