

# SEED Study to Explore Early Development

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*This is a semi-annual newsletter of the Centers for Disease Control and Prevention-funded Study to Explore Early Development (SEED). The purpose of this newsletter is to inform the public of the study's progress.*

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## Autism Spectrum Disorder: What Can Siblings Do To Help?



Danielle (from left), Alexis, and Amanda Wineman

About 1 in 68 children have been identified with autism spectrum disorder (ASD). The '1' in 1 in 68 represents thousands of families in communities across the United States living with the condition. Alexis Wineman, the first woman with ASD to participate in the Miss America competition, feels that her family, and particularly her siblings, have always been a source of strength and inspiration for her.

"Prior to being diagnosed with autism, neither I nor my family had an explanation for my meltdowns and other issues," Alexis says. "After the diagnosis, it was incredible how my siblings reacted. It was just amazing how they sprang into action after years of not knowing what was going on."

Alexis' family shared their advice for others who have a sibling with ASD.

"My advice for someone who has a sibling with autism would be to engage them and help them find their niche," says Kimberley, Alexis' mother.

"Practice empathy. I consider myself to be empathetic, and living with Alexis was a huge part of that," says Nicholas, Alexis' older brother.

"You have to become a solid shadow for your sibling. They might not fully understand how much you are putting in to be there for them. At the end of the day, each success, no matter how small, is part of you. You deserve to celebrate too. When you're diagnosed with autism, it's a diagnosis for the entire family and not just that person. It's really a test of family," says Danielle, Alexis' older sister.

"My advice is to be patient. As stressful as the role you have to play is, it's also rewarding. If you try to be patient, you get to share in success. Alexis' America's Choice Award during the Miss America competition ranks as one of the highlights of my life because I got to share in that success. Never give up on trying to help," says Amanda, Alexis' twin sister.

Events like Autism Awareness Month in April are an opportunity to celebrate the unique perspective of those living with the condition, like Alexis and her family. These types of events also offer the chance to highlight the increasing number of children identified with ASD and the urgent need to continue the search for answers.

CDC is committed to tracking the number and characteristics of children with ASD, researching what puts children at greater risk for ASD, and promoting early identification—the most powerful tool we have now for making a difference in the lives of children with ASD.

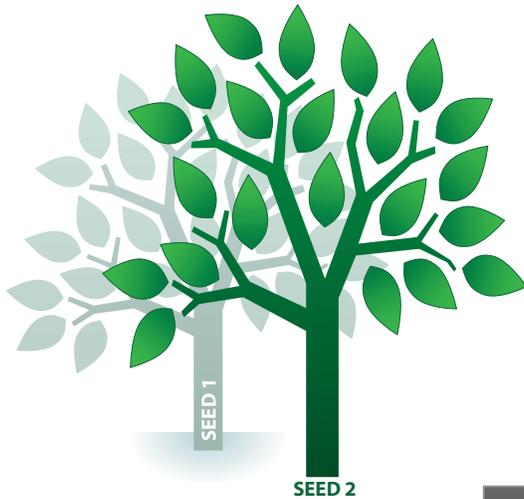
- To learn more about CDC's essential data on ASD, please visit [www.cdc.gov/ADDM](http://www.cdc.gov/ADDM)
- To download free resources for families, healthcare providers, and early childhood educators, please visit [www.cdc.gov/ActEarly](http://www.cdc.gov/ActEarly)



