



Study to Explore Early Development (SEED)

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**Site Snapshot:
Pennsylvania**

Pennsylvania Center for Autism and Developmental Disabilities Research and Epidemiology (PA-CADDRE)

PA-CADDRE is a joint-effort of the University of Pennsylvania, School of Nursing and The Children's Hospital of Philadelphia. The Center for Autism Research (CAR) is where the coordination and support for autism research from each center comes together.

The goals of CAR research efforts are to:

- Understand why and how children with ASD are different from each other
- How is development different for children with ASD
- What developmental and treatment needs do these children have

The research at CAR includes:

- Epidemiology
- Genetics
- Health services
- Neurobiology
- Neuroscience
- Social work
- Radiology
- Psychiatry, psychology
- Nursing
- Neuropsychology

Want to know more? Visit the Pennsylvania CAR website at <http://stokes.chop.edu/programs/car/> or call the toll-free number: **1-866-570-6524**.

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Highlights of SEED Progress

SEED started in winter 2008.

Our goal: 2,700 families combined from all the SEED study sites. We now have over 2300 families enrolled.

SEED staff works closely with families on each step of the study. Every step is important. The tables below show our progress. The more information SEED gets the more we all learn about children with Autism Spectrum Disorder (ASD) and other developmental disabilities.

Enrolled Families	2,304
Caregiver Interviews Done	1,711
Cheek Cell Samples	1,565
Questionnaire Packets	2,008
Developmental Tests Done	1,365
Physical Exams Done	1,186
Blood Samples	1,094
Diet Diary	752
Stool Diary	754

*As of February 1, 2010

STUDY TO
EXPLORE
EARLY
DEVELOPMENT

SEED



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.

WINTER 2010

ISSUE 2



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WELCOME to the second edition of the SEED Newsletter!

SEED – (*the Study to Explore Early Development*) is going very well. We have over 2300 families who have agreed to be a part of the study so far.

In this second edition of the newsletter, we will talk about what to look for in how your child develops. Of course, we will also give you more information on SEED!

Here we go...

Child Development

Growth is physical like weight gain and getting taller, but it is also how a child learns, how they play, how they talk and how they get along with other people. Every child develops at their own rate. **BUT**, there are clues to what you can expect to see at different ages (See Box on page 2). Your child may develop in a different way. Ask your child's doctor or nurse practitioner what you should expect.

The earlier that you can do something about a delay or change in your child's development, the better. Treatment should be started as early as possible to help your child develop the best he or she can. There are no blood tests to tell you if your child's development is right for his/her age. You and your health care provider should work together to watch how your child develops. If you think there is a problem with how your child is developing, **DO NOT WAIT**. Talk about it and ask questions. If there is a problem, it is very important to get your child help as soon as possible. A developmental delay (development that is slow) might make it harder for your child to learn when they start school. Recent surveys have found that in the United States 13% of children have developmental delay or behavioral problems (<http://www.cdc.gov/ncbddd/dd/ddsurv.htm>).

for links to information on child development and early actions at www.cdc.gov/actearly.

- Learn more about developmental disabilities at <http://www.cdc.gov/ncbddd/dd/default.htm>.

Your child's physical growth, emotional development and social relationships are all part of child development.

Eating the right foods, getting enough exercise, rest and sleep each day are very important for your child's health and development. Don't forget to laugh, play, read and sing with your child. Giving your child a safe home and taking the time to talk, watch TV, play and listen to music together can make a big difference in growth and development.

Another part of your child's development is their safety. Protecting your child is a part of being a parent. No parent wants to see their child harmed for any reason. Burns, falls and motor vehicle injuries, are some of the most common reasons for a child's injury or death in the United States.

- Learn more on what you can do to help protect your child. Talk with your healthcare provider and visit <http://www.cdc.gov/safekid/> for more information.

