

# 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.

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            |

Social skills are an important part of development for young children. Social skills in preschoolers include

- taking turns
- sharing
- asking for things
- following directions
- working with others

These skills are very important for making and keeping friends. There are many reasons to help your child to build friendships. For example, research has shown that children with good friends can feel less anxious and sad as they get older. Using good social skills to make friends can also help children feel accepted, increase their self-esteem, and be less vulnerable to bullying. While children in daycare and preschool are often in situations that teach good social skills, it is also important for parents to encourage these skills at home.

One way to help children learn how to have good social skills is to read with them about relating to others. Reading these types of books together and giving your child



the chance to talk about his or her actions and reactions in different situations may be a helpful way to teach about appropriate social skills. Focusing on situations in the books and not on the child's personal experiences might help him or her learn without causing anxiety or frustration. Good books that focus on developing good social skills include:

- *Can You Be a Friend?* by Nita Everly
- *I Can Share* by Karen Katz
- *We Are Best Friends* by Aiki
- *I Did It. I'm Sorry* by Caralyn Buehner

Vanderbilt University Center on Social and Emotional Foundations for Early Learning has a website (<http://csefel.vanderbilt.edu/resources/family.html>) with lots of family resources, including tips for teaching, supporting, and building particular social and emotional skills and tips for stopping unwanted behaviors. The website provides links to many other online resources for parents of preschool age children.

As children need to meet more people or go more places, families can also begin using Social Stories. These Stories may be helpful models for how to talk to and relate to others socially. Social Stories were developed by Carol Gray and are used in situations that children with autism or other developmental disabilities may find difficult or confusing. Social Stories describe a situation in detail and point out the important things for the child to notice, the reactions he or she might have, the actions and reactions others in the situation might have, and why. Social Stories aim to increase a child's understanding, level of comfort, and appropriate responses in particular situations. Playing out, or role modeling, a Social Story at home can lead to improved behavior in public. Two good websites with examples of Social Stories are:

<http://www.polyxo.com/socialstories/> and <http://www.thegraycenter.org/social-stories>

So talk with your child, or read with your child, about relating to others to help them grow emotionally and socially!

### Highlights of North Carolina SEED Progress

668 of 3787 (or 17.6%) of the total number of families enrolled in SEED have come from NC. We have finished enrolling families for the study. We invited 6395 families, 668 enrolled, and approximately 466 have finished their participation. A few families are still working through the study steps and a few have needed to drop out. Our North Carolina families have given a lot of time to support our research efforts and we are so thankful for them!

|  |     |
|--|-----|
| Enrolled Families                        | 668 |
| Caregiver Interview done                 | 542 |
| Cheek Swabs (# of families)              | 539 |
| Medical Records Releases (# of families) | 557 |
| Questionnaire Packet 1                   | 525 |
| Questionnaire Packet 2                   | 485 |
| Developmental Test done                  | 481 |
| Physical Exam done                       | 481 |
| Blood samples (# of families)            | 447 |
| Diet/Stool Diary                         | 349 |

\* as of December 12, 2011



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## 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.