

SEED Study to Explore Early Development

WINTER 2012 • ISSUE 6

This is a semi-annual newsletter of the CDC-funded Study to Explore Early Development. The purpose of this newsletter is to inform the public of the study's progress.

INSIDE THIS EDITION

Data Collections Corner 2

Highlights of SEED Progress 2

Site-Specific Page – GA SEED 3

Site Snapshot: North Carolina 4

Sprouting SEEDs: Young Children's Special Interests and Repetitive Behaviors

Many young children develop strong interests in certain objects or activities, and have the need for specific routines. Often, a child will have a favorite stuffed animal that must go everywhere with him or her, or find a favorite game to play or video to watch, over and over again. Young children also are likely to develop specific routines, especially around bedtime—always needing to hear the same song, read the same book, or put on the same pajamas before they can go to sleep. At times, these “just right” behaviors can be frustrating to parents and make daily tasks much harder or take longer. For most children, these behaviors go away as the children get older and they become more flexible about their routines and other activities. However, for some children, needing to have specific items with them or doing things “just right” lasts much longer and is more intense. Sometimes children might shift to new topics or objects that take a lot of their time and attention.

When children develop unusually intense interests that take up a lot of their time or are so inflexible that they cannot be calmed if a routine is changed, it might be a sign of a problem. For example, children with an autism spectrum disorder (ASD) or another developmental disability might develop strong attachments to, or interests in, common childhood things (e.g., trains or cartoons) or to more unusual objects (such as a coat hanger, or street signs). They also are more likely to develop specific routines, such as needing to close all the doors before leaving the house or becoming overly upset if a parent drives a different way to or from school. Sometimes these behaviors might be seen with repetitive body movements, such as hand flapping or body rocking. These children also might have strong reactions to sensory input, such as loud noises, strong smells, or particular textures.

For a child to be diagnosed with autism, some evidence of specific interests; strict routines or rituals; unusual body movements or repetitive behaviors, or both, must be present. It must be noted that children with other types of disabilities might have these interests or behaviors as well, but not have the social and communication challenges seen among those with an ASD.

All children develop their own interests and have individualized behaviors—this is what makes each child unique! However, it is important to monitor these behaviors so you can decide if they have become so intense and inflexible that they are affecting social growth and other areas of development. If that happens, it might be helpful to discuss these concerns with your child's health care provider to determine if a developmental assessment is needed.



National Center on Birth Defects and Developmental Disabilities
Office of the Director



DATA COLLECTIONS CORNER: TIME TO HARVEST

We have asked our enrolled families to give us a lot of information in many different ways—from interviews and questionnaires to medical record releases, physical examinations, and in-person evaluations. Each set of information gives us a different view of the health and development of a child and of the family circumstances of the child in general. In the coming months, all of these details will be combined and the information for families of children with an ASD and families of children without any ASD will be compared. Many, many different types of comparisons will be made as we try to discover what issues are similar across all families of young children and what issues are specific to families of children with autism. We now are putting all of these details into our computer system and making sure they are being entered correctly

(known as ‘data cleaning’). When data cleaning is done, we will begin making those important comparisons and publishing the results in professional journals. Plans have been made for the first few comparisons and we hope to publish those results in the near future. SEED scientists have completed a paper for publication that describes how the study was designed, how it was carried out at all of the sites, and the key science questions that we hope to answer with the information we have collected. We also are working on results for two publications: (1) behaviors and conditions that are more common among children with autism than among children who do not have autism, and (2) how genes and a mother’s characteristics during pregnancy might work together to increase the risk for autism.

HIGHLIGHTS OF SEED PROGRESS

As SEED finishes data collection, the enrollment stage is over and the last families are finishing their study steps. We are very pleased to have reached 100% of our enrollment goal, with more than 2,700 families enrolled.

It has been hard to get all of the information we need from every family. We want to get all the questionnaires and samples from every family, but we know that some families won’t be able to complete everything. So far, 58.1% of enrolled families have completed everything we need. Thank you to those families who have completed everything!

If you have not been able to complete everything yet, we appreciate what you have done but we hope that you will be able to complete all of your items. If you are still working on any of the questionnaires or diaries, please make time to complete them and mail them back to us. If we have called you about any missing items, please call us back. It is very important that we get all of your information.

SEED started enrolling families in the winter of 2008.

The table shows SEED progress as of December 8, 2011.



Enrolled Families	3,787
Caregiver Interviews Done	3,123
Cheek Cell Samples	2,917 (families)
Questionnaire Packets	5,476

Developmental Tests Done	2,807
Physical Examinations Done	2,670
Blood Samples	2,458 (families)
Diet Diary	1,722
Stool Diary	1,720
Complete Families	2,202

GA SEED — DYSMORPHOLOGY TEAM

The Georgia (GA) SEED Dysmorphology Team does visual examinations of a child's features. Team members measure the height, weight, and head size of each family member. They also collect biological samples such as blood and cheek swabs. This information might provide clues about factors that increase the risk for autism and other developmental disabilities.

