

# SEED Study to Explore Early Development

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*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.*

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## 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.



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## 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

## The People Who Make the SEED Study Happen in California

With the first 5-year phase of the investigation drawing to a close, we want to share some reflections of the study staff with whom our families have interacted. These are the very important and skilled individuals who helped 350 families get from one point to the next to complete the study.

The first people our families 'meet' are the CADDRE recruitment and interview staff who are located in Richmond, CA at the California Department of Public Health office.



**Angela Drake** is impressed by the readiness and commitment parents demonstrate as they move through the study. "Most parents will finish the interview in one sitting", she reflects; "it's a big time commitment, and a lot of times they're taking care

of kids or making dinner at the same time. It shows dedication." Angela believes that parents' decision to participate and share their opinions comes from "a sense of duty to help other people. Even though we ask for some very personal things, like biological samples, they still want to do their part." **Suzanne Wittwer** is also struck by how much parents want to help other parents who have a child with autism. She says they participate in the study "in hopes that their information and experiences will help families in the future."

As for her own role, Suzanne says, "scientific research isn't possible without good data to analyze, and they need people like me to help collect that information. Even though I'm not a scientist, I still feel like I'm a very important part of the process."

Once a family completes the series of questionnaires and interviews, they go to the clinic for their child's evaluation with the doctor.

At the San Jose Autism Spectrum Disorder Center, **Dr. Melanie Hsu**, a clinical psychologist, describes what it means to be a part of the SEED study. "I enjoy being able to work with a range of families with many different presentations. As a clinician at the ASD Center, most of my work is with children and families where there is a diagnostic question of whether the child is presenting with an autism spectrum disorder.



"In the SEED study, I work with families of typically developing children, children with other developmental issues, as well as with children on the spectrum, and it is very refreshing and helps to keep my clinical skills honed. I love feeling that I am a part of something that is bigger than what I see inside of our offices. I feel that I am connected to a large network of skilled clinicians, most of whom I've never met or talked with, and that we're all working together to make a contribution to society, and in trying to fit together more pieces of the autism spectrum puzzle."

Like Angela and Suzanne, Dr. Hsu gives parents a lot of credit. "It continually amazes me how much families are willing to give of themselves in volunteering their time. The SEED study is extremely thorough. It can be challenging for some children, and yet we have so many participants who are remarkably cheerful throughout the entire

process. I hope that they know how much we appreciate them and how much their participation helps with understanding more about autism spectrum disorders."

But it's the kids who bring her the most enjoyment. "My last name is spelled 'Hsu' and pronounced 'shoo'. I often tell families, it's pronounced 'shoe,' like what you wear on your feet. One of my 8-year-old patients was waiting for me in the waiting room while I talked with her parents, and when I came to get her, she had written "I LOVE YOU, DR. SHOE!" in large letters on the chalkboard.

Her colleague, **Lucia Murillo**, Clinical Assessor/Research Associate, says, "It is great to be able to work with the diverse group of families that are participating in SEED, including our Spanish-speaking families. Giving this population the opportunity to be a part of such an important study really seems to give them a sense of value knowing the findings will have important implications and will benefit many, many families like their own."

Following the evaluation, the child and parents go to the laboratory with one of the Research Assistants to give a blood sample that will be used to identify biomarkers of ASD. Families are typically curious about what happens to the blood after they leave the lab. Clinic Coordinator/Research Assistant, **Victoria Heffernan** explains it this way. "First, some of the blood is spun in order to separate the red and white blood cells. We package the samples in bubble wrap or sleeves in plastic containers to prevent breakage. Some samples are packed cold with ice packs and others are packed at room temperature, and shipped overnight to Johns Hopkins University where the blood is analyzed."

"Parents are mostly worried about their child having a bad experience. We explain we are taking them to a pediatric lab that has experience with children on the spectrum. We also explain we use a numbing cream to help the child with the pain.

With this preparation, the family meets a Laboratory Assistant who has special training in collecting blood from children. **Charissa Purefoy**, a Lab Assistant in Oakland shares, "I love working with kids. As a mother, I know the apprehension that comes along with someone drawing blood from my child. Pediatric Phlebotomy is a special acquired skill that takes lots of practice and a lot of understanding. I have been fortunate to have worked in hospital settings that have allowed me to acquire the knowledge and experience of working with babies and young children and I love it!"



She explains how good it feels to support both the parents and the kids to get through the blood draw. "Parents are special people, and the interaction that I witness is so inspiring. These parents know their children. They know how to comfort them, how to negotiate at times, and how to really communicate in very positive ways. For a lot of kids it's the build up to the actual blood draw that is scary. We try to get to it quickly and we explain what is going on, in a way they can understand that helps them not to be afraid. She says kids often surprise her, "like the boy who kept thanking me saying 'I couldn't have done it with out you.'"

Charissa is proud to work with the SEED study. "I know I am a small part of the process, but if the parents and children leave here feeling good about their decision to volunteer, and that child has learned that a blood draw is not so bad, then I am happy. I feel good knowing I am apart of something that may have big impact on the future."

Many thanks to the skilled staff who have worked so successfully with the California families participating in SEED!

## 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 (IDDRC), 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.



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