- Visit the Centers for Disease Control and Prevention (CDC) website

You are part of keeping your child safe. (See table on page 2)

<p>By the end of 7 months, many children are able to:</p> <ul style="list-style-type: none"> • turn head when name is called • smile back at another person • respond to sound with sounds • enjoy social play (such as peek-a-boo) 	<p>By the end of 1 1/2 years (18 months), many children are able to:</p> <ul style="list-style-type: none"> • do simple pretend play ("talk" on a toy phone) • point to interesting objects, look at object when you point and say "look!" • use several single words unprompted 	<p>By the end of 3 years (36 months), many children are able to:</p> <ul style="list-style-type: none"> • show affection for playmates • use 4- to 5-word sentences • imitate adults and playmates (run when other children run) • play make-believe with dolls, animals, and people ("feed" a teddy bear)
<p>By the end of 1 year (12 months), many children are able to:</p> <ul style="list-style-type: none"> • use simple gestures (waving "bye-bye") • make sounds such as "ma" and "da" • imitate actions in their play (clap when you clap) • respond when told "no" 	<p>By the end of 2 years (24 months), many children are able to:</p> <ul style="list-style-type: none"> • use 2- to 4-word phrases • follow simple instructions • become more interested in other children • point to object or picture when named 	<p>By the end of 4 years (48 months), many children are able to:</p> <ul style="list-style-type: none"> • use 5- to 6-word sentences • follow 3-step commands ("Get dressed, comb your hair, and wash your face.") • cooperate with other children

SEED Questions and Answers

1) How long is SEED? How long will my family be involved?

How long you are in SEED depends on how fast you go through each step. It usually takes 1 – 2 weeks to fill out all the forms and do the telephone interviews. After the forms are done, you will be scheduled for a clinic visit. After the clinic visit you will be asked to fill in the diet and stool diaries. Most families finish everything in about 10 hours over 4 months.

2) Do I have to send stool back to the study group?

No. The diet record and stool diary are filled in by you. We want you to write down everything your child eats for 3 days. We want you to look each time

your child has a stool and write down what it looks like. You only need to send in what you write down on the form we give you.

3) What if I don't remember my child's early development?

Answer each question as best you can with as much as you can remember. Your baby book (if you used one) might help you remember. Don't worry if you don't remember every date and every medicine. Any information is a big help.

4) I like helping with studies like this, are there other studies I can help with?

The SEED researchers or study staff located closest to you can help to answer this question.



Data Collections Corner: Diet and Stool Diaries

The diet and stool records are an important part of SEED. We are going to use them to look at how children eat and what their bowel movements are like. This is one of the last steps in SEED, but it is really important.

Food / Diet:

- We need you to write down what your child eats for 3 days.
- What do we need? – As much as you can give!
- Remember the "visualize your portion size" from the clinic visit? Use that as a guide to write down the amounts of each food. Remember to put the time for each meal and each snack.
- Write as much as you can about what your child eats. Was the cereal Kellogg or Post? Was it a cup or a bowl? Did you use 2% milk or regular milk? Did you put 1/2 cup or a full cup of milk in the bowl?

Bowel Movements: Poop – Who Knew!!!

- Yes, we want to know about your child's bowel movements. We need you to fill in the diary form we give at the clinic visit. The form tells you exactly what to write down.
- For example we would like to know
 - How many stools per day?
 - What does each stool look like?
- If you can, ask somebody else to help you explain and write down what the bowel movement looks like.

If you write the meals and the bowel movements down each day, it will not take a lot of time. There is a calendar in your packet, use it to help you remember when to start to keep track of food and bowel movements. Put it on the refrigerator or at your desk, this can be a reminder for you.

Remember, we want to know all the foods your child has eaten for 3 days, AND we want the bowel movements for 7 days.

Questions???? Call your SEED study office at **1-866-633-8003** and they will help you get this last part finished. THANKS.

From the NC Garden: What happens at a SEED developmental assessment?

The clinic visit, or developmental assessment, of the SEED study is an important activity and the point at which our staff gets to meet the children and families face to face. Not all parents and children do the same assessments at the clinic visit. Likewise, some families may participate in short interviews while others do longer interviews. Families and children are assigned to specific research groups based on a screening tool that is completed during an early phone call with families. Our clinicians and a few of the measures we use are introduced here.



