

# The Post CARD

*A Publication of the Center for Autism and Related Disabilities* Winter 2001

Dear Families and Friends of CARD,

Upon completing the first quarter of the 2001 - 2002 year (our ninth year of operation!), I want to thank the many families and professionals who have helped us in the past and continue to inspire us in our work here at the CARD UF/Gainesville. Whether you are newly acquainted or long familiar with CARD, we want you to know that we are grateful for the families who work collaboratively with us in so many ways--including serving on our Constituency Board, referring other families to our Center, providing us with information about professionals in our area, sharing books and materials, and giving presentations to and with CARD staff. Similarly, we appreciate the professionals in our area who help us achieve our goals by referring families to us, presenting at our training and information sessions, and helping us build teams of support for persons with autism and related disabilities.

Staff departures over the last six months leave us shorthanded at the moment. Two staff members have moved away to pursue other goals and one is on maternity leave. While we are delighted to be able to announce that Karin Marsh, who earned an M.A. at the University of Washington and has valuable teaching and early intervention experience, joined our team just this month, there's no ignoring the fact that we are currently operating with two fewer staff members than we were last year at this time. Unfortunately, the Florida Legislature's recent budget cuts prevent us from hiring additional staff for the foreseeable future. This means that, although we will continue to respond to every request we receive for our services, it is likely to take us a little longer to return your calls or schedule appointments to meet with you. All of us are traveling more and more to make up for the staff shortage. I thank you ahead of time for your patience in your contacts with us.

As we look forward to the coming winter and spring, we are excited about this year's Annual CARD Conference in Orlando, our Partnership Program with educators, our regional workshops, autism awareness activities, and evening information sessions both here at the CARD office in Gainesville and in the surrounding counties in our area. I want to thank all those who have agreed to receive our newsletters and training announcements electronically. That saves us valuable time and money. I thank you all again for your support.

Best wishes,

Greg Valcante, Ph.D.  
Director

# THE Post CARD's SOCIAL SECURITY NEWS

By Art Wallen

In this column, I will be sharing information about Federal and State Disability benefits with you. I have drawn the information from rules and regulations put out by the Social Security Administration (SSA), and I hope to present it in a way that helps you to clarify and extend your knowledge so that you will have an easier time navigating the rough waters of disability supports.

In this first installment, I describe the types of programs available to individuals with autism and related disabilities, explain the SSA's "Definition of Disability," and address some frequently asked questions regarding Social Security Disability Programs.

## **General Program Description**

The SSA has **two programs** that provide financial support based on disability.

### **⇒The Social Security Disability Insurance Program (Title 2 of the Social Security Act)**

Title 2 provides disability benefits to individuals who are "insured" under the SSA because they have contributed to the Social Security Trust Fund through paying Social Security tax on their incomes, as well as to some disabled dependents of insured individuals.

### **⇒The Supplemental Security Income (SSI) Program (Title 16 of the Social Security Act).**

Title 16 makes SSI payments to individuals (including children under 18) who are disabled AND have limited income and resources. In order to find out if you are eligible under Title 16, and what level of support you are entitled to if you are eligible, you will need to apply to a local Social Security office.

## **Definition of Disability**

The Social Security Administration defines disability in the same way for all individuals applying for disability benefits under Title 2 and for **adults** applying under Title 16. **The law defines disability as the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which have lasted or can be expected to last for a continuous period of 12 months or more.**

## **Definition of Disability for Children**

Under Title 16 (SSI), a child under the age of 18 is considered disabled if s/he has a medically determinable physical or mental impairment or combination of impairments that causes **marked and severe functional limitation**, and that can be expected to cause death or that has lasted or can be expected to last for a continuous period of 12 months or more.

## **What is a Medically Determinable Impairment?**

A medically determinable physical or mental impairment is an impairment that results from abnormalities that may be anatomical (having to do with body structure, e.g. a head injury), physiological (having to do with body function, e.g. seizures resulting from a head injury), or psychological. It must be possible to diagnose the impairment using medically accepted clinical and laboratory techniques. In order to prove that you have a medically determinable impairment, you must present medical evidence resulting from formal diagnostic procedures that take into account signs, symptoms, and laboratory findings. It is not enough for you simply to describe the symptoms to a Social Security employee yourself.

## **Who can get disability benefits under Social Security?**

Under the Social Security Disability Insurance Program (Title 2 of the Act), there are three (3) basic categories of people who can qualify for benefits on the basis of their disability:

- A disabled insured worker under 65
- A person disabled since childhood (before age 22) who is a dependent of a deceased insured parent or a parent entitled to Title 2 disability or retirement benefits.
- A disabled widow or widower age 50 - 60 if the deceased spouse was insured under Social Security.

