

# 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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**SEED sites** are fortunate to work with talented professionals who work with children everyday. In this edition, we share the expertise of one of these professionals in Colorado on issues important to most parents—toilet training!

### Tips for Toilet Training by Susan Hepburn, Ph.D.

Toilet training can be challenging for both parents and children. Although the process is often handled in different ways for different children, here are a few general tips.

Many parents are not sure when to begin toilet training. Before you start, visit your child's doctor to make sure your child is ready and that there are no health concerns. Team up with your child's teachers and therapists so everyone can work together. Be patient, it might take a long time. As one father of a boy with developmental disabilities said, "It's a marathon, not a sprint!"

#### Step 1: *Pre-Training: Steps to take while your child is still in diapers*

- Introduce toileting words to the child. Try to use the same words in all places.
- Take one trip to the bathroom per day to practice the routine, even while the child is still wearing diapers, and then slowly add trips.
- Change the child's diaper in the bathroom, and as soon as possible, so the child doesn't get used to the feeling of being wet or soiled.
- Dispose of waste (from diaper) in the toilet in view of the child.

#### Step 2: *Prepare to go without diapers*

Talk to the people involved in your child's care and discuss the possibility of losing the diapers. The most success comes from experience without diapers. It is important to start teaching your child how to urinate in the toilet or potty during the day. After your child has successfully learned this skill, you can teach your child bowel training and nighttime training.

#### Step 3: *Identify some things that can motivate your child*

Create a list of rewards for cooperating with a toileting routine. These rewards may include special foods, drinks, or toys. Keep the toy rewards on-hand in the bathroom, but out of reach of the child. Rewards should only be given when toilet training. Check out websites for toilet training products that make the process fun.

#### Step 4: *Decide how you will handle accidents*

Do not punish or scold. Your child is learning a new, difficult skill. Either correct the child gently and change the diaper, or place the child on the toilet right away and give a reward if the child gets the tiniest bit in. Stopping an accident and getting to the bathroom is the best way of teaching the connection.

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### **Step 5: Make a schedule**

For most kids just starting out, take them to the toilet at a time when you think they might be successful. For most kids, you don't want to do too many trips, or else it becomes meaningless. Aim for no more than a few trips to the toilet per day. Try not to interrupt the child doing something they enjoy. Instead, try to build trips to the toilet when going from one activity to another, like walking outside to play.

### **Step 6: Choose your teaching methods**

Use a combination of methods, depending upon the child's learning style.

- For a child who responds to pictures, use pictures of each step of the toileting routine, including the reward.
- For an active child, use a music box or radio. Reward them for sitting for very short periods and build the time up slowly to sit through to the end of the music.
- For a really social child, show the child what to do and give a lot of praise during the routine.
- For a child who is easily distracted, try not to talk during the routine, but use physical prompts such as gently guiding them to the toilet or touching their shoulder to remind them of the activity and use musical cues to keep their attention.
- For children who like books, make a homemade book that shows pictures and portrays the toileting routine.

### **Step 7: Commit to 3 weeks of pre-training (in diapers)**

Commit to following your plan for at least 3 weeks before you change it. If possible, have the child practice in many different places.

### **Step 8: Just do it**

- Lose the diapers during the day.
- Prompt the child through a toileting routine (sitting for 1–2 minutes, always flushing, and washing hands after time is up).
- Provide a small reward for cooperating with the routine. Provide a huge reward for getting anything into the toilet.
- If possible, interrupt accidents by startling the child, "Toilet!!" and get him/her there.

### **Step 9: Communicate with your team**

Look for signs the child has to use the toilet and when anyone sees the child indicating the need to go, encourage them to say "toilet" and take the child to the bathroom.

### **Step 10: Review your progress after 3 weeks**

Add any additional rewards or ways of teaching that you think will help to learn this skill.

### **Step 11: Make adjustments and try to stay consistent**

Pick a different activity or schedule, choose a different way to motivate the child, work on diet and fiber, increase exercise, add visual cues, or make a short video of the child doing the routine well.

### **Step 12: Celebrate all successes!**

If you do not get sufficient progress within 3 months, seek guidance from a professional who does toilet training. There are always new methods to try!

