

STUDY TO EXPLORE EARLY DEVELOPMENT

SEED



Center for Autism and Developmental Disabilities Research and Epidemiology

CADDRE

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.

SUMMER 2009

ISSUE 1

INSIDE THIS ISSUE

A Closer Look at SEED 2

SEED Highlights 2

Data Collections Corner 2

North Carolina SEED 3

Family Spotlight 3

A Snapshot of the CDC 4

SEED Meets Fertile Ground

WELCOME to the first edition of the Study to Explore Early Development (SEED) newsletter! This semiannual newsletter will provide up-to-date information on SEED for the benefit of people enrolled in SEED and those who have an interest in the study.

SEED is a multisite study being conducted by the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) Network set up and funded by the Centers for Disease Control and Prevention.

The CADDRE Network is made up of six study sites, a central laboratory, and a data coordinating center. The six CADDRE study sites are located in California, Colorado, Georgia, Maryland, North Carolina, and Pennsylvania. The CADDRE data coordinating center is in Michigan (see map).

SEED is the largest study to date of risk factors for autism spectrum disorders (ASDs) and other developmental disabilities. SEED will give researchers a better idea about

the many things that increase the chances a child will have autism or other developmental problems.

CADDRE began inviting families to participate in SEED in winter 2008. Staff at the CADDRE sites are working with partners in their respective communities to invite families to participate in SEED. Altogether about 2,700 children and their parents will be invited to take part in the study.

SEED will comprise children 2 through 5 years of age with ASDs, with other developmental disabilities, and with typical development. To take part, children will have to have been born and still be living in a CADDRE community.



Taking Root: The Science of SEED

What is SEED studying?

SEED is studying 3 areas:

Area 1: Physical and behavioral features of young children, such as how they behave and interact with others.

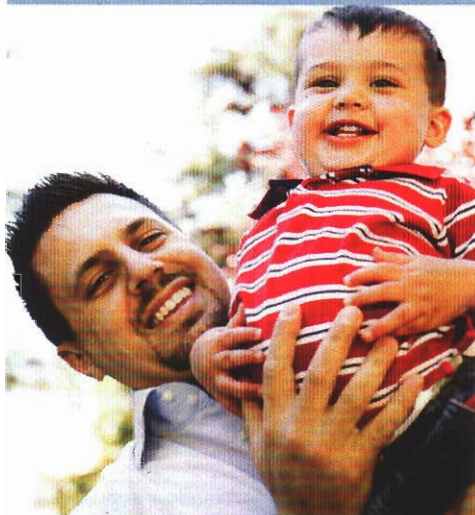
Area 2: Health-related conditions among young children, such as medical problems, sleep patterns, and diet.

Area 3: Risk factors for autism and other developmental problems, such as genes, family history, and experiences during pregnancy or early life.

What information is SEED collecting?

Parents are being asked to do the following:

- ▶ Complete questionnaires and interviews about their child's development and the family's medical history.
- ▶ Bring their child to a clinic for developmental testing and a brief physical examination.
- ▶ Give small samples of blood, hair, and cheek cells.
- ▶ Give permission to review the medical records of the mothers and children.



A Closer look at SEED

1. Should parents discuss their child's developmental test results with their primary care provider?

If parents have questions or concerns about their child's development they should talk with their child's health care provider or teacher, or both.

2. How is the information used?

All of the information collected will be used to see if something happens more or less often among the different groups of children enrolled in the study. SEED investigators are using a kind of math called "statistics" to make these comparisons. Then, they will publish papers to let the general public know of their findings.

3. When people read about SEED, will they be able to find individual information?

No, the study investigators are not looking at any one person's information, only at groups. So, study results will not be reported in a way that lets readers identify any one person. Also, study records that show names or other identifiers will be secured at the study location. Each SEED site has signed a certificate of confidentiality to add an extra level of protection for participants.

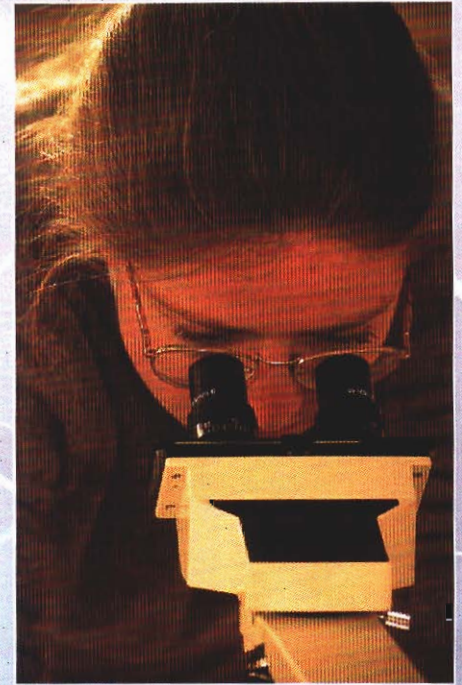
4. Are there parent support groups or advocacy groups for children with developmental disabilities or autism?

