

May - June 2004

ACT UP! Actors with Disabilities Make the Stage Their Own

“Professor” Harold Hill comes to 1912 River City, Iowa with the intention of swindling the townspeople out of their money, and he ends up uniting the community through the joy of music, falling in love along the way....

I was blessed to be exploring these themes of love and joy with this exceptional community of actors. Like Harold Hill’s band, when challenged with an opportunity and given the notion that they can do it, they DO! They continuously taught me the meanings of “courage” and “ability” as we progressed from auditions to closing night. Their joy was infectious, when it spilled over the footlights and flooded the theatre.

Dina Shadwell, Director of Habima Theatre

Habima, which means stage in Hebrew, may be the only theatre company in the United States featuring actors with developmental disabilities. It began in 1990, an offshoot of Cultural Arts Fun Days in the Department of Developmental Disabilities. Now Kim Goodfriend, Director of Arts and Entertainment at the Marcus Jewish Community Center of Atlanta, produces one show a year, usually in March, in conjunction with the Blonder Family Department for Developmental Disabilities. Most of the adults in the troupe, ranging in age from 18 to 60, have graduated from high school, have jobs, and many live independently or in group homes.

Acting gives people with disabilities all the benefits that performance gives anyone - it improves speech, facilitates socialization, and raises self-confidence. Participating in putting on a show increases the actors’ abilities to meet challenges with confidence, maturity, and self-discipline. “They enjoy what everyone enjoys,” Goodfriend says, and the process is the same as it would be in any theatre. “They’re asked to come to an audition. Once you’re up on stage and have an audience, you take it from there.”

It’s Goodfriend’s dream to take Habima productions on the road to schools....”It’s been 10 years in the making,” she says about the current company, and many things would have to change to bring the show to other venues, including packable sets. “The thing that has remained the same is the dignified theatre experience,” says Goodfriend. “Any community can do it.”

excerpt from an article originally published in the Summer 2003 issue of JCC Circle, and reprinted with their permission.

Editor’s Note: *The Habima Theatre is a program of the Marcus Jewish Community Center of Atlanta’s Blonder Family Department for Developmental Disabilities. The participants of this year’s production of “The Music Man, Jr.” included many (past and present) members of the Down Syndrome Association of Atlanta including Lori Bryan, Evan Nodvin, Cynthia Outman, Katie Rouille, Evan Dewey Shaw, Michael Silver, and Megan Sydney, to name a few.*

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From the Executive Director

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Every once in awhile, we get a knock on the door to remind us what is truly important in our lives. For most people, the birth of a child is one of those events. When that child is born with Down syndrome, we can look at that day as a day that changed the course of our lives. How we view the world, how we interact with others, how we form friendships, is all changed to some degree. Our priorities are different. The things that used to be critically important become relatively insignificant. And then we go on. This is our new life. And then, something else happens to remind us what is truly important. As I was going about my life of DSAA, PTA, Sunday School, therapies, piano lessons, soccer, baseball, potty training, book club, grocery shopping, IEP meetings, I received an email that made me stop. It made me think again about my priorities. Here is a part of the email I received:

Dear Sue,

My wife and I have been receiving "DSAA Today" for awhile. On March 13, 2004, our daughter, Jessica Erin Davidson, passed away from complications of a stroke suffered on March 9. She was born October 23, 1995 with Down syndrome and hypoplastic right heart disease. She'd undergone several surgeries during her short eight years of life, but that didn't stop her from living life to the fullest every day. She was always very outgoing, saying "Hi" to everyone like she was running for mayor or something.

Jessica entered my life when she was three, and at that time she gave me her "Good Housekeeping Seal of Approval" by giving me her "passy." The most memorable time we had together was just last October on Splash Mountain at Disney World. When we got off, she was jumping up and down and wanting to ride it again. You should have seen the look on her face.

Jessica has inspired me to carry on with life as she did. She bravely fought to recover for almost 90 hours in the cardiac intensive care unit at Egleston. She didn't leave us until we told her it was okay, then less than a minute later she left this life for a perfect eternal one. She is missed by her family and all those who knew her.

