



**NEW JERSEY GENERAL ASSEMBLY  
14TH LEGISLATIVE DISTRICT**

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NEW JERSEY LEGISLATIVE DISABILITY CAUCUS

April 23, 2021

Congressman Christopher Smith  
Washington, DC Office  
2373 Rayburn House Office Building  
Washington, D.C. 20515

Dear Congressman Smith,

I am writing in support of Autism New Jersey's application for a Congressional Community Improvement Project grant. I believe their outstanding work to connect with thousands of families and communities statewide to provide access to needed information and support for those with autism, makes them a very worthy applicant.

It is my understanding that this grant would allow Autism New Jersey to hire additional staff to connect with underserved communities and author content for their website to break down complex service delivery systems into family-friendly language (English and Spanish). This funding would expand their reach to those who need access to the information and support they provide the most through their toll free Helpline and website.

Autism New Jersey's 800.4.AUTISM Helpline and website have guided parents of children and adults with autism and the professionals who support them for more than five decades. The agency's skilled, compassionate Helpline Coordinators actively listen to the layered issues these families, individuals, and professionals face. Then, they combine deep lived experience with extensive professional expertise in social work and law to provide service navigation guidance and practical next steps on all autism-related topics throughout the lifespan.

This toll-free helpline reaches more than 1,300 families per year and is supplemented by volumes of lay-friendly website content on early intervention, special education, health insurance, adult services, evidence-based treatment, and more. This website informed 132,764 unique visitors last year alone. Helpline Coordinators also maintain a robust service provider database from which to make referrals. Parents and professionals alike consistently express their gratitude for the life-changing advice and support provided during their most difficult times. Autism New Jersey's 800.4.AUTISM Helpline staff compassionately and tangibly improves families' lives every day.

As the state with the highest autism prevalence in the country (1 in 32), this federal appropriation will address the tremendous unmet need here in New Jersey through a trusted resource. The 800.4.AUTISM Helpline will reach more New Jersey families, particularly those in underserved areas and monolingual Spanish speakers.

Again, I strongly support Autism New Jersey's application for a Congressional Community Improvement Project grant. I respectfully request that you consider them for this critical federal funding. Thank you very much for your assistance in this matter.

Sincerely,

Daniel R. Benson  
Assemblyman, 14<sup>th</sup> District

*Monmouth County*  
*Board of County Commissioners*

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April 23, 2021

U.S. Congressman Christopher Smith  
Washington, DC Office  
2373 Rayburn House Office Building  
Washington, D.C. 20515

Dear Congressman Smith:

Please accept this correspondence as my letter of support for Autism New Jersey's application for a Congressional Community Improvement Project Grant.

For decades, Autism New Jersey's 800.4.AUTISM Helpline has provided highly individualized advocacy services for parents of children and adults with autism, as well as the professionals who support them. Autism New Jersey staff combines deep lived experience with extensive professional expertise in social work and law to provide service navigation guidance and practical next steps on all autism-related topics throughout the lifespan.

This toll-free helpline reaches more than 1,300 families per year, and every person calling the helpline can be confident they will receive considered, thoughtful, and accurate answers to their questions about early intervention, special education, health insurance, adult services, evidence-based treatment, and more. When families need reliable advice and support, Autism New Jersey's 800.4.AUTISM Helpline is there to guide them.

As the state with the highest autism prevalence in the country (1 in 32), this federal appropriation will address the tremendous unmet need here in New Jersey, especially in Monmouth County through a trusted resource. This helpline will reach more New Jersey families, particularly those in underserved areas and monolingual Spanish speakers.

As the Vice Chair to the Monmouth Ocean Foundation for Children (MOFFC), a nonprofit that focuses exclusively on financially supporting programs that will enhance the lives of students diagnosed with Autism Spectrum Disorder, I fully support the efforts of Autism New Jersey to assist and advocate for our special needs community and their families.

Sincerely,

A handwritten signature in black ink that reads 'Thomas A. Arnone'.

