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< [Back to Regular Story Page](#)

Who should pay for treating children with autism?

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A popular method of therapy isn't covered by most insurance plans, putting families in a financial bind. A proposed state law would mandate coverage, but the insurance industry says the therapy is educational, not medical.

Grant Fulton is a busy boy.

Seated at a child-sized table in his family's Lacey living room, the 5-year-old kneads a ball of soft, claylike material. He talks about its colors, shapes and textures.

Laurie Waguespack, his therapist, subtly switches between play and learning. Her goal is to help Grant, who has autism, gain cognitive skills.

Waguespack grabs a deck of picture cards, and asks Grant to name the colors and shapes as she flips through them.

"Pentagon. Octagon. Diamond. Black. Circle. Rectangle. Yellow," says Grant, building speed as he identifies 34 of 35 cards correctly.

Eight months ago, says Denise Fulton, Grant's mother, it would have been difficult to get him to name shapes and colors. Two years ago, it would have been impossible. Grant has mastered this only through daily, step-by-step therapy administered by Waguespack and others.

"It's hard trying to rewire the brain," says Fulton.

It's also expensive, with in-home therapy costing anywhere from \$15 to \$25 per hour. None of it is covered by the family's health insurance plan.

Insurance industry representatives such as Susan Pisano, spokeswoman for the national industry trade group America's Health Insurance Plans, say some autism treatments aren't really medical treatments but are more educational in nature. They argue that education is the responsibility of public schools, not private health insurance.

But Susan K. Malmquist, a Shoreline educational consultant who works with children with autism, says schools can't go it alone.

"The federal government does not provide enough funding through the IDEA (Individuals with Disabilities Education Act), nor do we have enough local funding," she says.

Insurance companies also point out that increased benefits for some means premium increases for everyone.

"It is a public policy question," Pisano adds.

The question is being debated in state after state, as laws mandating insurance coverage for autism treatments are considered. At least seven states have passed laws targeting insurance coverage for autism treatment. And this year, the debate comes to Washington state with a proposed law by a group called Washington Autism Advocacy that would govern insurance coverage for autism.

Last month, the state Department of Health held a hearing on the proposal.

For three hours, parents of children with autism told their stories. They spoke of the strain that paying for their children's treatment places on families and marriages.

“We had \$200,000 in IRAs,” Adam Burns of Sammamish, the father of a 7-year-old boy with autism, told the Health Department panel. “It’s all gone.”

Burns said that even though therapy is helping his son, he has to cut back on treatments because of the cost.

Robert Ott, a Bellevue Realtor, said he spent \$68,000 last year on treatments for his 6-year-old son with autism.

“We have nowhere to turn for help,” he said at the hearing. Without insurance reform, Ott added, “I’ll always be broke. I’ll always have creditors calling.”

EFFECTIVE OR NOT?

The therapy that’s been so successful for Grant Fulton and other children with autism relies on a method called applied behavior analysis (ABA).

It uses one-on-one instruction, repetition, rewards and a structured environment to draw children with autism out of their strange, often silent world and teach them the communication skills they’re unable to learn on their own. The goal of ABA is to increase desired behaviors and decrease undesired behaviors by using prompts, cues and positive reinforcement, according to autism experts.

Some in the insurance industry argue that there haven’t been enough studies looking at the long-term results of ABA.

“A recent review of published peer-reviewed studies doesn’t confirm that ABA is actually proven effective,” says Dr. Diane Stein, a medical director for Regence BlueShield insurance in Seattle. She says many studies have shortcomings, such as small sample sizes or no control groups.

Still, while the positive effects of ABA-based therapy can vary from child to child, it’s widely accepted by autism experts. The therapy is “well-established in terms of efficacy for children with autism,” says Milani Smith, associate director and director of clinical services at the University of Washington Autism Center. “I’m sure there are people who find it controversial. It certainly doesn’t work for every child.”

For most Washington state families with children who have autism, medical insurance covers none of the cost of ABA therapy. If parents want it for their child, they must pay on their own. At the standard cost of \$15 to \$25 an hour, 40 hours a week can cost about \$50,000 a year.

