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STYLE

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Child Left Behind

How a special education crisis is pushing out the ones who need it most: the story of Adriana Long.

by Chris Dovi


Adriana Long outside Clover Hill Elementary School. Photo by Scott Elmquist

In the short span of her tender 10 years, Adriana Long has managed to serve as poster child for more than her share of causes.

Born with a terrifying host of congenital deformities, at just 11 days old Adriana died in her mother's arms. Revived by doctors against the odds, she'd endured more surgeries than there were months of life behind her by the time she was 1. Born with spina bifida, Adriana also has brittle bones prone to fractures and breaks, her knee joints don't bend fully, her arms can't extend above her head or reach around or behind. Her rib cage doesn't extend fully around her chest.

In 2000, she was a Children's Miracle Network poster child. At 4, she was a Make-a-Wish kid. In 2005, defying the doctors who said she'd never survive infancy, she was named student of the year at her elementary school in Chesterfield County.

"She's just a ham," says Adriana's mom, Anna Long, of the now bright-eyed, bubbly daughter who a decade ago she brought home from the hospital because she'd been told it would be best for her to die at home.

This year, Adriana becomes poster child of a different sort.

Virginia's Board of Education is considering a major overhaul of its special education regulations that may fundamentally alter the rights of parents like Anna Long. If adopted, the new rules allow localities to, at the extreme, remove all special education services from a child without parental consent.

They may also allow districts to severely curtail services they are willing to provide to children like Adriana. Adriana's case illustrates what happens when the special needs of one student meet headlong the harsh reality of a school system on a fixed budget that simply can't accommodate a growing population of students eligible for special education services.

That growth is caused by more aggressive diagnosis of problems such as attention deficit disorder, which, unlike Adriana’s disabilities, don’t necessarily manifest physically, according to medical and some education experts. But whether or not a child’s problem is invisible, it still may require a helping hand to overcome.

“The growth is undeniable, and it creates obviously some concerns for school boards and superintendents who have to meet the needs of all the children they are responsible for,” says John Kregel, chairman of the Department of Special Education and Disability Policy at Virginia Commonwealth University’s School of Education. “The dilemma is very real.”

In 2006, the most recent year for which state statistics are available, Adriana was one of 172,704 children in the state classified by their school districts as physically, cognitively or emotionally disabled and thus eligible for a menu of special services — some cheap and some very expensive — guaranteed and entitled to them by the Americans with Disabilities Act of 1990, the Individuals with Disabilities Education Act of 1975 and other federal laws.

Statewide, the number of kids who, like Adriana, have disabilities has grown more than 15 percent since 1997. As the number of students classified as eligible for special education services has risen over the last decade, school systems have had hard choices to make.

Each of those children classified as eligible for special education represents a dollar figure, money from a city or county’s education budget that must be spent on that child alone.

“There is an increase in the numbers of students who are eligible for special education services, and that has to do primarily with the increases in medical research and also in the increase of diagnosis — we now have a better understanding of what a disability is,” says Reginald Felton, director of federal relations with the National School Boards Association. “Certainly there are certain kinds of disorders that are more costly than others, but … [school districts] don’t have the choice of saying ‘I will only provide the most severe kinds of support and not provide those [others] with marginal support.’”

That’s what policy says, but in practice in Virginia, the special education question has caused districts to seek different solutions. Some districts, like Hanover and Richmond, have gained reputations as being friendly to certain classifications of special education students, while other localities have worked to hold their special education numbers at bay.

State numbers show these preferences: In Hanover — where local parent support groups say autistic kids get a fair shake — autism cases jumped from just 10 in 1997 to 74 in 2006. In 1997 Richmond had 990 students in a category the state uses as a catchall for such disorders as dyslexia, attention deficit disorder and other problems that don’t necessarily present themselves physically. By 2006 there were 1,767 such cases in

Richmond. The school district, meanwhile, shrank by 3,500 kids during the same period.

Chesterfield, according to some of the same parenting circles that tout Hanover and Richmond, is considered unfriendly. The district's "catchall" category shrank by 368 kids in the same 10-year period, while its overall student population grew by more than 8,000.

But neither Chesterfield's approach nor Richmond and Hanover's can accommodate the steady increase in kids being diagnosed. As the number rises, so too does the amount of money that is taken away from "regular" education needs.

