

New CDC Funding Will Expand Knowledge about Children with Autism Spectrum Disorder

Over the next 5 years, the Centers for Disease Control and Prevention (CDC) will invest more than \$27 million to carry out a new phase of the Study to Explore Early Development (SEED). SEED is one of the largest studies in the United States to help identify factors that may put children at risk for autism spectrum disorder (ASD) and other developmental disabilities. Understanding the risk factors that make a person more likely to develop an ASD will help us learn more about the causes.

SEED includes three groups of young children (2–5 years of age)—children with ASD, children with other developmental disabilities, and children in the general population. Detailed information is collected from children and their mothers about the child's development and health, the mother's pregnancies, and the family's health. Blood and saliva specimens are also collected. The three groups of study participants are compared to better understand

- Genetic and environmental factors related to having ASD,
- Health conditions among children with and without ASD, and
- The range of developmental and behavioral characteristics in children with ASD.

CDC has previously funded two phases of SEED. Over 5,000 children were enrolled in the study during these earlier phases. "We are so grateful to the thousands of families across the United States who have participated in SEED and made possible this critical work to better understand the complex risk factors for autism," said Cynthia Moore, MD, PhD, Director, Division of Congenital and Developmental Disorders, CDC's National Center on Birth Defects and Developmental Disabilities.

In the upcoming phase (SEED 3), CDC has funded five study sites to conduct the study. In addition, CDC will conduct the study as the sixth site (Georgia SEED). Altogether, the six SEED 3 sites will enroll over 2,100 children. Adding more children to SEED will mean that more kinds of studies of autism can be done. Recruitment and enrollment will begin this summer.

CDC also is funding a laboratory where blood and saliva samples will be processed and stored, and a data coordinating center to provide a centralized location to hold the study data. Finally, CDC is funding a follow-up study of children enrolled in the first phase of SEED. (See page 2)



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SEED 3 Sites

Colorado	JFK Partners, University of Colorado, Anschutz Medical Campus	www.coloradoseed.org
Georgia	Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities	https://www.cdc.gov/ncbddd/autism/seed-ga.html
Maryland	Johns Hopkins University	www.jhsph.edu/wkc/seed
Missouri	Washington University in St. Louis, Thompson Center in Columbia, Children's Mercy Kansas City	https://sdslab.wustl.edu/active-studies/SEED3/
North Carolina	University of North Carolina at Chapel Hill	www.ncseed.org
Wisconsin	University of Wisconsin-Madison	www.waisman.wisc.edu/ucedd/programs-Wisconsin-SEED.htm
SEED Data Coordinating Center	Michigan State University	

More Information:

To learn more about ASD, please visit: cdc.gov/autism
To learn more about SEED, please visit: cdc.gov/SEED



Announcing SEED Teen!

CDC is excited to be launching the Study to Explore Early Development Teen Follow-up Study or SEED Teen for short. Through SEED Teen we hope to better understand the following:

- How children with and without ASD develop as they become adolescents.
- The healthcare and social service needs of adolescents with and without ASD or other developmental disabilities.
- The needs of families caring for adolescents with and without ASD or other developmental disabilities.

Most ASD research to date has focused on young children. This research provides valuable information about maternal and child factors related to the development of ASD, the range of early ASD symptoms that children display, and the effect of early intervention programs. Now we plan to broaden our understanding of the health and development of individuals with ASD as they reach adolescence and adulthood. Currently, there is a big gap in our understanding of the health, functioning, and experiences of adolescents with ASD and other developmental disabilities. For instance, recent data from the Interagency Autism Coordinating Committee showed that less than 1% of autism research dollars were focused on lifespan issues.

SEED provides a wonderful opportunity to better understand the long-term developmental course of children. SEED includes one of the largest cohorts of children with and without ASD assembled to date. This year the children who participated in the first phase of SEED will be 10 to 14 years old. We hope to contact many of the SEED families over the next few years to ask them to participate in SEED Teen. Because of the detailed data collected during the first SEED project when children were 3 to 5 years old, we are in a unique position to examine how children's early health, developmental characteristics, and their family's health history affect their later health and development. This combination of data from both early childhood and the teenage years sets SEED Teen apart from most other studies of adolescents with ASD or other disabilities.

CDC funded the University of North Carolina at Chapel Hill (UNC) to work jointly with CDC to design SEED Teen. Both CDC and UNC will begin contacting families in 2018. The UNC team will contact and enroll families from North Carolina, Maryland, and Pennsylvania SEED sites, while CDC will contact and enroll families from Georgia SEED. We will ask parents to complete questionnaires about their child's health, development, education, and current functioning.

We are enthusiastic about this new phase of SEED and look forward to hearing from familiar families.



