Facing Autism: More Than 10,000 Autistic Children Have No Coverage in Washington

Facing Autism: 33-Year-Old Centralia Mother Works to Find Help for her Son and Clarify Common Misconceptions Following Her Husband’s Untimely Death


By Amy Nile anile@chronline.com | 0 comments

When Cynthia Paull’s husband died — leaving her with limited income and three boys to raise on her own — dealing with her 6-year-old son’s autism became even more challenging.

In the five months since, the 33-year-old Centralia mother has been doing the best she can to help her son navigate the world with the brain-based disorder, which causes difficulties in social interactions, communication and certain behaviors.

Paull, along with about 200 other area parents, educators, social workers and medical professionals, met recently at the second annual Lewis County Autism Coalition conference in Chehalis.

“It’s about getting people connected with resources so they know they’re not alone,” said Amber White, who is also raising a 6-year-old with autism in Toledo.

Because no two children with autism are the same, Paull faces the challenge of identifying which services are right for her son.

Additionally, Paull lost medical insurance coverage following her husband’s untimely death and now she has to pay for her son’s treatments out of pocket.

“The bills are astronomical,” the Centralia apartment manager said.

But even with coverage, parents face problems because insurance companies often don’t pay for the services needed to address the disorder.

Washington state has more than 10,000 autistic children that have never received coverage for their treatments, according to the coalition. But that may soon change as the state moves toward reforming coverage for behavioral disorders.

In the meantime, Rebecca Turnbull, Lewis County’s special education director, said it’s important for parents...
to know school districts will evaluate and provide services for children with disabilities like autism. More than 100 students in the 13 area school districts currently receive therapies for autism spectrum disorders, which now affect one in 88 children nationwide, according to the U.S. Centers for Disease Control and Prevention.

"Being a parent with a child with autism can be exhausting," Turnbull said. "We might see what looks like misbehavior but they're just trying to deal with feelings of discomfort."

Misperceptions of Autism

Because the communication issues often associated with autism leave children without words to express their feelings, they sometimes act out. The tantrums are often mistakenly perceived as poor parenting, a common misperception Paull knows all too well.

"It may be annoying or hard to see a child having a major tantrum," Paul said. "But I guarantee you it's much harder for that child."

Children with autism perceive the world differently and experience sensory overload. Paul said her doctor explained that having the disorder feels like locking oneself into a room, and flicking the lights on and off while turning the volume on both the radio and the TV up full blast.

On top of the sensory overload, autistic children often have trouble communicating those feelings, further adding to the frustration.

Additionally, the disorder often causes the child to depend on repetitive behavior and any interruption to their regular routine can cause detrimental feelings.

"The more he knows what's going to happen, the more his world is intact," said Amanda Prothero, about one of her twin boys with autism. "The less he knows, the more his world is falling apart."

One of the boys, Logan, needs routine and structure while the other, Charlie, gets bored with it.

Since the twins don't have any physical signs of autism, Prothero said it's hard because people treat them like normal 5-year-olds.

"It's kind of a double edged sword," the Chehalis mother said. "You can't see inside their head that there's a misfire of information that comes naturally to us."

Prothero learned sign language to help bridge the communication gap caused by the disorder. The more the twins learn to talk, Prothero said, the less they sign. But signing comes in handy in a moment of frustration where they are unable to articulate their feelings into words.

"That helps a lot with the starting of a meltdown," Prothero said. "If you promise something, you have to follow through. You can't be a lazy parent."

Teaching and Autism

Another thing that has helped, Prothero said, are the educators at Napavine Elementary School. Special education teachers, Joey Easley and Stacey Carbaugh, work with Logan and Charlie and about nine other students with autism.

"It's constant problem solving," Carbaugh said. "What works today might not work tomorrow."

The team uses a variety of learning tools like reward systems, task tools to help maintain structure, and story books, which feature the child acting appropriately when faced with a particular social behavior they are having difficulty with. Many of the social and academic activities center around things that are of particular interest to the student, like Angry Birds or Thomas the Tank Engine.

"It's using what motivates or drives them," Easley said.

Increasing Prevalence

While some autism cases can be linked to genetic abnormalities, the causes of the medical brain disorder are not yet well understood by doctors and psychiatrists. What is clear is that its prevalence is increasing.

"There's only one thing we know that doesn't cause autism and that's vaccination," said 30-year autism researcher Dr. Glenn Tripp, of Tacoma's Mary Bridge Children's Hospital, who diagnosed the Prothero twins.

The male dominant disorder is becoming increasingly prevalent, said Tripp, with autism now striking one in 54
Boys and one in 206 girls.

While about 70 percent of the increased prevalence can be explained by a higher rate of diagnosis, Tripp said, the rest remains unknown, which makes the epidemic a public health emergency.

That's why groups like the Lewis County Autism Coalition, which includes parents like Paull and Prothero and educators like Turnbull, are working to pool resources and help others dealing with the disorder.

"One of the unique things about Lewis County is the collaboration," Turnbull said. "We think outside the box and get things done."

Amy Nile: (360) 807-8235
twitter.com/AmyNileReports
www.facebook.com/AmyNileTheChronicle