



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

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## SITE SNAPSHOT: MARYLAND

Johns Hopkins University (JHU) and Kennedy Krieger Institute work together on SEED to invite families to participate, conduct visits, and collect data (with help from the Maryland State Department of Education and Department of Vital Statistics!). Below is a snapshot of other projects that are ongoing at JHU and Kennedy Krieger.

**EARLI:** Directed in Maryland by Dr. Daniele Fallin of Johns Hopkins, the Early Autism Risk Longitudinal Investigation – or EARLI study – is a research study funded by the National Institutes of Health to look at possible genetic and environmental risk factors for autism that may occur in pregnancy or early life. There are EARLI study sites in northern California, Philadelphia, and Maryland. The study follows moms through pregnancy and their new babies until age 3. This is the first autism-focused pregnancy study of its kind. More information is available at [www.earlistudy.org](http://www.earlistudy.org), or on the Facebook page for the Early Autism Risk Longitudinal Investigation!

**ADDM:** Autism and Developmental Disabilities Monitoring Network (ADDM), led in Maryland by Dr. Li-Ching Lee of Johns Hopkins, has surveillance sites in a dozen states. Funded by the Centers for Disease Control and Prevention, ADDM looks to understand the rate of Autism Spectrum Disorders and whether they are more common among certain populations or particular areas of the nation.

**The Early Intervention Study:** Directed by Dr. Rebecca Landa at Kennedy Krieger, this study is looking in to how a group-based early intervention affects social development in toddlers with ASD.

**The Autism Treatment Network (ATN):** Directed by Dr. Landa and Dr. Stewart Mostofsky, this study, funded by Autism Speaks, is developing a comprehensive medical care model for children with ASD. The ATN has over 200 specialists from a wide variety of areas, from 17 leading children's hospitals and academic medical centers throughout the United States and Canada.

# SEED Study to Explore Early Development

SUMMER 2011 • ISSUE 5

*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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In this edition, we share the knowledge of one of the professionals in Maryland on issues important to new parents or parents with young children!

### ASK THE EXPERT: Early Detection of Autism Spectrum Disorders

By Rebecca Landa, PhD, CCC-SLP, Director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute and Co-PI of the Maryland SEED Study

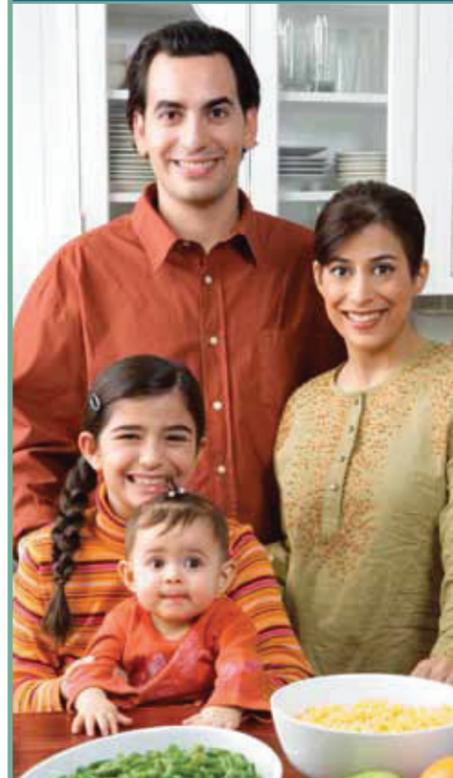
When a child's developmental delay is not apparent at birth, parents often search their memories for the earliest signs that something was not right. The idea of 'early detection' is not new, but recent research with infants and toddlers has shed light on particular signs of autism and milder social and communication delays. For one- and two-year-olds, these signs include things like:

- not responding to his or her name
- having poor eye contact with others
- rarely smiling back at someone who smiles at the child
- rarely trying to talk with others
- language delay
- lack of response to direction
- doing something over and over (repetitive play)
- strange movements (like turning the hand in circles).

When several signs are present at the same time, or if there is any loss of skills, a child should see a doctor who specializes in child development, such as a developmental pediatrician.

Early detection of autism is very important because it helps a child to receive early intervention services, such as speech therapy. Research has shown that most children with autism do not show much improvement in social development on their own during the second year of life. This means that children with autism need extra help to learn the skills that will open the doors to more successful social interaction and communication. The type of experiences that children receive in well-designed early intervention will have a great impact on how they make sense of the world around them. This is helpful to the developing brain. It is important for children with autism to have every opportunity to understand and enjoy social opportunities, and to interact as much as possible with loved ones.

At the Center for Autism and Related Disorders (CARD) at the Kennedy Krieger Institute (KKI), early intervention research is being done to better understand how to help the development of very young toddlers who are showing social and communication delays (even if they don't have a diagnosis of autism). Research is being done in parent training, parent education, and direct intervention with the children. In the parent training sessions, parents are coached in ways to help their child interact, communicate, and play with others. In the parent education classes, parents learn about child development and ways to enrich children's development, as well as share their experiences and wisdom with each other. In the direct child-intervention sessions, children are taught to share and play with other children, and to grow in their communication skills.



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Our hope is that, in the near future, most children with autism will be identified well before their third birthday. We also hope to learn how best to improve the course of development for young children with autism, and to give them a brighter future!

