Parents fight for money to help visually impaired kids

By Kate Santich, Orlando Sentinel
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Grace Braswell was born with no hands, no feet and profoundly limited vision.

Yet at age 6, she can race around her Casselberry home like a sprinter, even without prosthetics. She takes ballet lessons and writes using an electronic tablet. And she is so advanced in academics that her mom was just invited to have the girl tested for the gifted program at her mainstream elementary school.

She reads by using a handheld electronic magnifier to scan pages.

"Grace gets really frustrated that people assume she can't do something," says her mother, Alison Braswell. "I just want to give her every opportunity."

That's why Braswell and dozens of other parents of visually impaired children have traveled to Tallahassee in recent weeks, meeting with lawmakers to ask for more money for the state's Division of Blind Services.

The state agency currently funds early-intervention programs that help children from infancy through age 5. It also funds a separate transitional program for youth ages 14 to 22, preparing them to land a job and live on their own. In both cases, the money is funneled to regional nonprofit agencies that provide the actual instruction.

But from ages 6 to 13, there are no community-based programs. The kids do get help at school — typically, an hour a week of reading instruction or help navigating the campus. But advocates say it doesn't come close to offering the range of services that younger and older children get.

"To the best of our knowledge, the Division of Blind Services has never operated or funded a [community] program for ... children ages 6 to 13," says Department of Education spokeswoman Cheryl Etters.

The early-intervention program helps visually impaired infants and toddlers and their families understand the options in assistive technology. They teach kids Braille, provide computer and print magnification devices and help children learn to safely cross streets and negotiate unfamiliar terrain. Even simple tasks of daily living — such as pouring a glass of milk — are covered.

Stopping at age 6, says spokesman Richard Alleyne of Orlando-based Lighthouse Central Florida, makes no sense.

"This creates a population of visually impaired students who end up years behind their sighted peers," he says. "This is an issue that affects more than 900 Florida kids a year."

That's the number of 6- to 13-year-olds in the funding equivalent of the doughnut hole. To help them, the Florida Association of Agencies Serving the Blind is asking the state for $3 million this year — a figure that would cover a third of those eligible.

"It's pitiful, because this is the most critical time," says Sarah Pettit of Eustis, whose 6-year-old son, Creed, has a congenital disorder that causes extremely limited vision, especially in low lighting. It was misdiagnosed as a developmental disability until he was 3.
"Lighthouse has helped him so much. The impact is just huge. But we're still playing catch-up, and I worry how he's going to be at 14 without that extra support," she says.

Creed still can only read small words. An entire book is out of the question. But his piano and athletic skills are off the charts. And in math, Pettit says, Creed tested as gifted.

"But imagine getting to high school and still reading at an elementary-school level," his mother says. "I worry that's how it'll be."

Officials at the Florida Division of Blind Services declined to comment on the funding itself.

But state Sen. David Simmons, R-Altamonte Springs, who supports the $3 million for the gap years, said it's difficult to predict an outcome. Even though the request is relatively small — given an overall state budget of $77 billion — with uncertainty over Medicaid expansion and federal funding for poor and uninsured hospital patients, nothing should be taken for granted.

"Over the years, I think we've done a phenomenal job for the agencies serving the blind," Simmons says. "We worked very hard to capture as much in federal funding as we could. But everyone who is an advocate for these children should remain vigilant."

Alison Braswell will. Visually impaired herself, she knows what people who are legally blind can accomplish. She left her full-time teaching job when Grace was born and is now raising two very energetic children. Most days, she'll sit with Grace at their computer, using a magnifier to enlarge the words on the screen, supervising as her daughter reads.

"Studies have shown that kids who are visually impaired are often speech-delayed," Alison says. "You speak because you see things and say, 'What's that?' And you may be afraid to crawl or walk because you run into things. They're at a disadvantage right from the get go. Why wouldn't we want legislators to do what they can so these kids grow up to be active, involved, contributing members of the community?"