

ADHD? - NOT *MY* CHILD!

Laura Watts, M. Ed.
Program Director

It is 8 a.m. on a Saturday eleven years ago. Jonathan, age six, has already rearranged his furniture, "fixed" the newly painted molding with sandpaper and a hanger, prepared his own tuna/cereal breakfast creation and raked the front yard wearing nothing but my sheer pantyhose (pulled up to his arm pits), a ski mask and a broom. We had always known Jonathan had Down syndrome, but by that time we also knew he had something more.

When Jonathan was three years old we enrolled him in a neighborhood preschool with his typical neighborhood friends, where he was expected to sit while eating, walk in a line and listen attentively to a short story. No problem — children with Down syndrome can do those things. His teacher loved him and worked patiently with him, attempting to instill a desire to be cooperative in his restless spirit. At first I was proud of his energy and enthusiasm — nothing dull and lethargic here! His teacher and I worked on behavior management techniques and saw significant improvement in the classroom, although major issues such as hair pulling (only with his teachers) still needed to be resolved. Carrying on a conversation with Jonathan

was difficult because he preferred to look in any direction except the speaker's and was easily distracted by other activity. At home he was up at 5:30 a.m. and crashing at 9:30 p.m. Naps were ancient history, and rest for his family was quickly becoming a dream. I was seeing many of the same symptoms I had seen for six years as a music therapist for children with what was then termed "hyperactivity," but *those* children had dysfunctional families and ineffective parents. *We* were a strong family and had a perfectly "normal" daughter to prove it! Besides, I did not expect him to act like other children. After all, he had Down syndrome.

By the time Jonathan was five, it became apparent that he did not act like other children with Down syndrome either. At our Down Syndrome Association meetings, I was amazed to see how the other children sat still during story time and responded well to even mild reprimands. Moms shared

stories of reading victories and dads reported their sons could actually stand in one place long enough to throw a ball in the right direction! I began leaving Jonathan home with his sister under the guise of "quality sibling time" when we attended these functions. Comparing him with typical peers had not discouraged me, but seeing his developmentally equivalent peers hurt.

Memories of my music therapy years got stronger, along with my feelings of "not *my* child!" And then, a parent's unspoken fear came to pass — Jonathan was kicked out of kindergarten! How could a small, private Montessori school refuse such an endearing child? Sure, he pulled hair (but only with his teachers), refused to participate, had taken up permanent residence in the time-out chair and seemed to be in constant motion, but wasn't he cute?

I decided to speak to his pediatrician, who by now had almost become a member of our family. She suggested we try medication and I agreed (not that I thought he really needed it) as we considered the possibility of

ADHD. The proverbial "night and day" transformation was never more accurately demonstrated than in this child. For the first time, we saw compliance in group settings and cooperation in public places. Best of all, Jonathan seemed more relaxed and content, even when off the medication. It was as though he finally understood what we were trying to tell him when we asked him to "calm down" because, for the first time, he had actually experienced it.



Jonathan "Then"



Jonathan "Now"

Jonathan is now seventeen — a teenager who loves the Beach Boys, Elvis and basketball. The road from then to now has not been without bumps and potholes. At times certain medications would seem to make him too "foggy" and withdrawn. The "rebound" time when the medication wore off often seemed like an accelerated version of his pre-med days. Sleep remained a major problem until we changed prescriptions, but he still prefers to dance while reading or doing math. Yet he now knows what it means to be in control of his behavior, and his attempts at self-correction continue to be successful, even when taking a "break" from his medication. He is a well behaved teen whom I can proudly take to stores or meetings, and he has truly become a companion at concerts and movies. Once again I am thankful for his energy and

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The Down Syndrome Center at Hope Haven Children's Clinic and Family Center is

dedicated to bringing positive, strength-based assessments and information to the families of children with Down syndrome. An interdisciplinary team evaluation consists of an education consultation, behavioral / medical evaluations, physical, occupational and speech therapy evaluations.

Families receive a comprehensive report describing their child along with home and/or school suggestions for further growth.

In-school visits are available upon request.

DSC team evaluations are funded by a matching grant from the Jessie Ball duPont Fund and other individuals and businesses.

Current funding allows families to pay only a minimal co-payment for evaluations.

For information or to schedule an appointment, contact Amanda Harrington
 (904) 346-5100 ext. 266
 AmandaH@hope-haven.org
 www.Hope-Haven.org

These evaluations are not intended to replace primary care or services already in place.

WHY DOES MY CHILD ACT LIKE THIS?

PART 2 : IS IT ADHD?

(PART 1: SENSORY ISSUES AFFECTING BEHAVIORS
APPEARED IN THE MARCH 2004 ISSUE.)