“SEED Teen will provide unique information about how having ASD or a developmental difference may impact the physical and psychosocial health of adolescents and their families. We also hope to learn about differences in the healthcare and social services needs of adolescents with ASD and developmental differences.”

– Dr. Julie Daniels, UNC principal investigator

“We are so very grateful to the many families who have taken part in SEED over the years. With the data we have already collected, we are actively investigating relationships between ASD and genetic and environmental factors as well as the health and development of young children with and without ASD. The findings from those studies will be published soon and will provide new insights into our understanding of ASD in children. With SEED Teen we hope to extend our study to include a focus on the long-term health and service needs of children with ASD, children with other developmental disabilities, and children who are typically developing. Ultimately, we hope that the information from both SEED and SEED Teen might contribute to improved quality of life for children and their families.”

– Dr. Laura Schieve, CDC principal investigator



Meet our new SEED sites:

Two sites join Colorado, Georgia, Maryland, and North Carolina

Missouri



Missouri SEED straddles the Interstate 70 corridor across 22 counties, connecting Washington University in St. Louis, the University of Missouri – Columbia’s Thompson Center for Autism and Neurodevelopmental Disabilities, and Children’s Mercy Kansas City. These three centers are already designated Missouri Autism

Centers, commissioned by the state’s Department of Mental Health and Office of Autism Services to provide specialty services to children and families.

Each Missouri center has unique strengths. The William Greenleaf Eliot Division of Child and Adolescent Psychiatry at Washington University in St. Louis is the primary Missouri SEED site, led by John Constantino, MD, and Robert Fitzgerald, PhD, MPH. The Division offers diagnostic and intervention services as well as medical training in child psychiatry. Washington University has partnered with the CDC’s Autism and Developmental Disabilities Monitoring Network for over a decade, and it is home to one of the 15 Eunice Kennedy Shriver Intellectual & Developmental Disabilities Research Centers.

Stephen Kanne, PhD, leads Missouri SEED at the Thompson Center, which was established in 2005 as a hub for research, education, and medical care. In addition to diagnostic evaluations, the Thompson Center provides medical, behavioral, and other health services. It also engages in research ranging from explorations of the cause of ASD, such as underlying genetics, to the discoveries of new interventions and methods of assessing core ASD symptoms.

Cy Nadler, PhD, leads Missouri SEED at Children’s Mercy Kansas City, the only pediatric medical center between St. Louis and Denver. Children’s Mercy offers diagnostic and behavior therapy services and supports community and medical education. Researchers focus on ASD screening, early social communication, and using genetic information to improve health care.

“I wish the study was already complete,” said Robin Jordan, the Autism Family Resource Specialist at Children’s Mercy Kansas City and parent of a young adult with autism. “More than anything, I am excited about how SEED can help families to help their children be healthy and successful.”

Wisconsin

The Waisman Center at the University of Wisconsin-Madison is a new site for SEED. The Waisman Center is one of the first research centers in the United States to focus solely on intellectual and developmental disabilities in children. It brings research scientists, clinicians, educators, advocates, and students together under one roof to advance knowledge while providing care for individuals with developmental disabilities and their families. The University



Center for Excellence in Developmental Disabilities located within the Waisman Center helps ensure that individuals with developmental disabilities and their families receive the care and supports they need to thrive in their communities.

The Waisman Center’s Autism and Developmental Disabilities Clinic provides the full spectrum of medical, intellectual, behavioral, and developmental assessments for children with autism and other developmental disabilities. Investigators also study typically developing children to learn about how they acquire language and many aspects of health and development across the life course.

The SEED team in Wisconsin is led by Maureen Durkin, PhD, DrPH, a Professor of Population Health Sciences at the University of Wisconsin School of Medicine and Public Health. Dr. Durkin has extensive experience in designing and conducting studies of childhood disabilities. She also has a long history of working with the community, collaborating with other scientists at multiple research sites, and working with state and local agencies to make sure that projects are successful.

Dr. Maria Stanley is a developmental-behavioral pediatrician and Associate Professor of Pediatrics at the University of Wisconsin School of Medicine and Public Health. She cares for children with autism spectrum disorder and other complex health conditions. In particular, she helps address behavioral problems, anxiety, sleep problems, and feeding disorders in children with autism. Dr. Stanley is also the medical director of the Waisman Center clinics, which places her in a unique position to partner with the SEED project.



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Highlights of SEED Progress



SEED 1

SEED 2

**TOTAL
SEED
1+2**



SEED 2 is complete!

Last year we wrapped up the second phase of the SEED study (SEED 2). We will soon combine data with SEED 1 in order to get the numbers we need to provide a better picture of what puts children at risk of developing autism spectrum disorder.

Here is a look at our numbers from SEED so far.

Watch for future newsletters to see how SEED grows when we starting enrolling families for SEED 3 and visit www.cdc.gov/seed to see all the editions of the SEED newsletter.