"It's not optional," Felton says of the requirement to provide services. "It's the law."

But there's great latitude in how states choose to interpret that law.

In Virginia, interpretation of the federal law has always been to go above and beyond it. Parents, often the best advocates for a child with special needs, have long held a prominent place at the table, given great latitude in helping spell out exactly which costly services will be written into their child's individual education plan, or IEP.

These student plans are the federally mandated, legally binding documents that hold school districts accountable for the services children such as Adriana rely upon.

But what happens when parents aren't guaranteed a seat at that table?

Less than a week into the 2006-'07 school year, Anna Long says she discovered Chesterfield's attitude toward the child they'd so recently applauded as Student of the Year had changed dramatically. Also changed were the services the county was willing to provide. Without informing Long — a move she alleges was in violation of the law — the school district had removed the classroom aide who had been by Adriana's side every day since she entered the school system's Head Start program as a pre-kindergartener.

E-mails later obtained by Long's lawyers seem to reveal simple budget cuts as the culprit, but also a willful and almost malevolent intent to deny that Adriana ever needed or had the right to the aide. School employees reported on Adriana's activities in the community in an effort to provide evidence she was less disabled than her parents claimed. Some administrators were admonished for promising services.

An aide hired by Chesterfield at one point during negotiations with the Longs was simply let go for advocating too forcefully for the girl.

Oblivious to the behind-the-scenes machinations, Long says she tried working with the school district to get the aide restored. But after a series of fruitless interactions, she says, it became clear Chesterfield wasn't going to budge.

Meanwhile, Adriana, who must have assistance to use the bathroom and medically is not supposed to wait to go, began developing urinary tract infections and kidney troubles because she was unable to get to the toilet without assistance. Long says some days her daughter came home with feces caked to her legs, causing painful rashes: The girl had tried using the bathroom herself and, without the aide, simply could not clean herself (her joints don’t bend to allow it).

A fall on the playground, allegedly caused by a lack of supervision, may have caused a fractured hip.

Eventually, she required a kidney and hip operation to repair injuries that Long alleges occurred because of a lack of supervision at school.

Long alleges — and internal school district documents support her claim — that the aide position was part of Adriana’s legally binding student plan, the IEP. Long insisted in her battle with school officials that removing the aide was illegal because she didn’t consent to the change in Adriana’s student plan.

Anna Long’s reality is the nightmare many parents of special education children only dream about. But it also may be their future under the new regulations, which allow school districts to change a child’s IEP — and the services it guarantees — without involving the parents in the decision-making process.

Under the proposed changes in the law, revoking Adriana’s classroom aide would be well within the authority of a school district that comes to the conclusion that such an expensive service was no longer needed. Parents would simply be notified by letter after the fact.

In Long’s case, she eventually was left with no alternative. She found a lawyer to help her fight for what, she says, are her child’s rights.

“I had taken everything they dished out,” says Long of the months she spent trying to work with the school district to restore Adriana’s services. She says she had no intention of taking legal action against the school system. The family eventually filed a lawsuit against the county last year.

Some legal experts say that if the state board’s proposed regulation changes are adopted, legal action will likely be the only recourse for families like the Adriana’s.

Under the state’s planned regulation changes, a lawsuit may become the rule rather than the exception for parents who disagree with a school district’s decision to take away services.

Parents will still be able to voice their concerns, says Charles Pyle, a spokesman for the state Board of Education. Mediated meetings between parents and school officials and more litigious due process hearings — another name for lawsuits like Long’s that experts predict will proliferate — are the options parents will have.

Michele Burke, an attorney with Richmond law firm LeClairRyan, was one of Long's lawyers at Adriana's due process hearing — and before that at an IEP meeting.

Burke says she initially expected the case to be open and shut. She attended the IEP meeting, expecting that seeing a parent accompanied by an attorney would be enough to convince Chesterfield officials that Adriana should get the services she needed.

"Wrong," says Burke, calling the IEP that was offered afterward even less accommodating to Adriana's needs. In that IEP, rather than guaranteeing assistance for Adriana, assistance was guaranteed only for specific, necessary activities, like using the bathroom and eating lunch. There were no provisions for help during fire drills, on the playground or with carrying her school supplies. "A lot of help I did, right?" Burke says.