Laura Watts, M.Ed., Program Director
Joseph Pesek, MD, FAAP, Behavioral Pediatrician

At the Down Syndrome Center

we often are visited by parents who are anxious, confused or exhausted by the behavior of their child. In many instances, the parent has allowed the child more liberties than were allowed with their other children, due to a sincere belief that the child with Down syndrome does not understand his actions or the resulting consequences. These parents are often surprised and encouraged to learn that if a child can pick up a toy quickly if a bowl of ice-cream is offered and placed in view, he is also capable of following basic directions and "if, then" consequences. And, although motivation with a child with Down syndrome is often difficult, even a simple hug or exclamation of approval can serve as a strong reward if held back until requests are followed. Although these examples may be oversimplifications, the fact remains that children with Down syndrome can understand results of their actions and must be taught to take on the responsibilities of their own behaviors. However, the true difficulty lies in determining when these behaviors are aggravated by underlying causes such as trauma, divorce, significant home inconsistencies or a dual diagnosis of ADHD.

Dr. Pesek addresses the ADHD diagnosis as follows:

"The association of co-existing behavioral conditions such as oppositional defiant disorder, sleep problems, inattention and hyperactivity are found in the child with Down syndrome as they are in the general population. We have found that roughly five—ten percent of all children have ADHD and this is about the same in the Down syndrome population. Diagnosis is difficult due to some shared traits such as impulsivity, delayed processing, lack of safety perception and frustration at being

unable to communicate emo-

tions.

When considering a diagnosis of ADHD, one should take the child's cognitive age into consideration and then compare his behavior to other children of a similar developmental age. Check lists, such as the Conners' Global Index can be helpful. These rating scales, often provided by pediatricians or behavior therapists, are completed by both the parents and teachers and scored to see if there is enough concern to warrant additional investigation. A family history of ADHD in siblings or parents can also be important in diagnosing the condition.

Short term behavior management, which can benefit all children—and especially those with ADHD—and their parents, is the treatment of choice. However, a variety of medications, both stimulants and non-stimulants, can be of great assistance should further intervention be required."

With the above information in mind, it is strongly recommended that parents receiving a formal diagnosis of ADHD be referred to a behavior specialist for a management plan which may or may not be combined with appropriate medication.

For parents whose child does not indicate definite ADHD upon evaluation, regardless of significantly difficult and uncontrollable behaviors, a behavior specialist is also necessary to develop a management plan for home intervention which can also be recommended for the classroom. All caretakers, including teachers, siblings and other family members involved in the child's life, need to become committed to implementing this behavior plan whenever they are with the child. Inconsis-

tency in expectations as the child moves from setting to setting is frustrating and will accelerate the behaviors. It is also important to remember that when any new behavior plan is put in place, the child feels a threat to his ability to control and his behavior may temporarily increase far beyond what it was originally. In these situations, someone must win—and consistency, firmness and perseverance on the part of the parent will allow that parent to maintain control.

The role of the school in these situations varies according to teacher, county and state. Some schools can administer medications and include behavior specialists on the teams of children with diagnosed ADHD. Although ideally a plan that can be used at home and school should be implemented, this can be very difficult. And with a child who is a behavior concern but is not diagnosed with ADHD, a behavior specialist can usually only be used if the behaviors in the classroom are disruptive or unsafe—the specialist cannot be used to help the parents with a home plan for behaviors that are only evident when the child is with the parents. In these cases private therapists can be employed, but again, teachers may not follow through on home-based plans that may conflict with an established class-based behavior management plan.

Although consistent behavior management in any case is difficult, allowing a child to make his own rules and win his own behavior battles does him a great disservice, as it leaves him unprepared to become what he truly wants to be. Early identification of the cause of behavior problems—whether it be ADHD, sensory issues or a need for a stronger parenting plan—is the key for giving your child the same future we all desire—one filled with friends, family, safety and acceptance!

Due to the generous donation in honor of
Jackson Becker Lee

by Eric Rankin Lee and Family,
therapy equipment is available for check-out.
Contact Amanda Harrington at 346-5100 ext. 266.

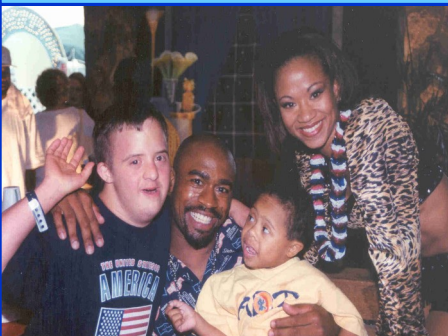
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enthusiasm!

As Program Director of the Down Syndrome Center, I have seen over 450 families from around the world. Many of these parents have stories that could be my own. They are often surprised to hear that such behavior is not necessarily "Down syndrome" but could be a personality or secondary diagnosis issue.

In a world where we now challenge our children to "fit in" with society and expect schools to welcome them in typical classrooms with open arms, it is imperative that we know our child's personality, abilities—and challenges. I hear frequently from teachers that behavior, not intellectual deficiency, is the major reason inclusion for children with Down syndrome fails. The possibility that an additional cause, such as ADHD, autism, dyslexia or other learning disability may be a contributory factor to inappropriate behavior is just now being understood. We are fortunate to be in a generation where "Down syndrome behavior" does not have to be an excuse for exclusion.

