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LIVING

THE BLADE, TOLEDO, OHIO ■ SUNDAY, AUGUST 21, 2005



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Schyler Young rests in a warm shaft of light in her family room.

Creative Jobs

Life with Schyler



West Toledo family is strengthened by caring for their special-needs child

By ANN WEBER
BLADE STAFF WRITER

Meeting someone for the first time, Schyler Young steps close and reaches for a hand. She draws it to her face. She sniffs.

"Her hands are her eyes," explains her mother, Stacey Young, adding that her disabled daughter also relies on her other senses to interpret the world. "She's going to feel you. She's going to smell."

Seven-year-old Schyler, middle child and only daughter of Scott and Stacey Young of West Toledo, is one of 464 children in the state with combined vision and hearing losses who were counted in the 2004 Ohio Deafblind Census.

The agency that does the counting believes there surely must be others.

In an effort to find and serve them, the Ohio Center for Deafblind Education has started an awareness campaign that features Schyler in a public service announcement for television that began airing in July.

The combined hearing and vision loss does not have to be total in order for a child to qualify for services, says John Saylor, coordinator of the Ohio center, by telephone from Columbus.

"Most people think if you're blind it's dark and if you're deaf there's silence, but both are on a

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continuum," he explains. A child could see some and hear some and still be eligible for services. "If the condition is such that it adversely affects the child's educational performance, these children can be declared dual-sensory or DB-impaired," he says.

Most children who are deafblind have one or more additional disabilities, along with behavior problems that can result from the inability to communicate. Mr. Saylor says, Schyler, for example, is developmentally delayed, has impaired speech, and low muscle tone which affects her coordination.

Her IQ, based on verbal testing, is 67.

In many ways, though, she's like any other child: she likes to swim, bounce a ball, roll Matchbox cars across the hardwood floor, and play with her brothers, Scotty, a 10-year-old fifth-grader at Zion Lutheran School, and Spencer, 2. Neither of the boys inherited the chromosomal abnormality that triggered Schyler's condition.

She carries on the usual up-and-down relationship with her

“We look at what Schyler can do, and not what she can't do.”

Stacey Young
Schyler's mother

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siblings. She celebrates the same victories other children do — learning to pump her legs on a swing, beating her parents fair and square at a game of UNO.

"We look at what Schyler can do, and not what she can't do," Mrs. Young says. "She has done great things. She has inspired people."

But what she cannot do is a daily fact of life in the Young home, challenging every member of the family to be extra vigilant, patient, and accepting of demands on their time — not just for appointments with doctors, therapists, and teachers but for the daily tasks that most 7-year-olds can do for themselves.

Scotty tries to help, but Schyler sometimes rudely rejects his efforts, Mrs. Young says. Spencer will sometimes snatch a toy from her, but he rises to the occasion when needed: when the toddler saw his sister heading for the street, "he jumped off his scooter and ran back and said, 'Sissy this way,' and he led her to the sidewalk," their mother says.

One could dwell on the negatives, Mr. Young reflects, "or you can get motivated and [decide] 'OK, now what can we do to make our daughter's life the best it can be?'"

Mr. and Mrs. Young, both 38, aren't sure exactly what Schyler is able to see. She is considered legally blind, with no vision in her left eye and limited vision in her right.

"We don't really know because she can't verbally tell us as far as a vision test," Mrs. Young says. "What we can assume is that she probably can see maybe five feet in front of her, but I don't think that she'd be able to make out what she's really seeing, just that there's



Schyler Young with her dad, Scott, brothers Scotty, 10, and Spencer, 2, and mother, Stacey, at their home.

something there."

Up close, she can make out shapes and colors. She knows her numbers and her letters.

The Youngs learned about five months into the pregnancy that something wasn't right. After an ultrasound showed fluid in the baby's chest cavity and abdomen, genetic testing confirmed that Mrs. Young has a chromosomal abnormality that she had not been aware of.

They chose to continue the pregnancy and prepared for the worst. They were told that Schyler could die shortly before or after birth.

"The first thing I said was, 'what's wrong with her left eye?'" Mrs. Young remembers. "But we were just glad she was alive."

Mr. Young says Schyler's vision won't worsen "as long as we keep the glaucoma under check and she doesn't detach a retina," which is a greater risk for her and makes even a simple fall a potentially major problem. The glasses she wears most of the time are primarily for protection.

"We try to let her be as independent as possible, but we have to watch her," he adds. They try to balance the need

to be more protective with the understanding that "you have to let her be herself ... you have to give her some freedom."

Schyler has had about 15 eye operations, major hip surgery this year that put her in a body cast for eight weeks, and physical therapy since she was 9 months old. She has weekly appointments with occupational and speech therapists.

Schyler's hearing loss was diagnosed about a year ago. She now wears hearing aids in both ears.

Like many young children, Schyler needed tubes in her ears to drain fluid and prevent infections. And like her brothers, she has a tendency to get a wax buildup in her ears. But as time went on and she was asking "Huh?" more frequently, her parents suspected a more serious problem, which tests confirmed.

That's when the Youngs became involved with the Ohio Center for Deafblind Education. Mrs. Young says she found the center while she was searching the Internet for resources after Schyler's hearing loss was discovered.

Since then they've attended parent retreats and called on

the center's staff for advice and materials to give to Schyler's teachers.

This fall, she'll attend kindergarten at Toledo's Elmhurst Elementary School, splitting her day between regular kindergarten and a class for the visually impaired where she'll be taught Braille.

It's an arrangement her mother fought for.

"[Last year] she ended up in the multiple-handicap class most of the year instead of kindergarten. This year, I took my stack of stuff and said, 'I want her in typical kindergarten.' The only place Schyler was not with typical kids was when she was in school," Mrs. Young says, explaining that her daughter plays with other children at their church, Zion Lutheran, and in the neighborhood.

"I said she can use vision-impaired [class] as a resource, but I want her to start and end her day with typical kindergarten. Because in the future, in the adult world, to be accepted, she needs to start with them now," she declares.

Mr. and Mrs. Young are less sure about the details of Schyler's future. They don't know if she'll be able to live independently, although Mrs. Young says that, "if it was up to her Daddy, she'd be with us for the rest of her life."

The Youngs, who celebrated their 14th wedding anniversary this month, say their little girl's special needs have strengthened their marriage. They work well together, they say, one stepping in to take over when the other gets stressed.

They say it also has strengthened their faith. When they're out in public with Schyler and other children stare and ask what's wrong, "Our response is 'that's how Jesus made her,'" Mrs. Young says.

"And not once did I ask why."

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