Thomas A. Arnone  
Commissioner Director, Monmouth County

“SEPTEMBER 2d, 1609 THIS IS A VERY GOOD LAND TO FALL IN WITH AND A PLEASANT LAND TO SEE.”

Entry in the log of Henry Hudson's Ship Half Moon made after the Dutch Explorer became the first European to come ashore in what was later known as Monmouth County



# BOROUGH OF FANWOOD

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FAX: (908) 322-7178

April 23, 2021

U.S. Congressman Christopher Smith  
Washington, DC Office  
2373 Rayburn House Office Building  
Washington, D.C. 20515

Dear Congressman Smith:

Please accept this letter of support for Autism New Jersey's application for a Congressional Community Improvement Project Grant for the expansion of their much valued and important helpline.

As the father of a 21-year-old son with autism, my wife and I have benefitted greatly from the services offered by Autism New Jersey and their 800.4.AUTISM Helpline throughout the years.

I serve my local community as a member of the Town Council of Fanwood. It is an honor and a privilege to do so and to share with my neighbors resources that can improve their lives.

So indebted has our family been that we've spearheaded a local music festival "Rockin' for Autism" that has raised tens of thousands of dollars in support of their efforts in the last decade. The entire town has embraced our efforts and the importance of the cause.

The services provided by Autism New Jersey have not only been effective, but they can be transformative. They set families like mine on a course to access treatment and services that have made a positive difference in my son's life.

The challenges our children with autism face do not lessen as they grow, especially when aging out of the educational system like my son will be doing this year. Certainly, this past year has challenged us all at the local, county, state and national level. It has been an especially difficult one for my family and neighbors. We look forward to brighter days ahead.

Recognizing these challenges and a substantial growing need for direction and guidance, Autism New Jersey's 800.4.AUTISM Helpline has maintained its commitment to excellence and a level of service, with not one call to its Helpline going unanswered during last year's lockdown. They've offered well-researched solutions and unending compassion. I look forward to what they could achieve with the federal support to allow them to grow these important services.

The results would be felt by my family here in Fanwood and in towns across the state.

Sincerely,

Jeff Banks  
Councilman, Borough of Fanwood  
Email: [jbanks@fanwoodnj.org](mailto:jbanks@fanwoodnj.org)

# New Jersey

MONTHLY

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## How Autism Health Care in Jersey Falls Short

For patients on the autism spectrum, finding qualified practitioners—and insurance coverage—for even the most basic health needs can be a challenge.

By [Tina Kelley](#) | | January 30, 2020 | Appears in the [February 2020](#) issue

When Ellie North noticed her 2-year-old daughter, Seraphina, retreating into herself, she took her to three doctors. The first said North wasn't spending enough time with her little girl. Another said Seraphina was a late talker. The third told her, wrongly, that girls don't get autism. Eventually, when the nurse practitioner at her pediatrician's office confirmed North's suspicions that Seraphina was autistic, it took six months to get an appointment with a developmental pediatrician.

In New Jersey, finding health care providers trained to care for children on the autism spectrum can be daunting. That goes for general health needs, including primary care doctors, dentists,



**It took Ellie North six months to get an appointment with a developmental pediatrician for her daughter, Seraphina—and three crucial years to fight for insurance coverage.** Photo by John Emerson

counselors, psychiatrists and therapists. But it also applies to practitioners specific to autism, like behavioral therapists. And even when families find the right provider, insurance coverage can be spotty. These problems often intensify as children age out of pediatric care into adulthood.

North's insurance at the time of Seraphina's diagnosis did not cover autism-related services. Fighting for coverage—"literally a full-time job," says North—took three crucial years at a time when Seraphina would have gotten the most benefit from behavior and speech therapy.

"I remember lying in bed around her fifth birthday," says North. "I hadn't gotten insurance and services secured yet, and I just remember sobbing and thinking I failed her."

