

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.

INSIDE THIS EDITION

Interacting With Autism 1-2

Highlights of SEED Progress 2

Parent Perspective 3

**Inside the study...
Medical records 4**

By Maha Abdelaziz, CDC public health associate

A video resource about autism:

Finding quality, evidence-based information about autism online isn't always easy. But a new website provides that – using professional videos on different topics in both English and Spanish.



Interacting with Autism was designed for people with Autism Spectrum Disorder and their families, as well as teachers and healthcare workers. The site, which debuted in September 2013, was directed by Mark Jonathan Harris and Marsha Kinder. See an interview with Harris below.

How did this video project started?

We received a grant from the Agency for Healthcare Research and Quality. We thought, since most material is text-based, our goal would be to provide information in video form, making it more accessible to viewers.

Do you have a personal connection to autism?

Yes, my grandson was diagnosed at the age of 2. I saw the confusion his parents went through. How do you treat this? What is the prognosis? What do you do? It was difficult for them to find the best approach to their son's condition and so I became interested in the topic.



What inspired you and Marsha to produce this website?

There is not much information for parents on how to choose a treatment, what the best treatment is, or what the most effective way to deal with autism is. We worked on the website and decided to divide it into 3 different sections. The treatment part is the centerpiece because promoting the best evidence-based treatment is one of the goals of the Agency for Healthcare Research and Quality. That section addresses those questions like, "How do I choose a therapist and how do I determine if the therapy is working well?" These were questions my family was struggling with.

How did you get families to participate?

We had a lot of people work on this website. In understanding autism, some of our staff knew families that would like to share their experience. We also involved several people who are on the autism spectrum in making the website. One of our editors is self-identified on the spectrum. Once the word got out about what we are doing, people turned up.

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National Center on Birth Defects and Developmental Disabilities
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What difficulties did you encounter when making this website?

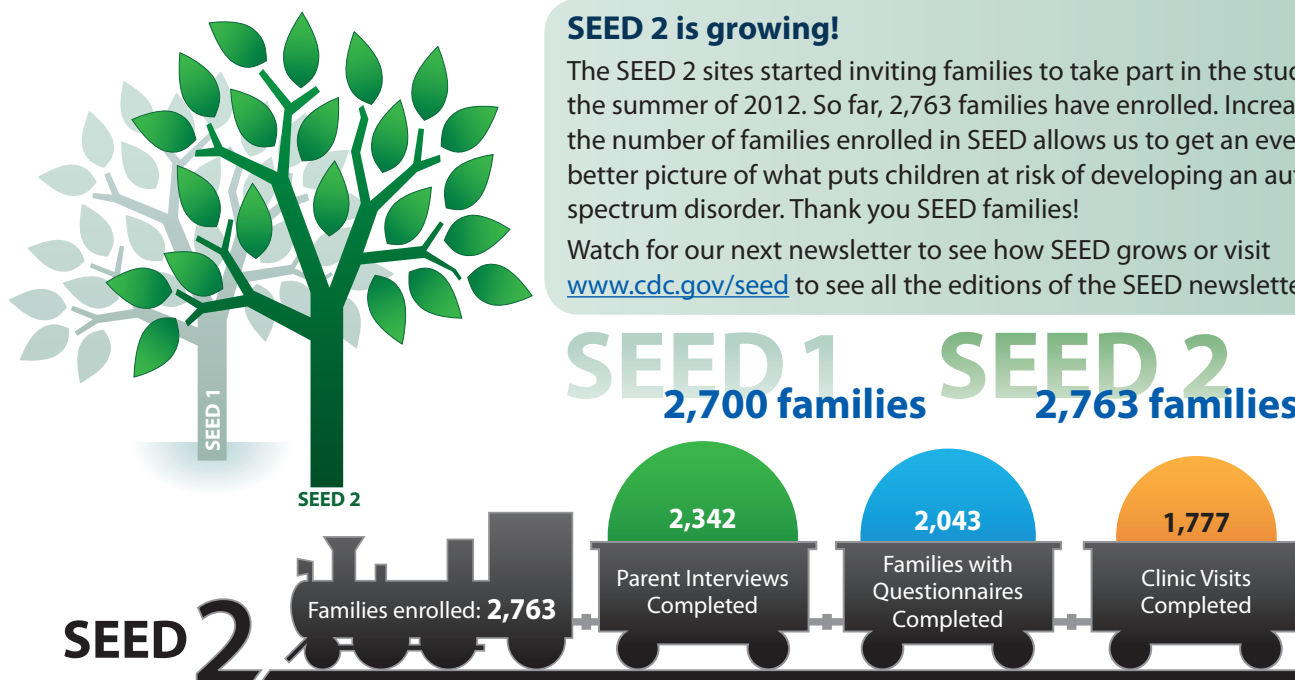
Putting together the website took time. We had a group of expert consultants who would watch our videos and make suggestions, and we would then make the changes. We also had a focus group with parents where we would show them the videos. We wanted the website to be accurate and to do a good job. It also takes time to win people's trust and to convince them that what we are doing will help others.