Under Title 16, or SSI, there are two big categories where financially needy individuals can get payments because of disability:

- An adult age 18 or older who is disabled
- A child under age 18 who is disabled.

Next PostCARD: How to Navigate within the Social Security System.

## Constituent Highlight: Jason Eskin

By John Murchek

Jason Eskin, a sixteen year-old CARD constituent diagnosed with Asperger's Syndrome, first found himself fascinated by Gainesville Regional Utilities (GRU) when he was in the fifth grade. Since then, he's become an absolute authority on GRU. He raided the local library for everything he could find about GRU. GRU Senior Engineer Donny Thompson, moreover, encouraged Jason's interest by enthusiastically arranging for Jason to visit the Deerhaven Generating Station and the John R. Kelly Generating Station after Jason's father, Dr. Tom Eskin, contacted him about his son's fascination a couple years ago. But, even though he had studied GRU and visited their facilities, Jason admits that he couldn't ever have imagined that on a July morning this year, under the careful supervision of a head operator, he would be at the Deerhaven Generating Station near Alachua standing atop a ten-story boiler looking out across north Florida towards Jacksonville. He describes the experience as "awesome."



Jason Eskin with GRU's Ron Behar.

Last spring, GRU Senior Human Resource Analyst Ron Behar received an inquiry from Blake Misura, a GRU employee and father of a CARD constituent. Misura wanted to know if it would be possible to provide Jason with access to GRU given his special interest in the utilities. Behar explains, "It is curious that the request ended up on my desk. Normally, it would have gone to someone in Corporate Communications. As it happens, though, I have a second cousin named Jay who has a form of autism. So, I'm aware that when you help children focus on their special areas of interest, you can increase their overall capability." Behar also discovered that, as a GRU enthusiast, Jason had met other GRU employees both during his earlier visits to GRU facilities and when he had attended GRU's annual Electrifying Celebration, which is held in conjunction with Public Power Week and enables GRU to say thank you to the community. He realized that GRU was in a unique position as far as Jason's interests were concerned. "Jason's special interest is in GRU, and there's no other GRU!" Behar had to conclude that this was plainly a "special situation."

Not long after Behar had received the initial inquiry, a meeting took place between CARD Support Specialist and Training Coordinator Cathy Zenko, Behar and other GRU department heads to find out exactly what could be done for Jason. Zenko took along with her a ten-minute videotape she'd made of Jason talking about GRU so that the GRU staff could see how much Jason knew about the utilities and get a sense of what Jason was like. As her discussion with the GRU staff began, Zenko thought that perhaps GRU would agree to a few visits. But, once everyone had seen the tape, the GRU staff started to propose more than she had expected. "It grew beyond my wildest imagination," Zenko recalls. "It was great to be working with people willing to create opportunities for Jason."

Ultimately, Behar and Zenko, in cooperation with Jason's parents, Dr. Tom Eskin and Elizabeth Hamilton, set up a series of opportunities for Jason to tour GRU's various facilities and to "shadow" GRU employees as they went about their jobs. The goal was to give Jason not only a "behind the scenes" look at GRU's operations, but also a sense of what it is actually like to work for the utilities.

Jason was thrilled to be shown through such sites as the Walter E. Murphree Water Treatment Plant, the Kanapaha Water Reclamation Facility, GRUCom, the John R. Kelly Generating Station, and Deerhaven itself. He came away thoroughly impressed by how carefully GRU has designed its systems to "control for everything." He explains that it isn't just that there are back-up systems in case there should be any problems, but that GRU so obviously "cares about Gainesville's environment." As proof of this care, Jason offers the moment when he actually saw protected deer on the Deerhaven site.

Shadowing GRU employees allowed Jason to talk with people who were well informed about the utilities and to get a feel for a wide range of daily work experiences at GRU. Though Jason's parents have encouraged his interest in GRU, neither his family nor his schoolmates can talk with Jason about GRU at a level anywhere near approaching his expertise. Shadowing GRU employees, however, put Jason in constant contact with people who

# SHOPPING WITH YOUR AUTISTIC CHILD

By Margie Garlin

We all know how much we dread shopping with our children--and those are our typical children! Try going shopping with a child who doesn't like being around people, who has a hard time with anything loud or noisy, and who is unpredictable and demanding. I don't think I need to tell you there's nothing fun or easy about it.

When my son Bryan was little, I thought I could get away with putting him in a shopping cart when I went to the store. I would run through the store grabbing things off the shelves like a crazy woman. As I ran, I kept hoping that I could get everything I needed and get out of there before he started having a meltdown because someone just happened to look at or speak to him. Unfortunately, I was never quite fast enough. Somehow, someone would always come up to us and say something like "Oh, how cute. What's your name, honey?" That would be all it took to set Bryan off, and he would start screaming. As I stood there frantically trying to calm him down, the person would walk away saying things like "What a brat" or "You need to spank that child." Some people would just stare at me like I was this terrible person who couldn't handle her child.