Sincerely, Gregg Davidson, father of Jessica

If we accomplish nothing else today, let's not forget to enjoy our children and the gifts they bring to us. I often tell people that having my son, Steven, has made me a better person. But Gregg's email reminded me that I often forget to be that person. Like most of you, I've never met the Davidson family. But I'd like to thank Gregg for telling me about Jessica and reminding me what is truly important in life. And I'd like to thank him for letting me pass his message along to you.

- Sue Joe

Voting Information for Georgia

2004 Election Dates

July 20 - General primaries
November 2 - General election



Voter Registration Deadlines

June 21 - General primaries
October 4 - General elections

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For more information on voter registration and other voting questions, please visit:

http://www.sos.state.ga.us/elections/info/voter_info_2003.htm

Poll locator

Don't know where to go to vote? Use the Georgia Secretary of State's poll locator <http://www.sos.state.ga.us/elections/locator.htm>.

Absentee Voting

You may vote by absentee ballot if:

- You will be absent from your precinct from 7:00 a.m. until 7:00 p.m. on election day.
- You are 75 years of age or older.
- You have a physical disability which prevents you from voting in person or you are a constant caregiver of a person with a disability.
- You are an election official.
- You are observing a religious holiday which prevents you from voting in person.
- You are required to remain on duty in your precinct for the protection of life, health, or safety of the public.
- An elector may cast an absentee ballot in person at the registrar's office during the period of Monday through Friday of the week immediately preceding the date of the primary, election, or run-off primary or election without having to provide a reason.

Research Participation Opportunity

We are looking for individuals with Down syndrome between the ages of 10 and 17 to participate in two sessions, each approximately 90 minutes long. We will reimburse you for your time.

Who are we?

The Language Processes Lab is part of the Department of Communication Sciences and Disorders at the University of Georgia under the supervision of Dr. Yolanda Keller-Bell. We study speech and language development in typically developing children and children with developmental disabilities.

What will my son or daughter have to do?

We will ask your child to complete several activities such as naming and pointing to pictures, talking about school and hobbies, and playing word games. We also will assess your child's speech and language skills.

The sessions usually occur on different days, but we may be able to schedule the sessions for the same day. All sessions will be held at a time and location that is convenient for you and your child.

Why is this study important?

The ability to communicate with friends, family, and others in the community is an important part of a child's development. We want to learn about the conditions that promote and the conditions that hinder the development of speech and language.

For more information, call 706-542-3037 or email langlab@coe.uga.edu

JOB OPPORTUNITY

National non-profit seeks full-time Meeting Planner and Resource Assistant. Primary duties involve planning & implementing annual convention. Secondary duties involve resource information and referral activities. Successful applicant must have a bachelor's degree and excellent organizational skills. Salary range: \$28 - \$33K. Submit letter of interest and resume to NDSC, 1370 Center Dr., Suite 102, Atlanta, GA 30338. May request expanded job description at 770/604-9500.

THE EMORY CONNECTION

We continue to be grateful for the interest that families and physicians have shown for the Down Syndrome Clinic at Emory University. Starting this July, we will be increasing the clinic days from once to twice each month.

Dr. Sonja Rasmussen will be returning to the CDC full-time due to increasing responsibilities in her role as Associate Director for Science in the Division of Birth Defects and Developmental Disabilities. Her last clinic day will be May 21st.

We are delighted to announce a newcomer to our clinic. Dr. Jeannie Visootsak will be leading our medical team beginning in June. She will take over for Dr. Rasmussen in seeing new families. Families who have seen Dr. Rasmussen in the past will be able to see Dr. Visootsak on return visits. Dr. Visootsak's specialization in developmental pediatrics will make her a terrific resource. In addition, although our clinic is presently limited to children three years of age or younger, having Dr. Visootsak on our team will allow us to make plans for seeing older children. For you information, here is a brief biography of Dr. Visootsak.