For more information, the Centers for Disease Control and Prevention has put together a website and free materials on what to look for in your child's development and what to do if you think there may be a problem: <http://www.cdc.gov/ncbddd/actearly/>

## SUMMER TIME HIGHLIGHTS: TRAVELING

Michelle Landrum is the mother of two sons, one who is on the ASD spectrum. Michelle, who works with SEED researchers at the Maryland site, offers these mom-tested sanity savers for traveling by plane, but will work for train or car travel too!

### ■ Know what to expect.

Before and during a trip, speak calmly with your children about what to expect. I hold on-the-spot 'family meetings' to let my kids know 'here's what's coming next.' Short stories or photographs of the plane may help too.

### ■ Try to keep yourself calm.

If I'm anxious, my kids know it. Remember: Whatever you forgot to pack, you can probably buy during your trip.

### ■ Be prepared.

Book plane trips with enough time between connecting flights. Pack snacks, juice boxes, a soft blanket, favorite toys, plus some new toys that your child hasn't yet seen. Earphones or ear buds are great to plug into a handheld videogame, MP3 player loaded with an audio book, and the plane's audio system if you're flying. If your child has very sensitive hearing, consider bringing ear protection.

### ■ Ask the Airline staff for help.

If your child has special needs, let the airline know ahead of time. You may be able to do a test-run at the airport, or to be among the first passengers to board.

## DATA COLLECTIONS CORNER: QUESTIONNAIRES

The SEED study is like a three-legged stool, supported equally by biological sampling, clinical visits, and self-reported questionnaires. If a participating family does not complete all three parts, they topple into SEED's "Incomplete" category and cannot contribute fully to our research. You might think the questionnaires we send to families' homes would be the easiest step to complete. But, in fact, they are one of the top reasons families may not be included in SEED's final results.

If you have lost your questionnaire packets, no worries! Just call your SEED contact and they'll mail you another packet. The questionnaires – covering topics such as parents' medical and work history, the child's early development, bowel

function and sleep habits – give important information that can be joined with biological samples and clinical information to help understand the causes of autism. There are no right or wrong answers to these questionnaires. Maryland SEED Project Coordinator Jamie Dahm says, "The questionnaire packets are just as important to SEED goals as the clinic visit and the phone interviews. They give the researchers a lot of information about the different aspects of ASD and perhaps tie some health or behavioral characteristics with the genetic information. We value all information collected, and ask that all parents do their best to send SEED staff any questionnaire packets they may receive".

## HIGHLIGHTS OF SEED PROGRESS

### SEED started enrolling families in the winter of 2008.

The table shows SEED progress as of June 22, 2011.



Enrolled Families	3,748
Caregiver Interviews Done	3,021
Cheek Cell Samples	2,800
Questionnaire Packets	2,370

Developmental Tests Done	2,589
Physical Examinations Done	2,402
Blood Samples	2,217
Diet Diary	1,526
Stool Diary	1,525
Complete Families	1,908

## VISUAL AIDS TO SUPPORT COMMUNICATION AND BEHAVIOR

Many of us use visual supports every day as reminders, instructions, or to make sure we do what we need to do (e.g., calendars, to-do lists, recipes). Visual supports are simply things in our environment that we see that give us additional information. Young children often need extra support to understand our expectations of them and to know what to do, how and when. In many cases, a lack of understanding by children can result in frustration and behavior problems, particularly if they have difficulty expressing their wants, needs, and emotions. The use of visual supports can reduce problem behaviors by helping children understand what is needed and communicate more effectively with others. Visual supports can range from simple gestures to objects, pictures or printed instructions. The best tool depends on the child's developmental level. Some common examples of visual supports include:

**Visual schedules:** Knowing the order of events can help children prepare for change and understand expectations for behavior throughout the day. Visual schedules can be organized left to right or top to bottom, and they can use key objects associated with the activity, photographs or pictures of the activity, or short written descriptions of the activity. It's often helpful to have the child take the object or picture to the activity, or remove the picture or written description from the list to transition between activities.



**Teaching new behaviors:** Visual schedules and strategies can also help children learn new skills. For example, a child learning to toilet independently could use a visual schedule showing each step that must be completed in order. Visual schedules can also be used to prevent problem behaviors by depicting

the steps in an activity (e.g. going to the store) and showing appropriate behaviors as steps (e.g. holding hands, only buying items on the list).

**Making choices:** Giving children the opportunity to make choices can prevent behavioral problems by providing them with a sense of control. At snack time, holding up a box of goldfish and a box of crackers can allow the child to choose by pointing to or reaching for the snack s/he wants. Playtime can be organized by providing pictures of several activities for the child to choose from, with an "X" over any choices that are not available.

**First-Then:** "First-then" sequences are clear ways of communicating expectations to young children. Stating verbally and visually that a child must first do something (e.g. finish a puzzle) to then get a reward (e.g. snack) gives the child a clear understanding of what to do. Saying, "you can't play with blocks until you finish your work," is often more difficult for young children to understand.



## HIGHLIGHTS OF NORTH CAROLINA SEED PROGRESS

668 of 3738 (or 17.9%) 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 400 have finished their participation. Many families are still working through the multiple study steps and a few have needed to drop out. We understand that families devote a lot of time to complete so many forms, interviews and assessments. Our North Carolina families have been wonderful about giving their time to support our research efforts and we are so thankful for them!

Enrolled Families	668
Caregiver Interview done	539
Cheek Swabs (# of families)	524
Medical Records Releases (# of families)	501
Questionnaire Packet 1	514
Questionnaire Packet 2	433
Developmental Test done	401
Physical Exam done	404
Blood samples (# of families)	301
Diet/Stool Diary	281

\* as of June 7, 2011