Autism is a developmental disorder with a wide range of symptoms, including difficulties with social interactions and communication. Because its severity varies, it's known as autism spectrum disorder. Of children on the autism spectrum, 44 percent have IQ scores in the average or above-average range. Others are severely disabled; one-third are unable to speak.

As has been widely reported, New Jersey has the highest prevalence of children with autism spectrum disorder in the nation. Among 8-year-olds, one child in 34 is on the spectrum, a rate that increased 43 percent between 2010 and 2014. While the causes behind these figures are uncertain, some cite high detection rates in New Jersey, as well as genetic and environmental factors.

A 2017 Rutgers Robert Wood Johnson Medical School study found only 1,000 developmental pediatricians nationwide and an average 5.5-month wait for a first appointment. In New Jersey, only 39 board-certified pediatricians are sub-certified in developmental behavioral pediatrics. The New Jersey chapter of the American Academy of Pediatrics confirms that waits of a year are common for initial appointments.

Some parents observe that general health care providers are not properly trained to work with people on the spectrum. Manisha Lad of Edison bristles when staff members at a doctor's office ask her, not her 18-year-old son, Akhil, if he can swallow pills.

*[RELATED: [An Immersive Play Space for People with Special Needs](#)]*

"They don't even give that respect," she says.

But it's not just the doctors who are often unprepared to treat patients on the spectrum. Even the environment matters.

Dr. Malia Beckwith, head of developmental behavioral pediatrics at [Children's Specialized Hospital](#) in Mountainside, says children on the spectrum often can't spend an hour in a waiting room, where crowds or excessive noise can cause a sensory overload.

Beckwith took part in a RWJBarnabas Health training program called Project ECHO, showing pediatricians how to work with children on the spectrum and create autism-friendly settings. For example, some doctors put maps of their offices online and describe the steps in a visit, in words or pictures, to help patients who need structure and routine. Some practices have set aside calm-down rooms or encourage the use of noise-cancelling headphones.

In addition to its special-needs services, Children's Specialized Hospital has a primary pediatric practice for families that have had trouble finding doctors comfortable with special needs. It also has a rehabilitation wing for children recovering from illness or surgery. The unit keeps patients on a careful schedule, with several quiet times throughout the day.

People on the spectrum often require more time from doctors because of difficulties in communicating and in functioning outside their routines. That can mean patient visits don't always conform to insurance guidelines.

Dr. Alison Smoller, a developmental pediatrician, does not accept insurance at all. She says that allows her to give new patients with special needs at least two hours for their first appointment, when she makes a full assessment and discusses treatment options. All patients must pay out of pocket.

"Reimbursement from insurance companies is so low that it would be impossible to sustain my practice," she says. "I would be forced to shorten my visits in order to allow more patients to be seen." She estimates her practice, Developmental Pediatrics of Central Jersey, in Ocean Township, saw 218 new patients in 2019 with special needs, including autism.

\* \* \*

Most children on the spectrum require more care than pediatricians can provide. Because autism comes with higher-than-usual rates of epilepsy, attention deficit and hyperactivity disorder (ADHD), anxiety, sleep problems and gastrointestinal disorders, families often need specialists in those areas, but finding ones trained to work with this population—and who accept insurance—can be next to impossible.

Shanthini Lawrence remembers that when her son, Mervin, now 21, was younger, the only pediatric neurologist she could find was through Children's Hospital of Philadelphia, an hour away from her home in Hamilton. However, that doctor wouldn't see Mervin because he was not having seizures. As a result, the boy did not see a neurologist during his entire childhood.

"The list was so small for specialists," says Lawrence. Her son needed an endocrinologist, otolaryngologist (an ear, nose and throat specialist), psychologist, psychiatrist and dentist. Often, the only available doctor was far away. And her insurance didn't cover mental health services. "We paid a lot out of pocket for a lot of things," she says.

