

SEED Study to Explore Early Development

SUMMER 2013 • ISSUE 9

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.

INSIDE THIS EDITION

Taking Care of You!..... 1-2

Highlights of SEED Progress..... 2

*Community Spotlight :
Parent Perspective 3*

Site Snapshot: Pennsylvania 4



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:

National Center on Birth Defects and Developmental Disabilities
Office of the Director



(continued from page 1)

- **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 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.

'The time is now!' All kinds of families united in the search for answers.



Julianna Bergener, 3, hams it up for the camera. Although their child is developing typically, Darlene and Jason Bergener are taking part in Maryland SEED as part of a control group, to help find answers about autism.

Families living with the challenges of autism or other disabilities naturally have an interest in joining the Study to Explore Early Development, Phase II. But what motivates families with typically developing children to take part in SEED II?

For Darlene Bergener of Maryland, it's simple: "The rates of autism keep rising and there are still so many questions. If there is anything we can do to find some answers and help our children, the time is now!"

Bergener knows lots of young families. She teaches pregnancy yoga, runs labor and delivery workshops for expecting couples, and is connected with several groups for new mothers. Autism, she says, is a concern for many expecting moms and parents with young children. As further motivation to join SEED II, Bergener has a relative with autism, and has seen firsthand the strain that autism can have on a child as well as a family.

When the Bergener family received a SEED II invitation packet mailed through Maryland's Department of Health and Mental Hygiene, she thought it was a natural fit for her family. Retired from her first career as a mechanical engineer, Bergener says she is very interested in scientific inquiry and research studies.

For SEED II, one of its scientific strengths is that it combines and compares data from thousands of same-age children in six states. The population-based, case-control design has three comparison groups: children who have an Autism Spectrum Disorder; those who are typically developing; and those who have a developmental delay other than autism.

In SEED II, families affected by ASDs or developmental delays can contact a site to be part of the study. But families in the typically developing control group are randomly invited to take part.

This study is good use of science to explore an issue of public concern, Darlene Bergener said.

"I'm excited to be a part of a well-designed study that can make a difference for all future generations," she said.

New Hopkins center to focus on autism, developmental disabilities.

The Johns Hopkins Bloomberg School of Public Health has established a new center to tackle the pressing public health challenges presented by autism and developmental disabilities. The **Wendy Klag Center for Autism & Developmental Disabilities** will promote research and education regarding the **origins, detection, measurement** and **prevention** of conditions that affect behavioral, socio-emotional and cognitive development, as well as evaluation of **services** and **policies** that support

affected children and families. The center will unify and expand current research and education efforts at the school, and promote partnerships with the School of Medicine and the Kennedy Krieger Institute. The center is named for the late wife of Michael Klag, the dean of the school of public health. M. Daniele Fallin, PhD, principal investigator of Maryland SEED and chairman of the school's Department of Mental Health, directs the new Wendy Klag Center.

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.



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

CADDRE

Center for Autism and
Developmental Disabilities Research
and Epidemiology

Johns Hopkins University, Bloomberg School of Public Health

615 N. Wolfe St, E6033
Baltimore MD 21205

