

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

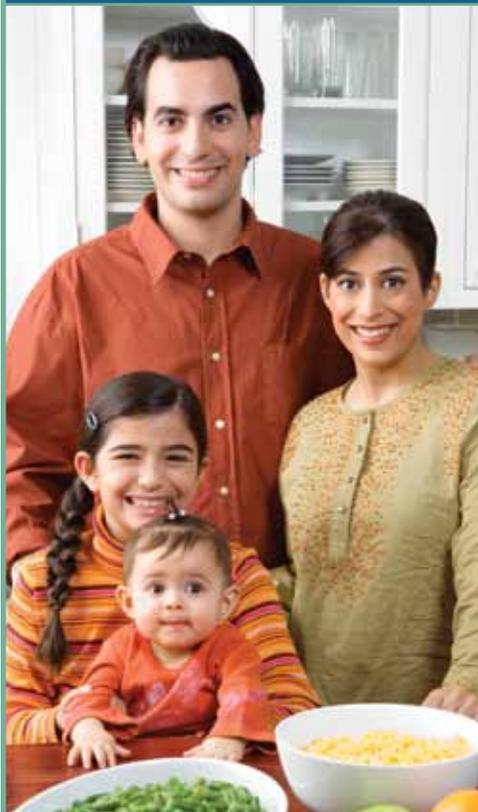
When a child's developmental delay is not apparent at birth, parents often search their memories for the earliest signs that something was not right. The idea of 'early detection' is not new, but recent research with infants and toddlers has shed light on particular signs of autism and milder social 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

GA SEED - DEVELOPMENTAL ASSESSMENT TEAM

The Developmental Assessment Team conducts parent interviews and child observations to assess a child's development. The parent interviews ask questions about the child's communication, social, behavioral development, and daily living skills. The child observations consist of asking the child to perform certain tasks and watching him or her play in order to understand early learning, communication, and social skills.



Monica DiRienzo, MA, DTR, is a new addition to the GA SEED team. Monica has spent the past three years working as a psychological clinician at the Emory Autism Center. Her research interests are early detection of autism spectrum disorders (ASD), intervention strategies, and nonverbal communication. Monica has more than five years of clinical experience working with the full spectrum of children and adults with ASDs and is well acquainted with a variety of methods and approaches used in the behavior sciences.

Nancy Caroline Hobson, PhD, is a psychologist who has been working with children for 40 years. Nancy works with the Autism and Developmental Disabilities Monitoring (ADDM) Network, the Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), the Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE), and GA SEED on many projects, including completing reviews of children's medical and school records and conducting developmental assessments of children. Before joining CDC as a contract psychologist, Nancy retired from the Hudspeth Regional Center as Director of Diagnostic Services in Brandon, Mississippi.



Lisa Wiggins, PhD, is an epidemiologist, developmental psychologist, and co-investigator for GA SEED and serves as chair of the clinical and behavioral phenotype workgroups for all SEED sites. In this role, Lisa is responsible for defining the behavioral profile of children with ASDs to better identify risk factors and causes, and oversees all clinical aspects of the study. Lisa works with an early intervention program in metropolitan Atlanta where she conducts autism evaluations and helps make diagnosis decisions and develop treatment plans. She has more than 10 years experience with psychological assessment and 9 years experience working with young children with ASDs. Lisa specializes in the early identification of children with ASDs and has published on a variety of topics, including the surveillance, epidemiology, and early detection of ASDs in young children.

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, 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.



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