When Bryan got a little older, I had this bright idea. Maybe I'd try letting him walk and just hold his hand. NOT! (as my daughter Lucy would say). Was that a BIG MISTAKE? Once, as we walked down the aisles at K-Mart, he saw something he wanted. He started pulling on my hand saying, "RUGRATS, RUGRATS." So, I held his hand a little tighter and quietly said, "No, Bryan. We need to get the dog food and leave. You don't need The RugRats right now." He looked me square in the eyes (who said this kid didn't make eye contact?), and started screaming, "HELP! HELP! SOMEBODY, HELP ME, PLEASE! LET ME GO! YOU'RE HURTING ME!" (Who said we wanted this kid to talk?) I could not believe it; I thought I was going to die. I looked over at Lucy for help and she was slowly walking away as if she wasn't even with us. Needless to say, we left everything in the cart, including the dog food, and walked (very quickly) out of the store.

Well, Bryan's nine years old now and weighs about 100 pounds, and I'm happy to say I've figured out some ways to help us do some shopping and get through it alive. Bryan and I actually enjoy shopping now. So, I thought I would share some hints with you.

✓ Plan your shopping trips with your child. Use lists or pictures to make a schedule. Unpredictability is hard for our children. Letting them know where they're going and what you're planning to buy helps them make sense of this whole shopping thing. Always remember that special place your child likes to go or thing your child likes to do and put it on your schedule. For me, putting something at the end of the schedule works well as a reward for good behavior, but remember that might not always work for everybody. For some children, making that your first stop would make the rest of the trip go more smoothly.

✓ When you take your child shopping, remember that stores are full of people and things that are loud, noisy, bright, sparkly, and unpredictable. All these things could easily upset our children. So, try to figure out what things in particular are upsetting to your child while shopping and avoid the places where your child is likely to encounter them. Also, try to find out what your child likes about shopping. Make sure it is included on every trip, and PUT IT ON THE SCHEDULE. You do want your child to enjoy shopping, because if your child is happy, then you're happy (and your hair stays on your head, not in your hands).

✓ Plan to go to the same stores most of the time. This is a good routine for your child. Also, it will allow the people who work at the store to get to know you and your child. Shopping is so much nicer when you don't have to explain a hundred times that your child has autism, that he's not a brat.

## Constituent Highlight (cont.)

shared his detailed knowledge. Ron Behar explains that the employees Jason shadowed were impressed by his "thirst for knowledge and by what he already knew." He adds, "I was a little embarrassed by the fact that I didn't know some of the things Jason knew about GRU's history." As Jason shadowed a Water Process Plant Operator, a Power Plant Operator, a System Control Operator, a Line Locator and Engineering Technicians, he also got to see and feel the concrete realities of their work lives: the places they work, the tools they use, the things they do. He was intrigued by these details. While shadowing the line locators, for example, Jason was particularly struck by the electronic device they used to locate the lines and by the way in which they used spray paint to mark the different utility lines. He came away from the experience thinking that he would really enjoy working as an operator in a wastewater plant, as a power plant mechanic, or in systems control.

GRU had a remaining surprise for Jason. He was invited to be a guest at the dedication of the John R. Kelley Generating Station repowering in May. In the course of the ceremony, GRU General Manager Mike Kurtz recognized Jason and asked him to stand and be acknowledged by the audience. Behar confesses that Kurtz's gesture "filled his heart." For his part, Jason was "glad to have had the privilege" of attending the event.

Everybody involved in Jason's experience at GRU came away with great feelings about what happened. Jaime Hope, who led Jason on his tour of the Main St. and Kanapaha Water Treatment Plants, told CARD's Cathy Zenko, "My time spent with Jason was very rewarding." And John Raimer, an Engineering Technician at the Springhill facility said, "Thank you for giving me the opportunity to have a part in his life." Jason's parents have been equally enthusiastic. His mother, Elizabeth Hamilton declares, "I cannot tell you how wonderful this experience has been for Jason and how excited he is to be part of such a great team at GRU!" Jason himself says, "Everyone at GRU was very nice. Thank you very much for giving me the opportunity!"

## STAFF HIGHLIGHT

### Margie Garlin

By John Murchek



If you have called CARD to request information or services any time during the last two years, Margie Garlin is almost certainly the first person to whom you will have spoken. And, if she was, you'll know what a perfect match she is for the job of Intake Coordinator. As the parent of a child with autism, Margie likes to think of herself as "bringing a parent's perspective to CARD and CARD's perspective to parents."