*For more information on toilet training check out <http://www.aap.org/healthtopics/toiletraining.cfm>.*

## **DATA COLLECTIONS CORNER: BIOLOGIC SAMPLING**

For most people with developmental disabilities, the cause is not known. As part of this study we are asking families for three types of biologic samples: cheek cells, blood, and hair (child only). We will look at materials in your child's hair (such as metals) which may be related to child development. We will look at things like immune response and hormone levels from the blood samples. These measures will help us to understand if certain things found in your child's blood are there just because they run in the family. All the

samples are sent to a central study laboratory and repository (storage area). The samples are processed for DNA and other substances. Samples from parents as well as children will help us find genes related to developmental disabilities. Analysis of the samples will begin in the next few years. Thank you to all of the children and parents who participated in the biologic sampling!

## HIGHLIGHTS OF SEED PROGRESS

# SEED started enrolling families in the winter of 2008.

*The table shows SEED progress as of January 2011.*



|                           |       |
|---------------------------|-------|
| Enrolled Families         | 3,314 |
| Caregiver Interviews Done | 2,600 |
| Cheek Cell Samples        | 2,400 |
| Questionnaire Packets     | 2,029 |

|                            |       |
|----------------------------|-------|
| Developmental Tests Done   | 2,029 |
| Physical Examinations Done | 1,979 |
| Blood Samples              | 1,852 |
| Diet Diary                 | 1,278 |
| Stool Diary                | 1,276 |
| Complete Families          | 1,480 |

## SITE-SPECIFIC PAGE – GA SEED

### ***We have amazing families in GA SEED and every one of them has a story. Here is one from a mom with young twins with autism.***

As a busy mother of 4 children in Atlanta, including two teenagers and 5 year old twins, the joys and challenges of a child with autism can be intense at times. For example, there are times when one of the twins can get really fussy while the other one is very calm and easy going. This makes it difficult for mom to always complete household tasks and projects. Also, with dad working in Texas during the week, juggling the twins and the older children's many activities can be very challenging. "Having to take care of all the responsibilities and two children with developmental disabilities can be very overwhelming." However, mom says "one thing that helps is the older kids are very helpful with the twins; they help me with a lot of tasks around the house including watching the twins."

Despite the daily challenges, there are many joyful things they look forward to as a family. Going out of town to visit Grandma is the most exciting time for the children. This is a great experience because the children have plenty of freedom to play and be

themselves. Mom and dad are at ease because they are with family who are not judging them about their children or their parenting. It is a comforting time for everyone. The kids show great behavior and are always looking forward to the next trip. As the twins get older and their social skills improve, visits to the park are enjoyable. Watching movies, drawing, and spending quiet time with mom are also pleasant and relaxing times. This mom says her family is special because "we have learned how to adapt and we have learned how to have fun together; we find activities that work best for us in the comfort of our home."

Her advice for other families who have many of the same challenges is "sticking together as a family." She relies mostly on her extended family for help and support. The school system can also be a great resource. "It has been exceptionally helpful since the twins enrolled in school – the school was responsible for potty training the twins." The twins were having an extremely difficult time with potty training, but the school managed to get it done!

## SITE SNAPSHOT: COLORADO

JFK Partners at the University of Colorado School of Medicine and the Colorado Department of Public Health and Environment (CDPHE) work together on SEED to invite families to participate, conduct visits, and collect data. The diverse experience of both organizations makes this partnership effective. Below is a snapshot of other projects related to developmental disabilities that are on-going at CDPHE and JFK Partners.

**CDPHE:** These multi-site projects, funded through the Centers of Disease Control and Prevention, monitor the number of children with these conditions to better understand how often they occur, if they are increasing, and other factors about the condition.

- The Autism and Developmental Disabilities Monitoring (ADDM) Network
- Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet)
- Fetal Alcohol Syndrome Surveillance Network

**JFK Partners:** Awarded funding as a University Center of Excellence in Developmental Disabilities (UCEDD) and Leadership Education in Neurodevelopmental Disabilities (LEND) Program. Below are other studies on-going at JFK Partners.

- Translational Nexus Registry: a participant database and blood bank on individuals with a variety of developmental challenges.
- Funds allocated through the Combating Autism Act of 2007 to study:
  - Training methods for mental health practitioners for youth with developmental disabilities
  - Videoconferencing to provide therapy and support for families of children with developmental disabilities living in rural Colorado
  - Nutrition and sleep in children with developmental disabilities
  - Identification of autism among Latino families.
- Autism Treatment Network, funded by Autism Speaks to evaluate and improve provision of medical care.
- Evaluation of the LENA system to identify children with autism as early as possible by analyzing early speech sounds.



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