

## Communication barrier

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Luis Angel Hernandez was 3 years old when his parents first noticed there was something about him that was different.

He wasn't interested in children or other people, was a delayed talker, and at times seemed to have a hearing problem.

"He was our third child and first son, so we just thought that was the way boys behaved," said Luis' mother, Ruth Hernandez of Salem.

Luis' unusual behavior followed him to kindergarten, where his teacher suggested he be evaluated by the school psychologist.

A distraught Ruth called her husband at work with the wrenching news: Luis was autistic.

"I remember crying and feeling so alone," the mother said. "I blamed myself for my son's autism."

Her husband, Luis Gerardo Hernandez, tried to comfort his wife. Neither parent knew much about the neurological disorder afflicting their son, so they set out to learn as much as they could about autism.

But they soon discovered there was very little information or support available for non-English-speaking parents of autistic children.

"The barrier is language," said Luz Rivera, the director of Juntos Podemos Family Center in Salem. "Language has a lot to do with the type of information and services parents get."

Whatever language they speak, parents in Oregon often find they must weave through a web of laws, programs and agencies to get services and care for their children with autism.

Dealing with health-care providers also can be a challenge.

In Oregon, a health benefit plan that provides rehabilitation or speech and occupational therapy services for its members must also provide those rehabilitation services to children diagnosed with autism, officials with the Oregon Insurance Division said.

However, state law does not require insurance companies to offer rehabilitation or speech and occupational therapy to Oregon families of children with developmental disabilities.



**andrea j. wright | Statesman Journal**  
Ruth Sanchez Hernandez (center) and her son Luis, 9, play educational games at the Juntos Podemos family center, which helps find resources for families with autistic children.

### By the numbers

7,078 — the total number of Oregonians, from birth to age 21, with a primary diagnosis of autism;

1,070 — the total number of autistic people, ages 3 to 21, in Marion County;

151 — the total number of people with autism, ages 3 to 21, in Polk County.

#### Languages

The following reflects the number of autistic people, from birth to 21 years, in Oregon and their primary language:

#### Statewide

6,355: English

237: Spanish

49: Vietnamese

12: Chinese

According to the state Department of Human Services, at least 2,362 Oregonians with some form autism receive assistance through the Oregon Health Plan.

Two years after Luis was diagnosed with autism, a family friend told the Hernandezes about Juntos Podemos, a nonprofit center that assists poor and underserved families of children with developmental and physical disabilities.

"Unless you've personally experienced it, you can't empathize with parents who have autistic children," said Ruth Hernandez, a stay-at-home mom who visits the center daily. "You can't possibly know the frustrations that parents like us face daily, because our autistic son or daughter can't communicate his or her needs or emotions to you."

At Juntos Podemos Family Center, the Hernandezes joined a support group where they met dozens of parents just like themselves, parents who speak little English and who have children disabled by a condition they know little about.

The center connects families of autistic children to a variety of resources, including physician information, parent trainings, respite care, Spanish-language reading materials, education workshops and a support group.

So does the Oregon Parent Training and Information Center in Salem, where interpreters are available to families who speak Spanish, Russian and Vietnamese, said Robin Wortman, statewide resource director for the PTI.

In Portland, the Jean Baton Swindells Resource Center for Children and Families also offers services in Spanish, Russian and Vietnamese, in addition to Chinese, Samoan, German and Czechoslovakian, said Ann Saraceno, the center's director.

Autism is a complex neurodevelopmental disorder that affects the part of the brain responsible for social interaction and communications skills. Because people with autism can have varying degrees of symptoms — impairments in language, learning, thinking and interacting with others — the disability is referred to as autism spectrum disorder.

It can be diagnosed as early as 18 months of age and lasts a lifetime, although research shows that early intervention can greatly improve a child's development.

The disorder occurs in all ethnic, racial and socioeconomic groups and is four times more prevalent in boys than girls.

There is no definitive test to determine whether a child has autism. Diagnosis typically involves an assessment that includes information about the child's emotional, social,

11: Russian

311: Undetermined

Marion and Polk counties

99: Spanish

6: Russian

\*Languages with counts of less than six are not available.

SOURCE: Oregon Department of Education

#### Resources

The following is a list of resource groups that offer services to families of children with autism:

Salem Oregon Autism Resources! (or SOAR!), offers weekly training and connects families with other resources. Information: Dana Campbell at [info@salemsoar.org](mailto:info@salemsoar.org) or [www.salemsoar.org](http://www.salemsoar.org).

Juntos Podemos Family Center offers informational services and monthly support groups for Spanish-speaking parents of children with developmental disabilities. Information: Luz Rivera at (503) 566-7727 or [lrivera@hsri.org](mailto:lrivera@hsri.org).

communication, and cognitive abilities.

That information is gathered through a specialist's direct interaction and observation of the child in a variety of settings. Information also is collected through interviews with parents about behaviors they observe in their child.

School staffers often are the first to recognize the signs of the disorder through early-childhood screenings, a practice that some medical experts claim can result in a number of children being mistakenly diagnosed with autism.

Experts still don't know what causes autism, although some blame vaccines or environmental factors.

"What we do know is that it involves a genetic component," said Dr. Robin McCoy, a developmental and behavioral pediatrician at the Oregon Health & Science University's Child Development and Rehabilitation Center.

The Center for Disease Control and Prevention estimates that 1 in 150 children born in the United States have autism.

The Autism Society of America estimates that as many as 1.5 million people in the nation have autism.

Earlier this year, the state Department of Education reported that more than 7,000 Oregon students have autism.

In the Latino community, children with autism can sometimes face an uphill battle because parents often refuse to believe there is anything wrong with their child, dismissing the problem as a childhood phase.

That's why Ruth Hernandez shares her knowledge about the disorder with Latino parents looking for answers about autism in their language.

"It's important that parents learn all they can about autism," she said. "They also need to know that they're not alone. There are many other families going through the same thing we were going through."

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Parent Training and Information Center, 2295 Liberty St. NE, connects families with a number of resources and offers interpreters in various languages. Information: (503) 581-8156 or [www.orpti.org](http://www.orpti.org).

Community Parent Resource Center, 830 NE 47th Ave. in Portland, offers informational, referral services and training. Information: (503) 215-2268 or [www.orfirst.org](http://www.orfirst.org).

The Autism Society of Oregon offers support and information to families of children with autism. Information: (503) 636-1676.

#### Warning signs

Here are some signs parents should look for if they suspect their child may have autism:

-Lack of or delay in spoken language

-Repetitive use of language and/or repetitive movements, for example, flapping the hands or twirling objects

-Little or no eye contact