Seven and a half years ago, her son Bryan was diagnosed with autism, and became a CARD constituent. So, Margie knows what parents might be feeling when they call to ask about getting a diagnosis or gaining access to CARD services. It is more likely than not, she says, "that a parent imagines that nobody knows what it feels like" to have a child who has received an autism diagnosis, and she wants to make sure that no parent hangs up the phone "feeling as if she is the only person in the world" who has had this experience. She understands how parents can feel confused about what their first steps should be. She is happy that she can "make parents' lives easier by letting them know what things to do."

For example, she knows from experience how important it is for parents to learn what resources are available for them in the community, and how to be strong advocates for their children. She joined and helped to found local support and advocacy groups. She ran the Gainesville Autism Society for three years; founded the Family Network on Disabilities of North Central Florida along with Melinda Morrison, and worked with it for four years; sat on the ESE Advisory

Council for three years; and continues to sit on the Family Care Council, an advisory board for District 3 Developmental Services. She remembers, too, long nights studying IDEA provisions prior to attending an early IEP for Bryan so that she could represent his interests effectively.

Margie's husband Ed Garlin has also pursued the goal of raising public awareness about autism. Since 1996, he has organized an annual Autism Awareness Benefit Race and Auction. This motocross event is held in the Gainesville/Ocala area in the first week of March each year, and draws competitors from as far away as California and Canada. In 2002, the race and auction will take place on March 3rd.

Margie feels that one of the most important things she can convey to parents is that once they've gotten over their initial reactions to having a child diagnosed with autism, "they need to settle in, get relaxed with the situation." With education and advocacy and steady, consistent efforts, things can change for their children. Still, she adds, "They need to realize that things won't happen over night." Optimism and sanity: these are the qualities Margie brings to CARD and to its constituents.

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for information about:

- \*current news about autism and related disabilities
- \*support groups
- \*trainings
- and more!

# Ask Robbin about Asperger's Syndrome

By Robbin Anderson

As a CARD Support Specialist, I frequently work with constituents who have Asperger's Syndrome. I'd like to take this opportunity to answer a couple of questions I'm most often asked about the diagnosis of AS for the readers of *The Post CARD*.

Is there a test to see if my child has Asperger's Syndrome?

Currently, there is no known medical test to confirm a diagnosis of Asperger's Syndrome (sometimes also referred to as "high functioning autism"). Some researchers are trying to discover whether there is a causal relation between a frontal lobe disorder that shows up on the brain scans of people with AS and AS itself, but that is all experimental. Others are looking for a genetic component to AS, but they have not yet identified one.

AS falls under the umbrella of diagnostic criteria called Pervasive Developmental Disorders. That means that a person is born with the neurological condition of AS and does not acquire it later in life. The majority of children who receive a medical diagnosis of AS have already been previously diagnosed with some of the following impairments: Attention Deficit Hyperactivity Disorder, Tourette's, Oppositional Defiant Disorder, Obsessive Compulsive Disorder, PDD/NOS, Bi-Polar Disorder and, sometimes, Social Anxiety Disorder.

Now that my child has a diagnosis of AS, does that mean that he does not have all the other problems?

It is unusual for an individual to receive a diagnosis of AS in early childhood; instead, I see a great number of children who get the diagnosis in their teens and sometimes in young adulthood. What does this mean if the child has previously diagnosed with other disorders? In cases like this, I like to think of AS being the most current diagnosis and the one that best fits the individual at this time according to the person doing the evaluation. The previous diagnosis may point to underlying issues related to AS. Take the example of a young man previously diagnosed with ADHD and OCD, who has recently received a diagnosis of AS. Getting the AS diagnosis does not mean that he no longer has hyperactivity or obsessions; it simply means that all of his behaviors and characteristics may be better explained as features of AS rather than as separate conditions. It is a bit like not seeing the forest for the trees. Looking at the whole individual rather than the parts is useful for effective behavior and medication management.

If you have comments or would like me to address specific questions, contact CARD.

CARD UF/Gainesville, the Florida Inclusion Network, and the Florida Department of Education  
Present a Workshop on

## Literacy for All Learners

**Date:** March 15, 2002  
9:00AM-3:30PM  
(Registration begins at 8:00AM)

**Location:** Best Western at 39th Avenue and I-75  
Gainesville, FL

**Presenter:** Dr. David Koppenhaver

**Cost:** FREE!

**Pre-registration is required.**  
Please call or email Carole Polefko  
352/846-3455/cpolefko@ufbi.ufl.edu

Dr. David Koppenhaver is the Grace and Bertil Pehrson Chair of Education at Gustavus Adolphus College in St. Peter, Minnesota. He is a nationally renowned expert on literacy and individuals who have developmental disabilities, including autism and related disabilities. Through his publications and his annual Summer Seminar on Literacy in Augmentative and Alternative Communication, he has made major contributions to the field of teaching literacy skills to individuals with significant disabilities. This workshop on literacy is free and will be of interest to any team member working with students with autism and related disabilities.