Burke's firm took the case pro bono and eventually settled out of court, though she and fellow attorney John Craddock agree that the firm's services could easily have stretched into the tens of thousands of dollars had Long been a paying customer.

Not everything was pro bono during the case, says Long, and the costs were not easy to shoulder since Long closed her Italian restaurant on Midlothian Turnpike years ago to take care of Adriana. Her husband, Lawrence, had rejoined the Army in order to qualify for retirement medical benefits that ensure his daughter will be cared for, but his military paycheck isn't enough to support the entire family.

"We took out payday loans just to get back and forth to [lawyer] meetings," says Anna Long. "We've been back and forth to the food bank because we can't even buy food."

The day the settlement agreement was reached, the Long family's water was turned off because the bill had not been paid.

"The intent is not to curtail parental rights or deny parental rights to children who need services," contends the state board's spokesman Pyle. Indeed, he says, there's every reason to trust that school districts have the best interest of their students at the forefront of their decision-making. If a child needs a service in order to get a fair public education, they'll get it, he says.

History says otherwise, says Pedro Noguera, a professor of sociology at New York University and a nationally known author and expert on both special education and urban education issues.

"I think what many parents of disabled children have learned — often the hard way if they aren't vigilant — [is that] if they don't watch carefully with regard to how their children are being served, too often they are not served," says Noguera. "It's very understandable that parents would be concerned that they would not be at the table."

That table has become increasingly large, says Kathy Mehfoud, a Richmond lawyer who has made a practice of providing special education legal services for as many as 80 school districts. Mehfoud, who spoke at a recent hearing on the proposed changes in Chesterfield, says state changes aim only to meet revised federal policy.

“Federal law has said kids are being over-identified,” Mehfoud says, questioning the outcry of parents who’ve received more from the state than they were ever entitled to. “If you have regulations that are far more permissive, you’re going against the direction that the U.S. Department of Education desires, because you are over-classifying children with disabilities.”

Pyle suggests the current regulations simply provide parents too much input. He compares the current situation to medical decisions, where a parent might second-guess a doctor’s diagnosis.

It’s an imperfect analogy, but something similar occurs in education as more and more kids take the cure that some school districts claim they don’t necessarily need to treat what ails them academically. Paying for their needs draws needed funds away from programs for other kids in the district.

“Special education is an under-funded mandate by the federal government,” says NYU professor Noguera. “The difficulty for the districts is in order to meet the needs of a kid like [Adriana], it means taking resources away from other kids. It means spending more on some and you have less for others.”

Pyle couldn’t agree more. “Resources are not infinite,” he says. “You want to make sure those resources are going to the students who need them. We don’t want to over-identify students for special education services.”

Even experts who’d like to see school systems given more latitude in how they provide services aren’t sure over-diagnosis of learning disabilities is a problem.

“There has been an increase in the diagnosis of conditions like ADD [attention deficit disorder] and LD [learning-disabled] and particularly autism,” says Daniel P. Hallahan, chairman of the University of Virginia’s education school’s Department of Curriculum, Instruction and Special Education. But increased diagnosis, he says, doesn’t equate to over-diagnosis. It simply means better diagnosis.

In fact, both he and Norman Geller, an assistant professor at VCU’s School of Education, agree that there are many more undiagnosed cases of such disorders as ADD. And there are also those medically diagnosed cases for which parents do not ask school districts to provide services. In those cases, often the child has developed their own coping mechanisms that allow them to achieve normally.

Regardless of how many kids are eligible, money will always be a factor for school districts: “I think there’s always a finite amount of funds,” says Geller, who’s also a nationally certified diagnostician who helps localities all over the state to identify special needs students.

“Schools in general have a very difficult balancing act. Parents want as much as they can get for their children,” Geller says, and as a result, localities are “just starting to burst at the seams.

“The schools are faced with a daunting challenge,” he says. “While I feel for this kid Adriana — and she is one of many kids who may be affected — the school is in a real dilemma. For the one or two kids who get hurt by the system, the kids who are getting really good services we don’t often hear about. The schools get beat up a lot.”

But not allowing parents at the table to make decisions in their children’s education, and instead forcing them to take legal action if they want to protest, is not fair either, says LeClairRyan’s Craddock.

“The bottom line is, it’s expensive to go through the due process hearing,” says Craddock, and at such hearings, the burden of proof is on the parents.