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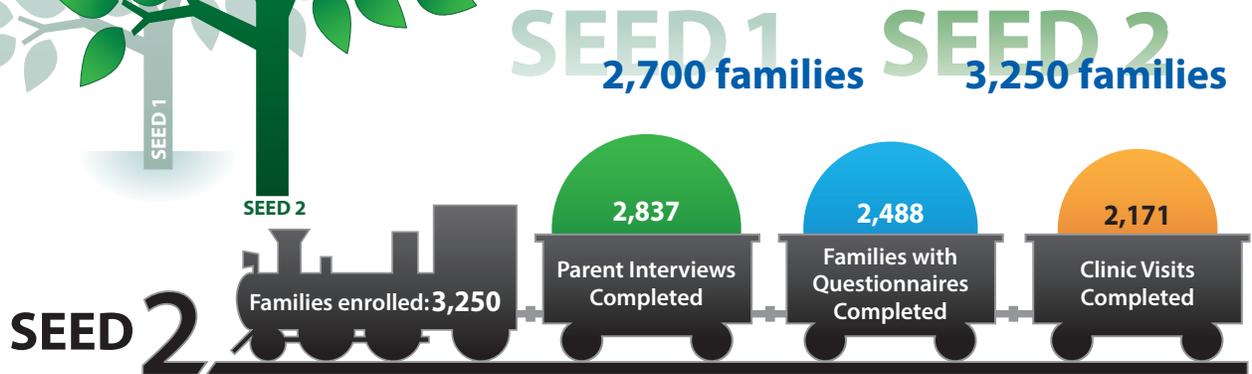
## HIGHLIGHTS OF SEED PROGRESS



### SEED 2 is growing!

The SEED 2 sites started inviting families to take part in the study in the summer of 2012. So far, 3,250 families have enrolled. Increasing the number of families enrolled in SEED allows us to get an even better picture of what puts children at risk of developing an autism spectrum disorder. Thank you SEED families!

Watch for our next newsletter to see how SEED grows or visit [www.cdc.gov/seed](http://www.cdc.gov/seed) to see all the editions of the SEED newsletter.



The graphic shows SEED 2 progress as of October 2015

**SEED involves several steps of data collection. To track the study's progress, the train graphic shows what has been collected so far:**

**Parent interview completed:** SEED parents complete an interview early in the study. This number shows how many have been done.

**Questionnaires completed:** In the middle of the study, parents complete a packet of questionnaires. This is how many have been completed.

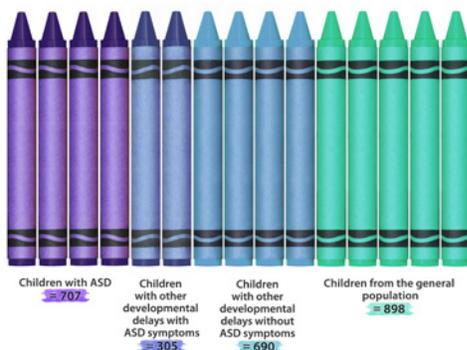
**Clinic visits completed:** The study's final step is a clinic visit. This number represents children who have been evaluated by SEED staff.

### Results Corner: Autism Symptoms among Children Enrolled in the Study to Explore Early Development

The *Journal of Autism and Developmental Disorders* has published a new analysis looking at autism spectrum disorder (ASD) symptoms among young children enrolled in [SEED](#). Researchers assessed children with ASD, children

with other developmental delays, such as language delays and physical delays, and children from the general population. Children with ASD had more problems with early learning, challenging behaviors, and interacting with others than children classified as having other developmental delays. However, some children with other developmental delays had ASD symptoms that posed significant challenges, even though the child did not meet the full criteria needed to be classified as having ASD. These results support the idea that ASD symptoms occur in children both with and without ASD and highlight the many needs of these children and their families. Because the study enrolled children with varying degrees of ASD symptoms, SEED researchers will be able to explore what puts children at risk for ASD and the different ways children may develop ASD.