Aimee Alexander, MS, CGC, is the GA SEED project coordinator. She helps get study approvals, oversees the GA site's progress, and examines children in the study. Aimee has a background in genetic counseling. She has helped start specialty clinics that serve children with developmental disabilities. Aimee enjoys meeting the wonderful families and children of taking part in the SEED study.

Isabella Hardwick, MPH, is the project coordinator for the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network that is working on SEED. She helps with clinic and home visits with GA SEED families. Isabella thinks these visits are very important because they help us identify factors that might put children at risk for an ASD. One thing Isabella really enjoys about the visits is the frequent requests she receives from the kids for a slumber party!

Tracy Johnson, LPN, is originally from Bronx, New York. She has been a nurse for more than 15 years. Tracy has worked with special needs children for the last 7 years. She has a personal interest in GA SEED; she has a 7-year-old son with autism. Tracy has declared herself the best phlebotomist on the East Coast!

Ashleigh McCraw, PCT, is a graduate of Kennesaw State University. She has 3 years of experience working with children with developmental disabilities. Ashleigh has a strong dedication to SEED because she has three very close family members with intellectual disabilities, including her younger sister. For Ashleigh, being a part of the GA SEED study is a privilege. Getting to meet and work with exceptional families is what makes her truly happy.

Charmaine McKenzie, MPA, is the study coordinator for the GA SEED study. Charmaine examines children during the home visits with the nurses. She is the lead reviewer for the diet diaries. Charmaine also oversees many administrative tasks to ensure the GA SEED study runs smoothly. She reviews participant data files and medical records requests for accuracy and completeness.



*Back Row: Tracy Johnson, Charmaine McKenzie, Isabella Hardwick.
Front Row: Ashleigh McCraw, Julia Richardson, Aimee Alexander.*

Julia Richardson, MPH, is a graduate of Emory University. She has a background in behavioral science and health education. Julia assists the nurses on home and clinic visits and is glad to spend time with families in the GA SEED study. She could not ask for more meaningful work.



Tiffannie Smart, is the friendly voice you hear when you are making appointments for completing forms. She also schedules the home and clinic visits. Though her career has been in corporate training and development, she finds it extremely rewarding to serve GA SEED study families.

SITE SNAPSHOT: NORTH CAROLINA

The Center for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) at the University of North Carolina at Chapel Hill (UNC) works with several agencies in North Carolina to invite families to participate in the NC SEED study and to conduct the NC Autism and Developmental Disabilities Monitoring Network (ADDM) study. In addition to these two large studies, UNC is home to several other autism and child development research centers and collaborative initiatives.

CIDD: The Carolina Institute for Developmental Disabilities (<http://www.cidd.unc.edu/>) was established to provide services, education, and research on child development for all of North Carolina. However its reach extends far beyond the borders of North Carolina. The CIDD is home to several research and education initiatives, including the University Center for Excellence in Developmental Disabilities (UCEDD), the Leadership Education in Neurodevelopmental Disabilities (LEND) program, the Intellectual and Developmental Disabilities Research Center (IDDR), and the LINK team. The LINK team includes two of the SEED investigators, Drs. Becky Pretzel and Debbie Reinhartsen, and offers trainings on interdisciplinary team assessment of children who are suspected of having an ASD. Drs. Pretzel and Reinhartsen

have trained over 150 interdisciplinary teams across the state, most of whom are school personnel who provide services to children 3 through 21 years of age.

FPG: The Frank Porter Graham Child Development Institute (<http://www.fpg.unc.edu/>) aims to ensure that all children have a strong foundation for academic success and full participation as caring and responsible citizens of a multicultural world. FPG researchers focus on parent and family support; early care and education; child health and development; early identification and intervention; equity, access, and inclusion; and early childhood policy.

TEACCH: The Treatment and Education of Autistic and Communication-related handicapped Children Center (<http://teacch.com/>) is an evidence-based service, training, and research program for individuals of all ages and skill levels with an ASD. Established in the early 1970s by Eric Schopler and colleagues, the TEACCH program has worked with thousands of individuals with an ASD and their families. The administrative headquarters of the TEACCH program are at UNC, and there are nine regional TEACCH Centers around the state of North Carolina. Most clinical services from the TEACCH Centers are free to citizens of North Carolina.



**Centers for Disease
Control and Prevention**
National Center on Birth Defects
and Developmental Disabilities

CADDRE
Center for Autism and
Developmental Disabilities
Research and Epidemiology

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control
and Prevention (CDC)
National Center on Birth Defects and
Developmental Disabilities (NCBDDD)
Attn.: Charmaine McKenzie
1600 Clifton Road, MS E-86
Atlanta, GA 30333

Official Business
Penalty for Private Use, \$300

FIRST-CLASS MAIL
POSTAGE & FEES PAID
PHS/CDC
Permit No. G-284