Are you still involved with the autism community?

Yes, we just received a second grant to promote and disseminate this website as well as study its effectiveness. We also got money to subtitle videos in Mandarin; we already have the website in English and Spanish. We are going to try to use social media to promote and update the website as much as possible. We won't be adding new videos, but rather making sure any new studies and news about autism is on the website and up to date.

www.InteractingWithAutism.com Facebook link: www.facebook.com/interactingwithautism

HIGHLIGHTS OF SEED PROGRESS



The graphic shows SEED 2 progress as of February 2015

SEED Results Corner: Using standardized diagnostic instruments to classify children with Autism Spectrum Disorder (ASD)

The *Journal of Autism and Developmental Disorders* has published a new analysis from CDC's [Study to Explore Early Development \(SEED\)](#), looking at how we classify children with Autism Spectrum Disorder (ASD). ASD is diagnosed by experienced clinicians (for example, developmental pediatricians and child psychologists) who thoroughly examine a child's behavior and development. The diagnosis may also be based on the results of standardized tools – such as observations and interviews – that offer a uniform way to define

(continued on page 3)

behaviors. This approach for diagnosing ASD, also known as clinical judgment, is considered the “gold standard” in ASD classification.

In the new published SEED analysis, researchers from CDC, Colorado, Pennsylvania and Maryland developed a method for classifying children with ASD that relies solely on standardized diagnostic tools – a parent interview and clinical observation of the child – that can be used to create well-defined groups of children to help guide treatment decisions or research designs. The researchers examined how well this method for classifying children with ASD compared with the clinical judgment “gold standard.”

The method used by the SEED researchers to classify children with ASD matches well with clinical judgment and identifies a diverse range of children with ASD. The method also provides guidance on how to resolve differences between parent report and clinical observation, and how to interpret some parent-reported ASD symptoms in young children. Lastly, the method

allows researchers to place children into different subgroups, which, in turn, can improve our ability to learn more about the similarities and differences between children with ASD. **These findings are important for researchers as they look for effective ways to classify children with ASD, in order to better understand the many causes of the disorder.**

COMMUNITY SPOTLIGHT: PARENT PERSPECTIVE



Debbie and Gabe Page

Debbie Page is a proactive parent who trusted her instincts, got interventions for her child, and has gone on to help countless other parents of children with autism.

In 2003, the Baltimore-area mother noticed that her son, Gabe, was not reaching his developmental milestones. Gabe was the second child for Debbie and her husband, Rob Page. Soon after Gabe

was born, they noticed that his development was delayed, in comparison to his older sibling. They were told not to worry and not to compare the children, and that boys typically developed slower than girls. Debbie was not content to wait and see how things would turn out. She sought help through her school system's Infants & Toddlers program to work on these developmental delays.