Jeannie Visootsak, M.D. is a Developmental Pediatrician who recently joined the Department of Human Genetics at Emory University School of Medicine. She received her MD from the University of California, Los Angeles and completed her Pediatric training and a fellowship in Developmental and Behavioral Pediatrics at King/Drew Medical Center, UCLA School of Medicine. Dr. Visootsak developed an interest in the behavior and development of individuals with genetic conditions such as Down syndrome. During her fellowship, she also participated in clinical research at the Cedars-Sinai Medical Center, Medical Genetics Birth Defects Center. Her research focused on the relationships between genes, brain, and behavior and how these relate to interventional therapy. Dr. Visootsak is on the scientific advisory boards of several national genetic organizations and has published widely in the field of behavior.

Finally, those of us who work with the Down Syndrome clinic welcome feedback or suggestions from families in order to improve our clinical services. Please address your comments to our Down Syndrome Clinic coordinator, Aimee Anido, MS (404-712-8232, aanido@genetics.emory.edu) or to Sallie Freeman, PhD (404-727-0495; sfreeman@genetics.emory.edu).

I want to express a personal thank you to the Habima Theatre and Department of Developmental Disabilities at the Marcus Jewish Community Center of Atlanta. Their March production of *The Music Man, Jr.*, with a cast of individuals with special needs was phenomenal!!! New parents often come to our Down Syndrome Clinic nervous about the future for their child. What a pleasure it will be to tell them of the incredible performances of Cynthia Outman, Evan Nodvin, Megan Sydney, Katie Rouille and all of the other young people who made *The Music Man, Jr.* a roaring success.

- Sallie Freeman

Upcoming Events

May 17 - 21

Region IV Independent Living Conference to be held at the Mariott Marquis, Atlanta. Contact James Aberson at 404-651-3529.

May 27 - 30

7th National Self-Advocacy Conference - "California Dreamin': Live the Dream." Visit www.peoplefirstca.org for details

June 9 - 12

International VSA Arts Festival in Washington, DC. Visit www.vsarts.org for details

June 14

The Washington Center Fall 2004 Internship Program For Students With Disabilities in Washington, DC. Contact: JT Taransky. Phone/TTY: 800-840-8844, ext. 22. Fax: 202-336-7609 Email: jennyt@twc.edu

June 14 - 22

March and Freedom Rally - A March (or roll for wheelchair users) from Central State Hospital in Milledgeville to the Capitol Building in Atlanta. Gathering at the Capitol on June 22 to celebrate the 5th Anniversary of the Olmstead Decision. Call People First of Atlanta at 404-687-8890.

July 22 - 25

NDSS National Conference in Washington, D.C. To register contact NDSS at 800-317-7554 or download the registration form at www.ndss.org

August 20 - 22

NDSC 32nd Annual Convention in Minneapolis. To register contact NDSC at 800-232-NDSC or download registration form at www.ndsccenter.org

August 27 - 29

A Family Fun Weekend through FOCUS at Camp Twin Lakes. Call 770-234-9111 for information and reservations.

October 14

National Rehabilitation Association Annual Training Conference & Exhibit Showcase to be held in Philadelphia. Contact: 888-258-4295 or visit www.nationalrehab.organization/websitenevents for details.

October 16

Mark your calendar! This years Buddy Walk will be at Marietta Square. We need sponsors! If you have any information please contact Lauren Biggs at 770-889-3030.

A message from Patty Smith at NDSS No Child Left Behind (NCLB) Final Regulations Released

On December 9, 2003, The Department of Education released its final regulations governing the provisions in NCLB that relate to the use of alternate achievement standards for students with the most significant cognitive disabilities. These regulations are intended to encourage high academic expectations for all students with disabilities while recognizing that the performance of students with the most significant cognitive disabilities should be measured against alternate, rather than grade level, achievement standards.

States, school systems and individual schools face serious consequences if Adequate Yearly Progress (AYP) is not met. AYP is the measurement used under NCLB, based on assessment scores and other indicators, to determine whether some intervention is necessary to improve the quality of education.