Dr. Becky Pretzel is a licensed psychologist and the North Carolina site Supervising Clinician. She conducts developmental and autism-specific assessments during

the clinic visits. As Supervising Clinician, Dr Pretzel oversees the work of others who assess children for the NC study site and assures that all clinicians do the assessments the same way. An example of an autism-specific assessment that some children complete is the ADOS (Autism Diagnostic Observation Schedule). This assessment can be used to help decide whether or not a child is displaying characteristics of an autism spectrum disorder. During an ADOS evaluation, Dr Pretzel would set up different play scenarios such as a birthday party, reading a book, and completing a puzzle. She will record what the child does or does not do during the play time. She focuses on the child's social, communication and behavioral skills because these are the key issues for those with autism. Dr Pretzel was a kindergarten teacher and decided to become a psychologist because she was fascinated by the differences in early learning and behavior during early childhood.



Dr. Debbie Reinhartsen is a speech and language pathologist. An autism-specific measure that she may conduct is the ADI-R (Autism Diagnostic

Interview – Revised). Dr. Reinhartsen would interview the child's parent or caregiver and ask many specific questions about the child's early and current development and behavior. She might ask about the child's language, his social interactions and interests, and any special talents the child has. The clinicians take a lot of notes during this extended interview. This is another of the assessments that only some families complete. Dr. Reinhartsen decided to become a speech-language pathologist while living in Japan. She was interested in differences among languages, particularly the way we use certain sounds and the differences in both verbal and nonverbal communication.



Dr. Signe Naftel is a licensed psychologist. She may complete the developmental assessment that all of the children in the study receive, the Mullen Scales

of Early Learning. This assessment can help identify strengths and weaknesses in learning and thinking in young children. This scale focuses on visual reception, fine motor skills, and receptive and expressive language abilities. During a Mullen assessment, Dr Naftel would sit with a child and ask him or her to do a variety of things such as matching objects, building with blocks, drawing, cutting, and answering questions. The clinicians write down the things a child can do and cannot do during this test. Dr. Naftel enjoys working on the SEED project because it allows her to work with wonderful families and children while also helping with research in a very important area.



Dr. Jean Mankowski is a licensed psychologist. She may conduct the adaptive behavior assessment (Vineland Adaptive Behavior Scales- II) which only

some families complete. She might ask the child's caregiver a lot of questions about how the child functions in activities of daily living such as dressing, eating, moving around, and communicating. During this interview,

Highlights of NC SEED Progress

394 of 2,304 (or 17%) of the total number of families enrolled in SEED have come from NC.

So far we have invited 3321 families, 394 have enrolled, and approximately 240 have finished their participation. Many families are still working through the multiple study steps and a few have needed to drop out. All study staff realize that families devote a lot of time to complete so many forms, interviews and assessments. We deeply appreciate our North Carolina families who have given their time to support our research efforts.

Enrolled Families	394
Caregiver Interview done	269
Cheek Swabs (# of families)	307
Medical Records Releases (# of families)	307
Questionnaire Packet 1	259
Questionnaire Packet 2	240
Developmental Test done	242
Physical Exam done	250
Blood samples (# of families)	235
Diet/Stool Diary	177

*As of February 1, 2010

the clinician would take notes on the caregiver's report of whether or not the child can do each thing she asks about. Dr. Mankowski chose her career path during high school after working at a summer camp for children with disabilities. She was so amazed by the determination and strength shown by these children and their families as they fought to overcome even the most daunting of obstacles. She knew then that she wanted to work in this field assisting children and families in reaching their maximum potential.

Several other clinicians also help with many of our Mullen and Vineland assessments. Their assistance with this research study is invaluable. The group includes Allison Ratto, Margaret DeRamus, Taylor Holloway, Rachel Kitson, Barbara Lowe-Greenlee, Hannah Harwood, and Kristin Cooley.