

# SEED Study to Explore Early Development

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*This is a semi-annual newsletter of the Centers for Disease Control and Prevention-funded Study to Explore Early Development (SEED). The purpose of this newsletter is to inform the public of the study's progress.*

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**Taking Care of You:** In this edition, we sat down with a professional in Pennsylvania to discuss how parents and caregivers of children with and without disabilities can take better care of their families by taking care of themselves first.

Being a parent is already a tough job, but being a parent of a child or children with special needs can sometimes leave you feeling overwhelmed. Gail Stein, LSW, is a Social Worker at the Center for Autism Research in Pennsylvania who has worked with many families who have a child with an autism spectrum disorder (ASD). Gail tells us that a very important part of coping is to remember who you are and who your family was before your child was diagnosed. Caring for your child with ASD is a small piece of who you are as a person. To maintain your outside interests, it is important to learn and use different ways to cope with stress.

### Handling Stress

It can be hard for parents to stop and take a breath. There is always something to do and someone to take care of. You might feel like you can't fit everything into one day. "To think clearly and stay on that high energy level you have got to take time for yourself," says Gail. Taking as little as **15 minutes a day to sit, breathe and focus on you** can actually save you time and energy long term! Letting your feelings out in a physical way such as going to the gym or taking a short walk can help you feel better.

### Respite: A Short Time of Rest or Relief

If possible, **ask for the help of a trusted friend, grandparent or adult** to take care of your child. If this is not available to you, **consider reaching out to local respite care providers** who will work with you to provide care for your child while you take some time for yourself. Respite care providers offer care in the home or outside of the home, and providers work with your schedule to supply you with temporary relief from caregiving. This service can give you time to maintain relationships that are important, such as catching up with a friend, spending alone time with your partner, or simply doing what you enjoy. You can contact your state's health department to find a list of licensed respite care providers in your area.

### Support Groups

It can also be stressful when family members have different opinions when it comes to caring for your family. Relationships with friends can become strained too, as they may not understand how to support you. Try to let go of these expectations. It is helpful instead to share your experiences with support groups such as:

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- **Local support groups of parents of children with special needs.** Support groups can serve many purposes, such as sharing tips on how to navigate different agencies and educational systems. Support groups can also provide an accepting environment to discuss your challenges and hopes. Some groups invite professionals to share their expertise. Support groups may even provide childcare for parents who would not be able to attend otherwise.
- **Sibling support groups** are available to siblings of children with special needs, allowing them a space to share their experiences while doing fun activities with peers.
- **Online support groups** can also be an option for parents who can't physically attend meetings, but want to share their advice and experiences with other caregivers.

### Seeking outside help

For many parents who have just received their child's diagnosis, keeping busy can be an escape from actually thinking about what that diagnosis means to their family

and child. For other parents, it can be the opposite, where they may not be able to pick up the phone to reach out to family, friends, or service providers (such as therapists or doctors). "If you are feeling overwhelmed and find yourself unable to do anything, consider seeking a counselor to discuss some of your challenges and to help you find ways to cope," says Gail. Stressful events like an Individualized Education Program (IEP) meeting can be easier if you bring someone with you to help listen to what is said and to help you remember the meeting. Either way, don't hesitate to ask for help and use resources in your community.

Taking care of yourself is a very important way to take care of your family. Making sure you have a team of people who can support you in taking care of yourself allows you more time to maintain friendships and outside interests. Take the time to reflect on how far your family has come and the small victories your child has achieved.

For more information on how to support yourself and your family, visit Autism Speaks website at <http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits>

## HIGHLIGHTS OF SEED PROGRESS



### SEED 2 is growing!

The SEED 2 sites started inviting families to take part in the study in the summer of 2012. So far, 1,052 families have enrolled. Increasing the number of families enrolled in SEED allows us to get an even better picture of what puts children at risk for developing an autism spectrum disorder. Thank you SEED families!

Look out for our next newsletter to watch SEED grow or visit [www.cdc.gov/seed](http://www.cdc.gov/seed) to see all the editions of the SEED newsletter.

SEED 1 2,700 families      SEED 2 1,052 families



The graphic shows SEED 2 progress as of June, 2013.

## COMMUNITY SPOTLIGHT: PARENT PERSPECTIVE



Pennsylvania SEED spent some time talking with Debra Dunn, Esq. who shared with us her experience in handling stress and taking care of her son Matt, who was diagnosed with Asperger Syndrome at the age of four. Deb's personal life has infused the work she

does, as she has served as the Director of Outreach and Study Recruitment at the Center for Autism Research (CAR) at The Children's Hospital of Philadelphia (CHOP). Prior to her work at CAR, Deb was an attorney for a litigation firm in Philadelphia. She continues to use her experience as an attorney to help parents understand and become effective advocates for themselves.