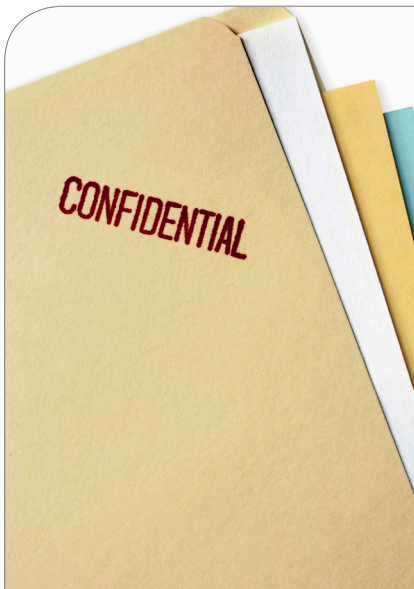
Debbie also discovered an internet site describing signs that might occur in a toddler with autism. She was surprised to see that Gabe had several of the signs. At 2 years old, he used a few words but could not use them to communicate basic wants and needs. He would not respond to his name and appeared not to be listening or paying attention to people and activities around him. "Instead of playing with his toys, he would line them up, and he flapped his hands continuously," Debbie recalled. Debbie had Gabe tested, and it was determined that he was on the autism spectrum. The psychologist who diagnosed Gabe gave Debbie and Rob a flier for a research study at Kennedy Krieger Institute (KKI), which is a partner in Maryland SEED. Gabe was accepted into the study, and the early intervention he received there, coupled with parent trainings and teacher home visits, led to great progress in a short period, Debbie recalls.

After the study, Gabe transitioned seamlessly into a Baltimore County Public School program at age 3. The preschool program was modeled after the KKI research classroom. He continued to progress and thrive. Soon after his transition to public school, Debbie began working for the county school system as a parent liaison, helping other parents navigate the autism journey and connecting them to resources. She also began volunteering on the Board of Directors for the Autism Society of Baltimore-Chesapeake (ASBC). Today, she is co-president and works hard to ensure that parents have consistent access to monthly support groups and opportunities to socialize with other families. She also chairs the Partnership Project, a collaboration between the ASBC, Baltimore County Public Schools, and Towson University. The project organizes a conference that brings together parents, professionals and individuals with autism to learn from one another.

Her advice for parents who are just beginning their autism journey is to reach out for help. "The autism community is vast and growing, and full of individuals who are willing to offer guidance and support," she said. "A diagnosis of autism can sometimes lead to a feeling of isolation. It's important to recognize that you aren't alone." Finding the time to volunteer is important to Debbie because she understands that parents are often the best resources for other parents, and the opportunity to connect with others who are experiencing similar challenges is a gift.

Gabe is now in 6th grade and thrives in his neighborhood middle school. Debbie describes Gabe as happy and confident. "Gabe speaks openly about his autism and is proud of who he is," Debbie says. "He understands that while it sometimes creates challenges and obstacles, his autism is also the special part of him that makes him the vibrant and unique individual he is. He has a belly laugh that is contagious and a sensitivity to others that is tender and genuine."

WHY DO YOU WANT TO SEE MY MEDICAL RECORDS?



A key part of the Study to Explore Early Development (SEED) is a uniform review of medical records for enrolled mothers and children. Researchers seek this information for all 2,763 enrolled families on a voluntary basis.

When a family agrees, the SEED staff systematically reviews these records for details they cannot get from the SEED interviews and surveys. Medical records also have details that mothers may have forgotten or weren't quite aware of during labor and delivery.

Research staff ask for records from all providers a mother saw for prenatal care during her enrolled child's pregnancy, the hospitals where she delivered, the hospitals that cared for the newborn, and all doctors that the child saw for routine pediatric care until age 3.

We understand that families may have concerns about privacy. Not every family is comfortable with allowing study staff to review these medical records, and SEED researchers understand that it's a family's right to decline or to limit the records that SEED staff may review. Although it's very helpful for the study to have the entire record, mothers can choose to allow access only to certain records or certain parts of records.



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