Because Denise Fulton and her husband, Dean, have seen how much individualized ABA therapy has helped Grant, they pay for it themselves. They also pay for a special diet and alternative medicine treatments that they say have allowed their son to flourish.

To afford Grant’s therapy, the Fultons drive a used car. They have tapped into savings but are trying hard not to touch their 401(k) retirement fund.

The total out-of-pocket cost for Grant’s therapy, diet and treatments are “pretty much like buying a new car every year,” says Dean Fulton.

‘A HUGE TASK’

Arzu Forough, a Kirkland mother of two sons with autism, would like to change the insurance coverage picture. She's leading an effort in Washington state for legislation to mandate insurance coverage for autism and related disorders, known as autism spectrum disorders (ASDs).

“We have a huge task on our hands to educate Washington that autism is treatable, and that it is an epidemic that is not going away,” says Forough.

The Washington proposal, backed by Washington Autism Advocacy and the state chapter of the national group called Autism Speaks, would require insurance companies that cover public employees in Washington state and sell policies to the public to include coverage for diagnosis and treatment for individuals with autism to age 21. The proposed legislation would:

- Require coverage for ABA-based treatments, along with coverage for medication, occupational, speech and other types of therapy – as long as they are prescribed by a licensed physician or a licensed psychologist.
- Prohibit insurers from dropping coverage of individuals with autism based solely on their diagnosis. Forough and other parents say this has happened.
- Remove limits on the number of visits an individual can make to an autism treatment provider.
- Cap benefit payouts for treatment of autism at \$50,000 a year – a figure that would be adjusted for inflation annually.

An initial analysis by the Washington State Health Care Authority, which administers health benefits for the state's public employees, estimates that the new law could increase premium costs for those employees by at least 1 percent or slightly more. That could mean an additional \$17 million or more in 2010.

Washington state's Autism Task Force, appointed by the Legislature, made an autism insurance mandate its highest priority in a report published in 2007.

“Insurance that covers evidence-based services for ASD is severely lacking in Washington,” the task force noted in the report to the governor and Legislature.

In the absence of such coverage, parents must pay for therapies and treatments themselves.

Corey and Lorina Gardner of University Place, seeking treatment for Zander, their 5-year-old son who has autism, have abandoned insurance coverage.

Corey Gardner owns his own business, while Lorina Gardner is a stay-at-home mom for Zander and his older sister, Vegas. They lean toward alternative medicine treatments not covered by insurance. They decided that instead of paying for insurance that Lorina Gardner says was largely useless, they would spend money on Zander's treatments, including in-home ABA therapy and a special diet.

“We think and act outside the box to heal our son,” says Corey Gardner.

And, “it works for our child,” says Lorina Gardner.

MAGNANIMOUS MICROSOFT

While the proposed law could help many Washington families, it wouldn't reach those who get their insurance through some of the state's largest employers.

Many large companies are self-insured, which means they contract with an insurance company to administer their plans but actually pay the claims to employees themselves.

“Under federal law, states cannot tell self-insured employers what benefits they can offer,” says state Sen. Karen Keiser, D-Kent, chairwoman of the Senate health care committee.

But Keiser says that state insurance mandates do tend to raise the bar for everyone.

“Large employers like to retain and recruit employees,” she says. “They tend to meet the standard quickly.”

One large self-insured employer is already setting the standard: Microsoft has covered ABA therapy for children with autism since 2001.

The addition of autism coverage came at the request of employees, says Julie Sheehy, who manages the company’s insurance benefits for U.S. employees.

“Microsoft has a long history of striving to offer comprehensive benefits packages,” she says.

Sheehy wouldn’t outline specifics of the plan, nor would she say how much the added benefit has cost the company. But the benefits aren’t limited by a child’s age, and employees do pay a portion of the treatment costs.

Ronnie Thibault of Monroe, Snohomish County, is the mother of a child with autism, and her husband works at Microsoft.