*SEED: What was the most stressful thing you encountered when you learned Matt was diagnosed with an autism spectrum disorder (ASD)?*

I think it was very overwhelming in the beginning. He was 4.5 years old by the time he was diagnosed. He had been evaluated as early as 2 years old and was given an Attention Deficit/ Hyperactivity Disorder diagnosis, which never seemed to fit. So in some respects it was a relief, but it was also frightening to hear the word autism and have these preconceived notions of what that meant. I think when he was first diagnosed the toughest thing for me was changing my expectations or not knowing whether I needed to change my expectations, not knowing what to do and not knowing what his outcome would look like.

*SEED: What has been most helpful for you in dealing with stress?*

For me, it was finding a network of people that understood the challenges that I was going through and the challenges that my son was going through. I found that joining a

support group and making a couple of really close friends in that group that would be my point of contact was essential to dealing with the diagnosis, dealing with the ups and downs, vetting out possible treatments, and dealing with the emotional roller coaster that comes with having a child on the autism spectrum.

*SEED: What is the greatest moment to date that you have had with your child?*

I think it's the milestones and the times where you naturally reflect on your child's accomplishments. For me, one of the things looking back was when he graduated from middle school. They have a graduation ceremony where a teacher is assigned to read something about each student, what they are good at and what they have accomplished. Listening to the teacher say such really positive things about Matt and his accomplishments was a really prideful moment for me particularly because it made me think back to a time when he had a similar graduation from preschool, which was not a very happy memory for me. It was like this natural point of reflection where I could see all that he had accomplished in a relatively short period of time. They're small moments that probably most people wouldn't think were a big deal, but to a parent of a child with ASD, they're just times when you are so proud of your child and what they can do.

*SEED: Is there any advice you would like to give our SEED parents?*

Don't let any one thing get you down too much. Celebrate all the small joys because they will more than balance out the tough times. Putting the tough times into perspective is the only way to get through them. By putting them "into perspective", I mean recognize that they will pass. There will be many joys and many positive moments. Continue to work through the tough times knowing that it will be worth it.

*SEED: Thank you Deb!*

### Highlights of North Carolina SEED II Progress

174 of 1,052 (or about 17 %) of the total number of families enrolled in SEED II have come from North Carolina.

We have invited 1395 families, 174 enrolled, and approximately 81 have finished their participation. Most families are still working through the study steps. Our North Carolina families have been so wonderful to support our research and we are so thankful for them!

|  |     |
|--|-----|
| Enrolled Families                        | 174 |
| Maternal Interview done                  | 130 |
| Medical Records Releases (# of families) | 81  |
| Questionnaire Packets                    | 126 |
| Developmental Test done                  | 81  |
| Saliva samples (# of families)           | 74  |
| Blood samples (# of families)            | 68  |

*\* as of May 31, 2013*





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

## CADDRE

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## SITE SNAPSHOT: PENNSYLVANIA



### For the first time, Pennsylvania SEED is out in the community!

Pennsylvania SEED's partners at the Center for Autism Research (CAR) at the Children's Hospital of Philadelphia consist of a team of professionals and researchers who, through research and community programs, are trying to support research on autism spectrum disorders (ASDs) and coordinate ways to share information with the public. We are grateful to collaborate with our partners and promote the efforts of SEED, as well as CAR, out in the community.

In Pennsylvania, we attended eight outreach events in 2012 and we are planning to attend at least five more in 2013. We have met many families who have expressed an interest in learning more about SEED, and people have said they have

heard of our study through many different avenues. We really enjoy going to these events to explain what SEED is all about, to meet professionals in the field of autism and most importantly, to meet families who have either been affected by ASD and/or support our efforts to learn more about it. Attending community events is our opportunity to provide all individuals, who are interested in educating children and promoting their development, the support and resources they deserve. Please enjoy some pictures of the Pennsylvania SEED team participating in various outreach events; we hope to see you out there soon!



For more information about Pennsylvania SEED, please visit us at our **new website** <http://www.nursing.upenn.edu/caddre/Pages/SEED.aspx> or call us toll-free at 1-855-516-0371.

For more information about the Center for Autism Research, please visit <http://www.centerforautismresearch.com/> or call toll-free 1-866-570-6524.