

My name is Richard Foster. I'm projects editor at Richmond Magazine and the parent of a child with autism. I've spent the last couple months working on a series of articles looking at the state of government aid for developmentally disabled Virginians. In the course of researching this series, I talked to dozens upon dozens of parents and professionals, visited juvenile and adult group homes around the state as well as two of the five state training centers and Grafton School in Winchester. I'd like to share with you some of what I've learned while telling you my family's personal struggle against autism.

This is my 5-year-old son Jack. Jack was diagnosed with autism right after his second birthday.

When I first heard this news, I had a lot of misconceptions about autism. My view of autism was the same as most people's and it all came from movies and TV — I pictured people with autism as either human vegetables rocking in a corner or as idiot savants like Dustin Hoffman in *Rain Man*, reciting the phone book from memory or sitting down and playing a piano concerto with practicing.

Jack has changed my views of autism as well as my views of lots of other things, such as how our state and local governments are responding to the needs of those who are least able to help themselves.

Jack is on the more severe end of the autistic spectrum. Autism manifests itself in lots of ways — ranging from people who are largely unable to communicate to people who are a little quirky and eccentric and who have unusual interests.

The best way I can describe Jack is that he is like an active toddler in the body of a 5-year-old. He wears diapers because he isn't toilet trained and he doesn't talk. He can't tell you if his stomach hurts or if he's hungry or what his favorite ice cream is. Mostly he makes cooing or squealing noises like an infant. When other children are chasing each other on the playground at daycare, Jack is usually off by himself, pulling grass from the ground to put in his mouth. Anything and everything goes in Jack's mouth; it's how he explores the world. He pulls apart carpet, clothing and blankets to make the strings he must obsessively carry in his hands and mouth.

But Jack breaks a lot of Hollywood autism stereotypes too. He's very affectionate and loves to hug and kiss and laugh. He giggles quite a bit at Elmo on *Sesame Street*.

My journey to understanding autism hasn't been an easy one.

Jack started talking like a normal child until at around 1 year of age he stopped talking. The family pediatrician told us not to worry, that he was just a late bloomer and everything would be fine.

When I took Jack to a specialist who identified him as autistic, it was a relief to know what was wrong, but also a nightmare.

No one gave us a manual or told us what to do with our autistic child — not the pediatrician, not the specialist.

Only through persistent calls to local government did we find out that there was a free early intervention preschool program where special-ed teachers would work with Jack. So we enrolled him. It turned out to be a glorified day care.

Eventually through outside reading I did on my own I learned that a teaching therapy called ABA (Applied Behavioral Analysis) is the only clinically proven method of reversing autism. About half the kids who receive two or three years of intensive ABA instruction *before* age 6 went on to lead more or less normal, independent lives.

I remembered hearing about the Faison School for Autism teaching ABA here in Richmond. Great, I thought. No problem — there's help out there for Jack.

And then I discovered that Faison, a branch of Virginia Commonwealth University, has an annual tuition of \$57,000. Insurance won't cover it. I've met families who took out second mortgages to send a child there. That wasn't an option in my case, so after calling virtually every school system in this state we learned that Fairfax County Public Schools is the only school system in the state that is teaching a pure ABA curriculum for children with autism. So my ex-wife and I made the decision that she would move to Fairfax to enroll Jack. That was more than a year ago. Because of child support I cannot afford to move to Fairfax to be closer to Jack and my other son, Daniel, so I commute to get them on the weekends. It's a long, exhausting drive for all of us but we've gotten used to it.

Fairfax is exceptional for a public school in its attention to autism, but it's still not as rigorous as some of the private schools like Faison. And that \$57,000 annual tuition that Faison charges is in line with other private schools in Virginia for children with autism. Because of these steep tuitions, though, only about 100 children total have gotten the benefit of these private schools in Virginia over the last five years or so.

One hundred children. And how many children have autism in Virginia? Some estimates say more than 6,000. The state

Department of Education said last year that more than 5,000 children with autism were enrolled in Virginia public schools. That's double the number from just two years before.

There is a crisis across the world with an as yet unexplained meteoric rise in autism. The prevalence rate for autism 20 years ago was one in every 2,000 births; now it's one in every 166 births.

Going on prevalence rates, there are more people with autism in Virginia than people with mental retardation. Yet there is no state agency devoted to autism. The state Department of Mental Health, Mental Retardation and Substance Abuse has "mental retardation" in its name but does not actively study autism and has no office devoted to this disability with a larger — and growing — population.

While I am certainly not advocating that less resources be devoted to Virginians with primary diagnoses of mental retardation, I am advocating for an immediate look at realigning the state's mental-health priorities. Instead of an office of Mental Retardation, why not follow the leads of many other states (such as our neighbor to the north, Maryland) and have a state Office of Developmental Disabilities that would advocate for Virginians with an array of disabilities, such as autism, mental retardation, Down syndrome and cerebral palsy?

As you well know, despite the fact that Virginia has one of the wealthiest state governments in the U.S., Virginia also ranks near the bottom in spending on services for those with developmental disabilities.

This needs to change.

Primarily because a major crisis is coming — the population of Virginians with autism is exploding and Virginia is doing

nothing about it, and without appropriate early intervention, the state will be dealing with tens of thousands of people requiring an ICFMR level of care in just a couple decades.

According to the Autism Society of America, it costs government \$4.4 million to care for one individual with untreated autism over their lifetime, most of it to pay for residential services when they're an adult. But if an autistic individual receives appropriate educational therapy, they can contribute \$1.5 million to society instead of being a drain on government. Lifelong care for autistic adults can be reduced by 2/3 with appropriate early intervention.

I offer the following additional suggestions:

- We need Virginia public school systems to come together to create satellite public early-intervention schools for children with autism, based on the Faison School and Fairfax. A blueprint for regional schools already exists with the state's governor's schools. This could be implemented mostly by rearranging existing resources.
- Virginia needs to catch up on its Medicaid waiver waiting lists so it is not caught flat-footed when today's children with autism become tomorrow's adults needing services outside the public school system. And of course waiver reimbursement rates need to be raised.
- Add more waiver options and make waivers more friendly to people with autism. Currently in Virginia to get residential services covered by waiver a person with autism must also get a secondary diagnosis of mental retardation. Many parents of children with autism do not want their children to receive diagnoses of mental retardation out of fear that public schools will use this as an excuse not to provide special education services

geared specifically to autism, which require different educational methods than mental retardation. Virginia's Developmental Disabilities waiver is geared more toward higher functioning people with autism. Also there is no waiver specifically for children with autism. Maryland's state Department of Education offers a waiver that provides for respite, therapy and other services outside of public school for children with autism.