Local SEED staff may be contacted for a list of community partners who might be able to provide advice or services.

Highlights of SEED Progress

Since SEED started in winter 2008 about 1,350 families have agreed to participate. To reach the final goal of 2,700 families, SEED will continue to enroll families for about another 18 months to 2 years.

SEED staff work closely with families to complete each step of the study. The adjacent tables show how much progress the SEED families have made at each step so far. Each step is important because it adds more information for each area that SEED is studying. The more information SEED gets at each step, the more clues there will be about the many things that increase the chances a child will have autism or other developmental disabilities.



Enrolled Families	1339
Caregiver Interviews Done	984
Cheek Cell Samples	881
Questionnaire Packet 1	834
Questionnaire Packet 2	667
Developmental Tests Done	730
Physical Exams Done	681
Blood Samples	618
Hair Samples	627
Diet Diary	393
Stool Diary	392

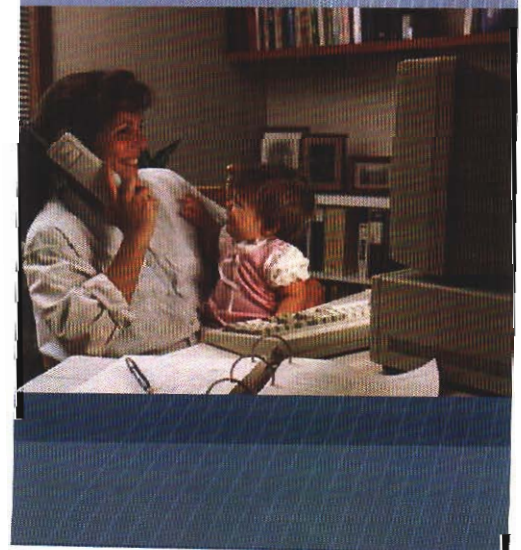
*As of June 1, 2009

Data Collections Corner: The Caregiver Interview

Participating in the caregiver interview is one of the early steps that families take in SEED. The interview is an important way to find out if experiences of the mother during pregnancy or of the child around the time of birth or in early life could lead to autism or other developmental problems. During the interview, questions will be asked about the mother's pregnancy history, family background, and lifestyle, as well as health conditions she and the child might have had and medications and treatments they might have received. Questions also will be asked about the

birth father's background, his health, and some medications he might have taken during and around the time of the pregnancy.

The interview takes about one and a half hours to complete and usually is given over the telephone using a computer-assisted telephone interview (CATI) set-up. If the primary caregiver is not the birth mother, the caregiver will be asked about his or her own background, health conditions of the child and medications and treatments the child has received.



From the Garden: How do families become SEED families?

Many families have chosen to make a difference for autism research by participating in our study. NC SEED is enrolling families in a ten-county area in central North Carolina who have a child born between September 1, 2003 and August 31, 2005 (see map). NC SEED is being conducted by researchers at The University of North Carolina at Chapel Hill. Our study team is led by Dr. Julie Daniels, associate professor of Epidemiology. NC began enrolling families in January 2008. Researchers here are very excited about the positive response from those we have invited to be in the study.

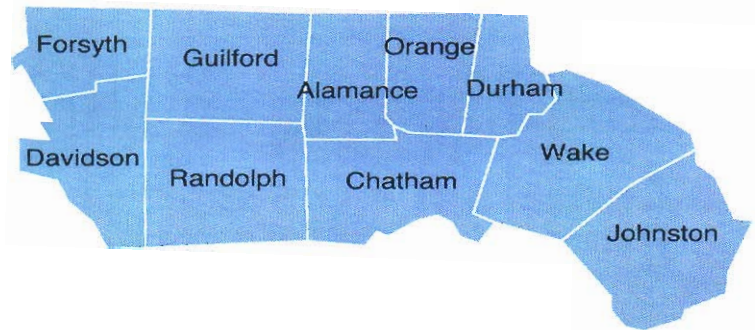
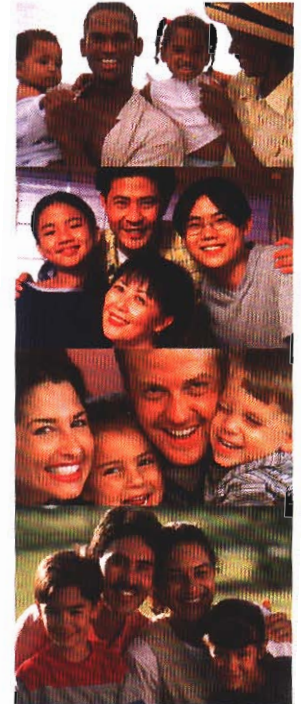
We invite families from several sources. One source is birth records for central North Carolina. Our study staff invites families who were picked by the NC State Center for Health Statistics from among the 34,000+ births that occurred in those ten counties during our selected birth years. If these invited families return an interest card giving us their phone number, we call them to describe the study, find out if they are eligible to participate, and let them decide if they want to enroll.