“When my son was diagnosed at age 5 two years ago, I didn’t know how privileged we were,” she says.

Thibault says that when she deals with health care providers, all she has to do is tell them her husband works at Microsoft and her son’s treatment is “completely free of hassles. All families deserve what my son is getting.”

RESTRICTION RATIONALES

Why is insurance coverage for autism so restrictive? The insurance industry argues that some treatments – including ABA therapy – should be the responsibility of public schools, which are mandated under federal law to provide services to disabled children from ages 3 to 21.

School districts routinely offer speech therapy, occupational therapy and physical therapy, says Doug Gill, director of special education for the state Office of the Superintendent of Public Instruction.

But how many use ABA therapy is unknown, he adds.

“Autism is pretty complex, in terms of how it plays out,” says Gill. “You have to look at the individual needs of a student and what works best. The issue is what is an appropriate program for the child.”

Keoni Smith, co-director of special services for the Sumner School District, says that while there has been research focusing on what works for very young children with autism, “there has not really been as much with school-age students, especially secondary-age (middle school and high school) students.”

Smith says Sumner teachers might use ABA-related or other types of behavioral therapy, but students would be unlikely to receive one-on-one therapy exclusively.

“We do have students in our preschool who might receive 20 to 25 hours of services,” says Smith. But those hours would likely include both individual therapy and group classroom time, he adds.

Vanessa Tucker, a Tacoma special-education teacher with expertise in autism, says the educational and health care systems need to collaborate.

“It’s not something any one agency should be responsible for,” she says.

“The insurance companies say let the schools take care of it,” adds state Sen. Darlene Fairley, D-Lake Forest Park, who’s supported past unsuccessful legislative efforts to expand insurance coverage for kids with autism. “But the schools have so much else to do. You can’t just leave kids to be cared for by the schools.”

Stein, of Regence BlueShield insurance, sees it differently.

“Typically, providers of behavioral interventions such as applied behavior analysis are not licensed health care professionals,” she says. “Rather, they are teachers and others with training in ABA ... such as paraprofessionals and parents, and therefore not eligible for health plan coverage as providers.”

Stein notes that other medical and rehabilitation services for autism are covered, including those provided by pediatricians, physical therapists, occupational therapists and mental health professionals.

But parents of children with autism say insurance policies often limit the number of visits per year for occupational, physical or speech therapy, in effect cutting off therapy after a matter of months and rendering it ineffective.

“There may be limits on physical therapy or occupational therapy, regardless of the cause,” says insurance industry spokeswoman Pisano. “It’s not specific to kids with autism.”

Jenny and Chris Hazelton of Lacey have insurance that covers occupational therapy for their 4-year-old son, Noah, who has autism. They pay about \$40 a week in co-pays for occupational therapy. But Jenny Hazelton says that about once a quarter – when Noah reaches his 25-visit limit – therapy stops for 45 days or so before he can become re-eligible for coverage.

It’s difficult for the Hazeltons to afford both occupational therapy, with its on-and-off coverage, and ABA therapy, which isn’t covered by insurance at all. Due to the family’s medical bills, the couple has never owned a home.

“We’re basically spending every dime we have on Noah,” says Jenny Hazelton, who worries about what will happen when the family is no longer able to find money for treatment.

POTENTIAL ALLIES

If Washington’s proposed autism insurance mandate turns into a bill in the January legislative session, it could find some allies in both the state House of Representatives and the Senate.

Sen. Marilyn Rasmussen, D-Eatonville, has a grandson with autism. So does Sen. Pam Roach, R-Auburn. Both Roach and Rasmussen have served on the state Autism Task Force.

Roach’s son, state Rep. Dan Roach, R-Bonney Lake, has a 6-year-old son, Drew, who has autism.

“This is a huge burden on families financially,” says Dan Roach’s wife, Melanie Roach, the Olympic weightlifter who recently competed in Beijing. She says their family spent an estimated \$25,000 in less than two years paying for ABA therapy for Drew, then stopped last fall due to the cost.