Fortunately, the Department of Education resisted these pressures and has issued regulations that contain very strong language on the importance of accountability for all students, including those with the most significant cognitive disabilities.

WHAT YOU NEED TO KNOW:

Pursuant to these regulations, the IEP team at your meeting to plan the 2004-2005 school year will determine whether your child will take the regular assessment (with or without accommodations), an alternate assessment based on grade level achievement standards (e.g. mastery of grade level content measured in ways other than a standard multiple choice test) or an alternate assessment based on alternate achievement standards. An alternate achievement standard differs in complexity from the grade level achievement standard. For example, the grade level multiplication and division achievement standard may have a corresponding alternate achievement standard that expects mastery of less

symbols "x" and "=" or that $3 \times 5 = 5 \times 3$. The alternate assessment based on an alternate achievement standard is intended to be used only for students with the most significant cognitive disabilities. The States are expected to provide guidance to the school systems to help IEP teams choose the appropriate assessment and achievement standard for each student.

These regulations have the potential to motivate tremendous improvements in the education of students with disabilities. However, NDSS is concerned about the abuses that may take place in implementation, in spite of the safeguards in the regulations. It is important that parents of children with Down syndrome understand that this diagnosis should not automatically mean placement in the alternate assessment based on alternate achievement standards. This decision will depend on your child's achievement level after appropriate instruction, supports and accommodations have been made available. If your child is taking an alternate assessment on an alternate achievement standard, the assessment should be appropriately challenging. Until the Department of Education can set up an effective mechanism for monitoring the implementation of these regulations, it will be up to parents to play the role of watchdog.

BUDDING TEENAGERS

Are you the parent of a child with Down syndrome between the ages of 11 and 16? Are you interested in forming a social club for budding teenagers that would meet once a month? If you are interested in coming to the initial planning meeting on Sunday, May 16th, please contact Denise Quigley at 770-934-5788. Please also plan to bring your son or daughter.

United....We Can Make A Difference!

As I reflect on the last few months, I'm amazed by the power of advocacy and how we can impact change in our children's lives! When I had Jacob (4 years old with Down syndrome), I had no idea how my life would change for the better and how God uses us to help make this world a better place for everyone (especially our very special children!).

Many of you might know me as "Mom" to Jacob, co-founder of the SOS (Save Our Special) Kids rally, or as Co-Vice President for DSAA ...but the one "thing" that I am most proud of is advocating for children with special needs in Georgia! I've come to realize the POWER parents have in advocating for our children when we unite as one. We have been able to remove the sliding scale premium from the Katie Beckett Waiver due to our advocacy efforts and continue to fight for services through the Department of Community Health and advocate in the education arena.

I thought it might be helpful to list some of the things that I have learned in the last few months through my advocacy efforts in hopes that you might see how very important it is to get involved for our children's sake.

- Know your legislators. You can find them by going to www.vote-smart.org. They can help fight for change in legislation, as well as help you get in contact with other organizations.
- When you do write/fax your advocacy letters, include pictures of your child(ren). This makes the letter personal. I have found that I get more responses that way.

- Get involved with the Governor's Council on Developmental Disabilities (www.gcdd.org) and the Atlanta Alliance on Developmental Disabilities (www.aadd.org). They have a lot of resources and can guide you in your advocacy efforts.

- Networking is key to success in your personal and business life and advocacy is no different. The more people you know the better!

- Join advocacy internet groups for updated information.

- Don't be intimidated by contacting your legislator and/or the Governor's office, if it is something you believe in!

Most important, take an active interest in what is going on with your child and **KNOW THAT YOU CAN MAKE A DIFFERENCE!**

Heidi J. Moore
(Mother to Jacob –4 years old with Down syndrome and Jared – 2 years old)

If you wish to have additional informational e-mails distributed from time to time on advocacy issues, please contact Heidi J. Moore at heidijmoore@comcast.net and be asked to be placed on her mailing list.