Another source we work with to invite families are the five Children's Developmental Services Agencies (CDSAs) who serve our ten participating counties. These CDSAs invite families who received services through their

offices. If the families tell the CDSA representative they will allow it, their contact information is sent to the study office and we call them.

The UNC Autism Research Registry is also inviting families of children who have been evaluated by their local TEAACH center and who want to participate in research related to autism. The Registry director sends study packets to families in their database whose current address is in one of our ten participating counties. If those families agree for their contact information to be sent to the study office, then we call them.

Because each of these sources invites families independently, some families get invited more than once. However, each family is only allowed to participate one time.



Highlights of North Carolina SEED Progress

So far we have invited 2290 families, 298 have enrolled, and about 100 have finished their participation. Many families are still working through the study steps and a few have dropped out. We will be enrolling until summer of 2010 and will finish collecting data by early 2011. We realize families devote a lot of time to complete so many forms and interviews. We are very grateful for help from so many North Carolina families who have given their time to support our research efforts.

Enrolled Families	
Caregiver Interview done	167
Cheek Swabs (# of families)	210
Medical Records Releases (# of families)	246
Questionnaire Packet 1	202
Questionnaire Packet 2	174
Developmental Test done	166

Physical Exam done	175
Blood samples (# of families)	137
Hair samples	167
Diet/Stool Diary	111

*As of July 9, 2009



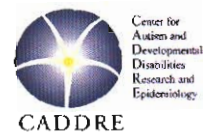
298 of 1513 (or 19.7%) of the total number of families enrolled in SEED have come from NC.



Study to Explore Early Development (SEED)

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ADDRESS SERVICE REQUESTED



The Centers for Disease Control and Prevention: A Snapshot

The Centers for Disease Control and Prevention (CDC) is a part of the U.S. Department of Health and Human Services. CDC is the primary government agency that carries out and supports public health activities in the United States.

At CDC, the National Center on Birth Defects and Developmental Disabilities (NCBDDD) works to prevent, monitor the occurrence, and find the causes of birth defects and developmental disabilities as well as finds ways to help all children reach their full potential by promoting health and well-being across their lifespan. To do this, NCBDDD uses a public health approach with three important parts: surveillance or monitoring, research, and prevention (see Figure).

Developmental Disability surveillance. Information from public health surveillance can be used:

1. To find out about the characteristics of people who have a particular health condition.
2. To find out how often a health condition occurs in a community and if that changes over time.
3. To understand better the differences in health among different racial, ethnic, and

socioeconomic groups.

4. To plan for health services.
5. To measure how well health programs are working, and to give clues about where more health research is needed.

Metropolitan Atlanta Developmental Disabilities Surveillance Monitoring Program (MADDSP)

Today, MADDSP monitors the prevalence of five developmental disabilities (cerebral palsy, hearing loss, vision loss, intellectual disability, and autism) among 8-year-old children living in the Atlanta area.

Autism and Developmental Disabilities Monitoring Network (ADDM).

To better understand the occurrence of developmental disabilities in the United States, CDC started the Autism and Developmental Disabilities Monitoring (ADDM) Network in 2000 using the MADDSP model. The ADDM Network monitors the prevalence of autism at 11 sites in the U.S. A group of these ADDM sites monitor cerebral palsy and/or intellectual disability in addition to autism.

Developmental Disabilities Research Research is the next step following surveillance. For instance, MADDSP and

Findings from research studies like SEED can help shape public health action.

ADDM can help find groups of children who are at high risk for having developmental disabilities. With this information, researchers can do studies to find specific risk factors that might increase the chances a child will have a developmental disability.

Study to Explore Early Development (SEED)

SEED is NCBDDD's main research study of autism and other developmental disabilities. Findings from research studies such as SEED can help shape public health action.

Prevention of Developmental Disabilities

NCBDDD's "Learn the Signs. Act Early" campaign is an example of a public health prevention activity for developmental disabilities. This campaign focuses on educating parents, health care providers, and educators about the early warning signs of a developmental delay, because this could be a sign of a developmental problem, even autism.