#### CDC's Study to Explore Early Development



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You can read the abstract of the article [here](#). Main findings:

- Children enrolled in the study were classified into one of three major categories after an in-depth assessment: children with a primary diagnosis of ASD, children with other developmental delays, and children from the general population.
- Children with ASD had more problems with early learning, challenging behaviors, and interacting with others than children in other study groups. Children with ASD were also more likely to have parent-reported vision problems and sensory integration disorder (a condition in which a child has issues receiving and responding to sensory information, such as seeing, hearing, smelling, tasting, and touching) than children in other study groups.
- Children with other developmental delays also had problems with early learning, challenging behaviors, and social interaction, but at lower levels than among children with ASD.
- About a third of children with other developmental delays had some [symptoms of ASD](#), but did not meet the full criteria needed to be classified as having

ASD. For example, the child might avoid eye contact, have little interest in other children, or get upset by minor changes in routine, but still not fit the criteria necessary to be classified as having ASD.

- Children classified with other developmental delays with ASD symptoms had more problems with early learning, challenging behaviors, and social interaction than children classified with other developmental delays without ASD symptoms.
- Children classified with other developmental delays with ASD symptoms were more likely to have parent-reported Attention Deficit Hyperactivity Disorder (ADHD) than other children in the study.
- On average, children from the general population had early learning abilities within the typical range, and few of the general population children had behavioral or social challenges or parent-reported conditions.
- Overall, these results suggest that the groups of children enrolled in SEED have varying degrees of ASD symptoms. Identifying children with a range of ASD symptoms can help shed light on the different ways children might develop ASD.

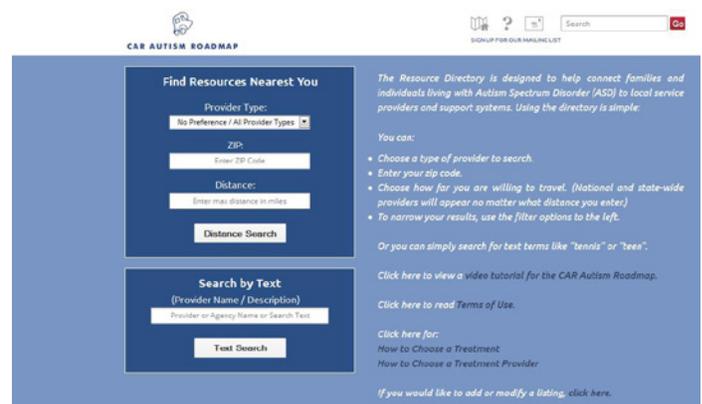
### Children's Hospital of Philadelphia Website Rounds up Autism Resources

Pennsylvania SEED's partners at the Center for Autism Research (CAR) at the Children's Hospital of Philadelphia (CHOP) have developed a comprehensive, one-stop website to provide families with accurate, up-to-date information about autism spectrum disorder (ASD). The website offers customized information based on a family's need - whether their child has just been diagnosed, or they have hit an obstacle and are looking for new ideas and resources.



For more information about Pennsylvania SEED, visit <http://www.nursing.upenn.edu/caddre/Pages/SEED.aspx> or call toll-free at 1-855-516-0371.

For more information about the Center for Autism Research, visit <http://www.centerforautismresearch.com/> or call toll-free 1-866-570-6524.



Designed by experts at CHOP's Center for Autism Research, new website offers families customizable support with up-to-date research, advice and resources.

The concept for the CAR Autism Roadmap was developed

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by Deb Dun, the outreach director at the Center for Autism Research, and Gail Stein, its head social worker. In addition, autism specialists at the Center for Autism Research reviewed all the content. Website development also involved extensive input and testing from families to ensure that it was comprehensive and easy to use. The site will be updated as new information becomes available or as resources and community information change.

In addition to providing general information about autism, the CAR Autism Roadmap also provides an abundance of information on services in the Greater Philadelphia area and beyond. The services provided

include referrals to treatment specialists, and community-based social and recreational opportunities for adolescents and pre-adolescents with autism. The Roadmap has become one of the most comprehensive collections of community-based resources available to families in the Philadelphia region.

As an online tool for clinicians, the CAR Autism Roadmap allows primary care providers, developmental pediatricians and other specialists to access information about potential autism treatments and resources. It also helps them make appropriate referrals to other specialists in the area.



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