Aaron Beasley Down Syndrome Fundraiser
July 4, 2003



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Go Jags!!

Gail Beasley with Channel 4's
Tammie Filelds

MARK YOUR CALENDARS

The promise of a song...
The love of a child...
The gift of hope...

Concert and Silent Auction

Featuring

Charlotte Mabrey and Friends

Tuesday, November 30, 2004, 6 p.m.

Nathan H. Wilson Center for the Arts
At FCCJ South Campus

to benefit programs for children with Down syndrome or autism at
Hope Haven Children's Clinic and Family Center

Sponsored by **Bank of America Fidelity Information Services**
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All funds raised at this event will be matched by the
Jessie Ball duPont Fund

Contact Anne Wall at (904) 346-5100 ext. 250
for tickets or information.



Cottage By The Sea

Imports

Come Shop for Christmas!

Date: Saturday, November 6th from 4-7pm

Address: 401 S. Third St.

Phone: (904)246-8411

**20% of all purchases will be donated to the
Down Syndrome Center**

Wine & Cheese will be served.

Did you hear that **Admiral Homes** is donating a **playhouse** for our Concert and Silent Auction? Raffle tickets are \$10 each or 3 for \$25. See our homepage for more details at www.hope-haven.org and click on Silent Auction Playhouse.



Cal Fischer

Down Syndrome Association of Jacksonville

offering parent support, public awareness, social activities, and program funding.

The **DSAJ** provides **scholarships** for the following services offered at Hope Haven Children's Clinic and Family Center:

- **Social Skills Groups**
 - Age-based groups focusing on emotions and socially acceptable behaviors
 - Age and gender-based groups focusing on sexuality
- **Individualized Assisted Tutoring**
 - DSA individualized computer instruction program:
This program can be tailored to provide help with classroom studies and homework, introduce basic computer skills or supplement a child's academic instruction, depending on parent request.
 - Small group weekly computer sessions focusing on fun academic programs
- **Keyboarding Classes**
 - A tutor-based keyboarding class with OT consultation introducing basic keyboarding skills and introducing email and keyboarding skills for employment
- **Speech Therapy**
- **Summer Programs**

For more information, contact **Debbie Revels** at (904) 346-5100 ext. 286 or via email at dsa@hope-haven.org

Mark your calendars: Buddy Walk — October 9, 2004



WE NEED

YOUR HELP!

WE ARE SEEKING ITEMS

FOR THE

NOVEMBER 30, 2004

SILENT AUCTION AND

CONCERT.

SUGGESTED DONATIONS

INCLUDE:

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**CALL ANNE WALL AT
(904) 346-5100 EXT. 250
FOR INFORMATION**



Spotlight on Trey Henderson

By Sherri Henderson

When you are told you have a child with Down Syndrome, many people begin to tell you all the things that your child will not be able to do. The negatives can sometimes seem so much more overwhelming than the positives. Our son, Trey, is definitely a positive.

Trey is an active 15 year-old young man studying to get his learner's permit to drive. He participates in Scouting, community service projects, church programs and acting classes. In the summer you can find Trey most often in the backyard pool. He is the only young man in his Scout troop to have successfully completed the Mile Swim. We try to keep Trey busy and involved just as we do his two younger siblings, Cameron and Maria.

Our goal for Trey is for him to be as independent and successful as either one of our other children. In striving for this, we treat Trey just as we do the others, expecting him to do his share of the chores around the house and to maintain his grades at school. The words "I can't" are not allowed until 100 percent effort has been given. We encourage and support the same attitude with others who are around Trey. One day Trey will be on his own out there in the big wide world—we want both him and the world ready. Here is Trey's input:



Trey salutes you!

Hi. My name is Trey Henderson. I am 15 years old. I will go to Ridgeview High School. I am in the 9th grade. My favorite parts of school are gym and math. When I am at home I like to swing, play my game-boy and listen to my country CDs. I go to Mandarin Christian Church. I started scouting over 6 years ago as a Bear Cub Scout. I have made the rank of Life Scout in Boy Scout Troop 542. I am a member of the Order of the Arrow too. Now I am trying to raise money for my Eagle Project. I need a whole lot of money. I want to redo a playground to make it nicer and safer. I want to be an Eagle because some people don't think I can because I have Down Syndrome. They are wrong! Being a kid with Down Syndrome can be tough. People look at me like I'm weird or they should feel sorry for me. But I just want to tell them that I can do anything I want as long as I do my best. Never doubt yourself—

I don't.

Trey's parents are the founders and managers of Henderson Haven, which provides non-residential services in Clay and the surrounding counties in the areas of respite care, personal care assistance, non-residential support, in-home support, homemaker services, and companion services. For more information about their services, contact them at www.HendersonHaven.Org.

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