Even twice-yearly visits to the dentist can be complicated for families with someone on the spectrum. Teresa Taylor of West Windsor could not find dental care for her son for several years. Lad describes a dentist who put her son, then 10, in a restraint, called a papoose, to fill a cavity. Her son was crying and unable to walk afterwards; she took him to a hospital for subsequent dental treatment. North says her daughter needs anesthesia for regular dental checkups. The care is costly; the co-pay for a regular exam under anesthesia is \$5,000; the same goes for a root canal. Without insurance, each would have cost \$13,000, she says.

**Shanthini Lawrence had to travel an hour or more to find specialists or even a dentist to care for her son Mervin, now 21. Insurance coverage was also a problem. “We paid out of pocket for a lot of things,” says the Hamilton mom.**

Photo by John Emerson

services vary depending on whether the family is insured through an individual plan on the health care exchanges, an employer-based plan (some of which are self-funded by the employer); or government-sponsored coverage (such as Medicare or Medicaid). While New Jersey state law mandates that private insurers cover autism services, self-insured plans are not required to follow state rules. (Autism New Jersey, a nonprofit advocacy group, provides a helpline, 800-4-AUTISM, for families with questions on insurance matters.)

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The difficulty of finding behavioral therapy for children on the spectrum is especially troubling, because such therapy can help those children become more independent adults. Suzanne Buchanan, the executive director of [Autism New Jersey](#), says 30 percent of children who receive high-quality, intensive Applied Behavior Analysis (ABA) therapy—which adjusts social behaviors—become indistinguishable from their neurologically typical peers. But an estimated 2 percent of children on the spectrum receive that level of therapy, which works best for children under five and involves 20–40 hours of one-on-one interactions a week.

While the state mandates that private insurance must cover such therapy, not all self-funded plans do so, and Medicaid covers ABA only through a pilot program, primarily for older children. Even when ABA is covered, families may have difficulty finding qualified therapists willing to work for low reimbursement rates, sometimes the equivalent of minimum wage.

Finding appropriate and affordable mental health care is also a challenge for people on the autism spectrum. Sher Genova of Flemington reports searching for three years to find a psychiatrist to treat her son. Long waits are common even for people who need immediate help. And Buchanan echoes parents' complaints that few psychiatric hospitals or outpatient programs accept children with autism. Fewer still are prepared to provide the specialized care they need.

Sometimes, children and adults with autism have episodes of violence that put themselves and their caregivers at risk. Parents and experts tell of individuals on the spectrum who hit themselves in the head repeatedly, hard enough to detach a retina, and parents who get concussions and bruises while trying to keep their children from hurting themselves.

According to Autism New Jersey, 24,000 children and adults in the state engage in "severe challenging behavior." Their families have few options when outbursts occur. Some counties have mobile crisis units that can come to a home and help calm people down. But parents report that some of the crisis units don't operate on weekends. Others have inexperienced workers or refuse to send staff into dangerous situations. Some have lost their funding.

Paul Aronsohn, the state's ombudsman for individuals with intellectual or developmental disabilities and their families, is concerned by the lack of services available for families in such crises. If an ambulance takes them to an emergency room, doctors often don't know how to treat them. In some cases, it's "anywhere between three hours and three weeks before being discharged on a mix of psychotropic medicines," he reports.

Such tales are harrowing, but more so for poor families, where the breadwinners have to work multiple jobs, leaving little time to fight autism-related battles.

"The kids whose parents [through no fault of their own] don't have the resources or the knowledge end up being much more traumatized," says Jen Schonger, of East Windsor, whose 6-year-old daughter is on the spectrum. "They're not being given adequate opportunities, their medical needs get ignored, and people might be attributing the way they act to behavior, when their legitimate medical needs are not being addressed." She cites a study from the U.S. Commission on Civil Rights that showed that a disproportionate number of children of color with disabilities end up in prison.

\* \* \*

For parents with children on the spectrum, life gets more complicated in adulthood. In New Jersey, young people with autism receive school-based services through age 21, leaving them and their families with a difficult transition into adulthood.