Dan Roach argues that mandating insurance coverage for treatment of children with autism would ultimately save tax dollars. He says children who aren’t treated early in life risk becoming dependent on the state as adults.

“If you understand what’s really going on with autism, it’s hard to argue,” says Dan Roach. “If you want to save taxpayer dollars, it’s much better to do the mandate now.”

Adds Rasmussen: “If we take care of these kids, if we start early, we can mainstream them in classrooms by the time they are 8 or 9 years old. We are going to make this (new law) happen. It saves money in the long run.”

State Sen. Keiser predicts the proposed autism insurance law will face stiff opposition from insurers.

“It will be hard fought,” she says, comparing it to the battle over past legislation that mandated more coverage of mental illness.

“These things happen with a lot of effort,” Keiser says. “It’s an incremental, painful and harmful method of dealing with health care issues. We can do so much better.”

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An autism Q&A: What it is, how it's recognized

Children with autism suffer from a developmental disorder that can leave them locked in a lonely world, unable to interact or communicate with others.

The cause of autism is unknown, but theories include some combination of genes and environmental factors. One of the more prevalent theories, often put forth by parents of children with autism, is that vaccines are a possible cause. But a series of scientific studies has found no link.

The most recent study was published last month in PLoS, the online journal of the Public Library of Science. A team of researchers led by scientists at Columbia University found no association between the measles vaccine and autism.

Although there is no cure for autism, experts believe that if treatment is started early enough, it’s possible to teach many children with autism the kinds of skills that come almost effortlessly to typical toddlers – increasing their vocabulary, pointing to objects of interest, making eye contact, and engaging with the world and the people in it.

What is autism?

A group of related conditions is commonly referred to as autism spectrum disorders, or ASDs. Children with ASDs can fall anywhere on the spectrum, and exhibit a variety of symptoms from mild to severe.

The classic characteristics of autism include impaired social interaction and problems with speech, as well as unusual and repetitive actions, such as hand flapping, and severely limited interests.

Children with autism may focus intensely on one thing, such as dinosaurs or guitars, to the exclusion of other objects. They often fail to learn to gesture and point to objects. They may act as if they’re unaware of their surrounding environment or other people. They may have poor coordination and may be inclined to self-injury, such as hair pulling or head banging.

What are some other problems that go along with autism?

Sleep disturbances, stomach problems and/or diarrhea, seizures and food sensitivities are common.

How common is autism?

One estimate from the federal government says that as many as one in 150 American children fall somewhere on the autism spectrum.

In Washington state, more than 5,000 children with autism were in public schools in 2006.

There is debate about whether the incidence of autism is increasing, or whether doctors are simply becoming better at recognizing and diagnosing the condition.

What are common signs of autism?

Children with autism have problems with social interactions and communication. Some exhibit extreme tantrums.

Signs of autism may be present from birth; for example, a baby who is unresponsive to people. Other children develop normally for a year or two, then regress, losing the ability to speak and exhibiting other symptoms, such as withdrawal from social contact.

Children with autism cannot understand facial expressions, such as a smile, or other social cues. They often ignore other children and may prefer to play alone.

Some children with autism are insensitive to pain, but are abnormally sensitive to light, texture or touch.

Debbie Cafazzo, The News Tribune

WEB RESOURCES

State, regional organizations

Washington Autism Advocacy

www.washingtonautismadvocacy.org

Northwest Autism Foundation

www.autismnwaf.org

University of Washington Autism Center (including Tacoma satellite office)

<http://depts.washington.edu/uwautism>

Talk About Curing Autism (TACA) of Washington State

<http://groups.tacanow.org/washington>

Autism Society of Washington

www.autismsocietyofwa.org

National organizations

Autism Society of America

www.autism-society.org

Talk About Curing Autism

www.talkaboutcuringautism.org

Center for the Study of Autism

www.autism.org

National Institute of Child Health and Human Development

www.nichd.nih.gov/autism

National Institute of Mental Health

www.nimh.nih.gov

Centers for Disease Control and Prevention

www.cdc.gov/ncbddd/autism

Autism Speaks

www.autismspeaks.org



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