“Disruptive” behaviors during the school day? Try making use of a Behavior Intervention Plan

by Robert Raubach, Attorney with the Georgia Advocacy Office

Parents and advocates become increasingly concerned about the challenges of students whose disability affects their behavior. If a disability results in behavior that violates a school code of conduct, then a student with a disability might be suspended or even referred to a court for his disability. Students who are frequently suspended get behind in class and become discouraged and disillusioned. Referral to juvenile or criminal court brings an array of new problems for parent and student alike.

Students with disabilities affecting behavior should have a behavior intervention plan (bip) as part of an IEP or 504 Plan. The Georgia Advocacy Office (GAO) has developed an Addendum to a behavior intervention plan designed to limit both the loss of instructional time through suspensions and unnecessary referrals to juvenile or criminal court. If your student has a disability that might typically result in behavior that could be said to violate school rules or to constitute a crime, ask that the addendum be part of the plan when your committee meets. If the committee refuses to make the addendum part of the plan, ask that the committee put its reasons in writing. If an incident arises or if, based on the student's recent behavior and the school's response, you are fairly certain that an incident will certainly soon take place, please contact a trained advocate, an attorney, or the GAO to discuss what can be done. If a school is concerned that a student be punished for conduct in violation of its student code, then there are many other types of consequences--writing an essay, apologizing, teaching a lesson about behavior, staying after school, staying before school, losing lunch period with friends, even just informing the parent to impose punishment--that may be imposed if appropriate. Here is the addendum. Please feel free to copy it.

Addendum to a Behavior Intervention Plan

Since the mission of the school is to educate students, including students with disabilities, and to prepare them to lead productive lives, students should not be deprived of opportunities to receive instruction unless unavoidable. In accordance with the behavior intervention plan, countermeasures and consequences that reduce or avoid the loss of instructional time will be utilized whenever practicable.

If other measures are not immediately effective or appropriate, a student with a disability whose conduct disrupts the learning process of himself or others may be removed from the instructional opportunity for the period of time that the disruptive behavior continues or is likely to continue. Once the disruptive behavior ends or reaches a resolution indicating that it will not recommence upon return to class, the student will return to class for instruction.

As an institution of learning, the school recognizes that the criminal justice system should not be a favored means to address disability-related behavior in the school setting. The school does not need to refer a student with a disability to juvenile or criminal court unless required by law.

Where the law does not require referral but the school nevertheless chooses to refer a student with a disability to juvenile or criminal court, the school must first conduct a manifestation determination review of the student. Referral to juvenile or criminal court may result in a de facto change of placement for more than ten days for which a manifestation determination review is otherwise required. A determination that the behavior in question is not a manifestation of a disability must be made by the review committee before the school can refer the student to juvenile or criminal court to address the behavior as alleged criminal conduct.

May Birthdays

Elijah Adrien	Raaj Mann
Jackson Bowers	Michelle Martos
Claire Burke	Akaya Norweck
Donovan Canter	Quinton Pressley
Carly Craig	Angel Rodriguez
Corbett Dishman	Katie Rouille
Joshua Eaton	Megan Sanders
Hunter Estep	Victoria Sparks
Jeremy Foster	Sean Stevenson
Noah Gazaway	Darby Taylor
Caitlin Gleason	Lily Von Schmeling
Pamela Gomez	Javonni Stevenson
Lindsey Hales	Paige Washington
Brandon Hoback	Madison Grace Wilson
Christina King	Maddie Wright
Michael Kozicki	Edwin Zalamanca

June Birthdays

Katie Bender	Dale Potter
Laura Benitez	Cevin Prater
Anders Bezanson	Mary Catherine Price
Mark Butler	Antonio Rodriguez
Paula Camac	Madison Sherrer
Dylan Collins	Daniel Skandera
Jennie Linn Dunn	Nathan Sykes
Noah Gray	Victoria Webb
Courtney Jones	Ciara Zachary
PJ Keaveney	
Jacob Knight	
Kathleen Lewis	
Edgar Magallanes	
Araceli Martinez	
Taylor Matyas	
Katie Norris	

If we have missed your child's birthday, please let us know. We want to correct our records.