

By Elizabeth Cohen
CNN

Autism Unraveling The Mystery

In recognition of World Autism Awareness Day April 2, CNN reports on the global impact, latest science and controversies related to the brain disorder. Watch for expanded coverage on CNN.com and CNN TV.

ATLANTA, Georgia (CNN) -- When her son Justin was a newborn, Shannon Kinninger looked up from the kitchen where she was watching dishes, and saw a large, heavy toy fall on Justin's his head. Justin didn't cry.



Kinninger thought that was odd, and it wasn't the only thing that seemed strange about Justin. At her weekly playgroup, she watched the other babies hit their developmental milestones more or less on schedule. Justin lagged far behind.


"When he was supposed to be sitting up, he wasn't sitting up. When he was supposed to be holding his head up, he wasn't holding his head up. When he was supposed to be rolling over, he wasn't rolling over," says Kinninger, a nurse who lives in Fayetteville, Georgia.

Kinninger brought up her concerns to her pediatrician, but he told her not to worry. "The doctor kept saying that boys develop more slowly than girls," she says. "He kept reassuring me he'd be OK."

Even though she felt frustrated, Kinninger accepted this explanation for years. Finally, when Justin was 4, she decided enough was enough. Justin wasn't potty trained, and he had unusual repetitive behaviors, such as switching lights on and

off for extended periods of time, or washing his hands over and over. Plus, he wouldn't look at people -- he looked "through" them.

She switched doctors, and the new pediatrician referred her to a developmental pediatrician. "He said, 'He's autistic. I knew five minutes after you came in,' " Kinnering says. "I thought, finally, we get a diagnosis."

Now Kinnering thinks about all those lost years -- from babyhood to 4 years old -- critical years when Justin could have been receiving therapy for children with autism, but didn't. She now tells other parents of children with autism they need to be advocates for their children, from the very first moment they show signs of having autism.  [Empowered Patient: Steps to take to get help for a child with autism »](#)

Here, from mothers of children with autism, are ways parents should fight for their children with autism, from babyhood through the school years.

1. Trouble getting a diagnosis? Bring in video, letters.

If you're concerned your child has autism, and you're getting the same response Kinnering got from her pediatrician, remember doctor's visits are often short, and your child may not be displaying the worrisome behavior you've seen so often at home. Alison Singer, executive vice president of [Autism Speaks](#), an awareness and advocacy organization, suggests videotaping your child's behavior and showing it to the doctor. "You could play it on your laptop, or even just bring in the video camera," she says.

Getting a letter of support from your child's day-care provider or preschool teacher might also help.

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"Teachers are seen as other professionals, and a letter saying, 'In 20 years of teaching, this behavior is really unusual,' can go far," says Singer, who has a 10-year-old daughter with autism. If your child isn't in day care or school, even a letter from a neighbor who knows your child could help, she says.

Singer emphasizes that parents shouldn't push their pediatrician for a diagnosis. "We're saying, refer the child to a developmental pediatrician for additional screening and testing. Because when a parent thinks something is wrong with their child, they're usually right," she says.

Educating yourself about autism will also help you have a discussion with your pediatrician. Autism Speaks, [First Signs](#), and the [American Academy of](#)

Pediatrics all give excellent overviews. Autism Speaks' **Video Glossary** has more than 100 video clips comparing the behavior of children with autism spectrum disorders with the behavior of a typical child.

2. Sign up for early intervention

Any child younger than age 3 with a developmental delay is eligible to receive services through Early Intervention, a government-mandated program that provides services to eligible children. Services are free of charge, and vary from state to state, but may include speech and language instruction and occupational and physical therapy.

To learn how to apply for Early Intervention, click on this **state-by-state directory** from the **National Dissemination Center for Children with Disabilities** and scroll down.

Early Intervention is invaluable because it links parents to services in the community, but Lisa Goring, mother of a child with autism and director of family services at Autism Speaks, warns that parents may also have to search on their own, since it can be hard to find services without a long waiting list. "There just aren't enough service providers for the kids who need them," Goring says. To find services on your own, **wrightslaw.com**, which offers information about special education law and advocacy, has a **Yellow Pages for Kids** that lists providers.

Long waits are so prevalent that **Nancy Wiseman**, founder and president of the advocacy group First Signs, whose 12-year-old daughter has autism, has a few suggestions for how to get in quicker. First, parents should stress the age of their child (many clinics will give priority to children under 3), and should ask the pediatrician to make a call to the specialist. More suggestions are in her book **"Could it be Autism? A Parent's Guide to the First Signs and Next Steps."**

3. Know your child's rights in school

When your child enters public school, he or she has rights under federal and state laws. The U.S. Department of Education has information about **federal laws** and **state laws**. The **National Association of Parents with Children in Special Education** has information about children's legal rights as well.

Wiseman says that even with these protections, you'll still have to work to get what's best for your child.

For example, Wiseman moved to get into a different school district, and then a few years later, when that district no longer worked well for her daughter, she twice fought to place her child out of the district.

"It's very frustrating to battle a school, and you really have to do your homework," she says.

You and the district will come up with an Individual Education Plan. Wiseman recommends "[The Complete IEP Guide: How to Advocate for Your Special Ed Child](#)" by attorney Lawrence Siegel.

Also, school districts often have a Special Education Parent Teacher Association. Parents there can often give good advice on how to work with the school district.

4. Sign up for a research study

If you live near a major research university, Wiseman suggests finding out whether anyone is looking for children with autism for research studies. Sometimes, these universities will provide care for your child as part of the study. Wiseman's group, First Signs, has [a list](#), as does [Autism Speaks](#).


5. Get support from other parents

Health Library

MayoClinic.com: [Autism](#)

Judith Steuber, who raised two grandsons with autism, said that if she had to do it all over again, she would do one thing very differently. "From the beginning, I wish I'd had more support from other parents," says Steuber, who now acts as a mentor for special-needs parents in her school district. "I think that makes a big difference."

Autism Speaks has a [state-by-state list of support groups](#). You can find a chapter of The Autism Society of America [here](#).

There are electronic support groups on Yahoo, the [Berkeley Parents Network](#), and [Autism Web](#). The Arc has [support groups for people with intellectual and developmental disabilities](#); Wiseman says many have a large number of parents of children with autism. [E-mail to a friend](#) 

Elizabeth Cohen is a correspondent with CNN Medical News. Senior producer Jennifer Pifer and intern Jennifer Kabak contributed to this report.