"We kind of live in a society where people's image of autism is focused around children. We see such a huge fall off the cliff at 21, when we're out of school, in terms of supports needed and in terms of health care overall," says [Kerry Magro](#), an advocate and public speaker about autism, who



lives in Hoboken. “Not only is there a lack of overall health care opportunities, there’s also a lack of education about adults with autism and the supports we truly need.”

Aronsohn adds that, because adults on the spectrum typically receive Medicaid, they often find fewer health care practitioners who accept that program’s historically low reimbursements.

The Arc of New Jersey helps young adults and their families find medical support. Beverly Roberts, of the nonprofit’s mainstreaming medical care program, says that, under state law, some young adults with autism are able to stay on their parents’ private health insurance even past age 26. (Parents must make the request before the individual turns 26.) In addition, the Children’s Hospital of Philadelphia runs the New Jersey Transition to Adult Coordinated Care, based in Plainsboro, another group helping young adults move from pediatricians to adult primary care doctors and specialists.

**Genevieve Kumapley is concerned about where she’ll find caregivers for her son Nicholas, who is 18 and has complex medical needs. She believes the state should require doctors to learn more about caring for people with disabilities.** Photo by John Emerson

Genevieve Kumapley, who has worked with that group, says some pediatricians will keep seeing patients up to age 30, which isn’t ideal. “There needs to be a physician specialty in the area of developmental disabilities,” she says. Her son Nicholas is 18 and has complex medical needs.

“We have not fully put together a team for him that can take care of him,” says Kumapley, a pharmacist. She wishes the state would require doctors to take some of their continuing-education credits in topics related to disabilities, much as pharmacists have been required to learn about the opioid epidemic.

There has been some progress. Some state institutions are training more health-care providers on the needs of people on the spectrum. Based at Rutgers Robert Wood Johnson Medical School, the federally funded Leadership Education in Neurodevelopmental Disabilities (LEND) program

provides 300 hours of training in culturally appropriate care for children on the spectrum, aimed at graduate fellows in health-related disciplines, family members and self-advocates. Every medical student at the school must take a seminar as part of the curriculum and visit the family home of a person with disabilities. At Children's Specialized Hospital, medical residents do rotations to learn about pediatric disabilities.

Still, much of the work falls to parents of young people on the spectrum.

"Parents have had to create their own support group, and social media has been a blessing to them," says Liz Torres, the principal investigator at the New Jersey Autism Center of Excellence. While many find it difficult to make face-to-face meetings, online or phone services help them get and share information without having to drive or find babysitters.

The search for services can be exhausting. Ellie North, who lives in Warren County, where services are scarce, knows this firsthand. "I'm not going to stop until I get her to her best life," she says of her daughter, now 6. "I think most special-needs parents are like that."

## ***WHEN EMERGENCIES STRIKE***

Emergency situations can be especially problematic for people with autism. Loud noises, bright lights, barking police dogs, and strangers can all trigger sensory overload.

"A trip to the ER is every parent's nightmare," says Franny Hines, autism and special-needs coordinator for the Monmouth County Sheriff's office. He notes that emergency vehicles and emergency rooms tend to be bright and noisy, with lots of beeping machines. That can be "intimidating for a kid on the spectrum with sensory issues."

Monmouth County trains its police recruits to work with people with autism and other disabilities, and it keeps a voluntary registry of people with special needs, including sensitive ways to approach them.

"The kid has already had a bad day because you're there. They're sick or injured, and leery of everybody," says Hines. "If he's hurt or in pain, his anxiety level will go to a point where he's going to be unreachable."

Hines, a longtime emergency medical technician, runs a state-approved training class that provides continuing-education credits for EMTs.

"A little bit of awareness goes a long way," Hines says. He wishes ambulances could take people on the spectrum to emergency rooms staffed by people trained in soothing patients in such chaotic environments, but he is not aware of any in the state.