“If people don’t have a lawyer, they’re just going to get run over by the school board lawyers,” says Craddock. “If you don’t know what the rules are, and you don’t know how to effectively combat the school board lawyers, you’re starting the fight with two hands tied behind your back.”

Supporters of the proposed state regulation changes say they’ll be better able to work around parents whose disinterest in their children’s education often serves as a barrier.

“We are very appreciative of the Virginia Department of Education’s efforts to reduce where Virginia’s special education regulations exceed federal requirements,” says Elizabeth Ewing, director of legal and policy services for the Virginia School Boards Association, one of several groups representing educators or localities that support the changes.

If school district funds are not infinite, for most families they’re infinitesimal.

“Parents lose 88 to 90 percent of the cases, varying from year to year,” says Meg Sanders, an attorney who’s working on her doctorate degree in special education at VCU and writing her dissertation on parents who represent themselves in due process hearings.

“Understanding your rights under a federal statute is always difficult,” Sanders says. “If you have an unrepresented parent litigating on the issues against an attorney, they probably didn’t get all the facts out there. They probably don’t know what all the facts are. They probably don’t know how to question witnesses. … A due process hearing is an administrative hearing, but it’s still litigation.”

Mehfoud disagrees that parents aren't qualified to represent themselves. And she disagrees that, with the new rulings, hearings will increase or attorneys will step up to fill a market need for more lawyers dealing in special education law.

"Parents can handle administrative hearings and court cases," she says. "Many of the parents enjoy engaging in the legal disputes. A lot of them are lawyers."

She suggests litigation would actually decrease under the new regulations, which would seem to make it not in Mehfoud's interest to lobby for the proposed changes. In a single case, Newport News paid her firm $49,000. She also defended Chesterfield in Adriana's case.

Mehfoud disagrees with the premise that parents are at a disadvantage when squaring off against education experts. "As parents tell you all the time, they're experts in their child," she says.

Even for affluent families, shouldering the burden of litigation against a school system can fundamentally alter their financial status.

J. Bradley Purcell, whose son is severely dyslexic, recently spoke at the state Board of Education's public hearing in Chesterfield.

"He had an IEP from the very beginning," Purcell told Style. That didn't stop Henrico County from providing what he says were inadequate services for his son. Purcell filed two due process hearings and, like Long, eventually settled out of court.

Unlike Long, he paid his own legal expenses. "This lawsuit — just legal fees — cost us right around $40,000, and that doesn't count that we didn't have as extensive expert witness fees as they could have been."

Had the case gone to court, Purcell says, the cost "might have been double that."

Now multiply those costs by hundreds — maybe thousands — once litigation becomes the norm if the proposed changes to state law go into effect. It would likely create a cottage industry within the legal community, suggests doctoral student Sanders "Special education attorneys are very few [in Virginia]," she says. But "as parents realize how difficult it is to succeed in due process, more attorneys will familiarize themselves with the statute and then the fees will go up."

Already those fees can be between $125 and $350 an hour.

"If you need an attorney just to go to the IEP meeting, you may need several hundred dollars — never mind due process," Sanders says.

But there's another side, too, says the Virginia School Boards Association's Ewing.

“Litigation is expensive for the school division also,” Ewing says. “School systems never choose to go that direction lightly. School divisions try to work with parents. They don’t always agree on things, but they do try.”

But there’s an economy of scale that weighs things in favor of school divisions, Sanders says.

“It’s well-established that there is deference to the educators — because the educators are experts,” she says. “They have degrees in the field of whatever it is they’re testifying on secondary education, special education, physical therapy. They’re employed by the school system, so the school system has their expert on staff.”

But the big difference? “Parents don’t have an attorney on retainer,” Sanders says.

It’s a dilemma Long knows well.

“Ever since Adriana was born, we’ve been told she can’t or she won’t,” she says. “She won’t walk. She won’t talk. She won’t sit up. She won’t live. She can — and she has.”

But in court, even with pro bono lawyers fighting for her daughter, and even with the preponderance of documented evidence — including e-mails between schools officials that seemed to indicate collusion to deny services — Long says the settlement agreement she signed didn’t go nearly as far as she’d hoped toward restoring Adriana’s fair access to education.

“We felt forced to sign,” she says. “We got the short end of the stick.” **S**