

DSAM insights

quarterly newsletter to support individuals with Down syndrome and their families



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Jawanda Mast

From the desk of the Executive Director...

I want to dedicate this column to our fabulous volunteers! The Down Syndrome Association of Memphis and the Mid-South (DSAM) is fortunate to have many outstanding volunteers. We have volunteers who help at the office, plant flowers for us, transport self-advocates, write for the newsletter, and serve on our board, to name just a few of the roles they fill. We couldn't do what we do without all these great "helpers." Just a few weeks ago we had the opportunity to recognize **Darlene Winters** for her contributions to DSAM through her volunteer leadership with Company d. Darlene was honored as the 3rd place winner in the Adult Volunteer Category for the Volunteer Memphis Spirit of Giving Awards. Thank you and Congratulations Darlene! In August, our own **Carol Greenwald** will be recognized as one of Memphis Women's Magazine's 50 Women Who Make a Difference. Carol has given her time and talents for a long time to support individuals with Down syndrome and other disabilities and to help our organization grow. Thank you and congratulations Carol! Although there isn't enough space in this newsletter to mention all of our wonderful volunteers, I do want to mention **Ken and Melissa Zaletski**. Ken and Melissa came to DSAM about four years ago. Mr. Z (as we know him) was the manager of a local retail store. After seeing an article about the DSAM Buddy Walk in the paper, Melissa called us. It was the beginning of a beautiful friendship and only the start of many, many hours of volunteer work! Melissa became our Buddy Walk Donation Guru and was always the first to offer to help with registration, set up, or anything else that needed to be done. Just recently, Melissa joined our Kids on the Block (KOTB) puppet program as puppeteer. The Zaletski's have retired and will move closer to their children. We want to say a heartfelt thank you for all they have done for DSAM and people with Down syndrome. Thank you Melissa & Ken! We wish you all the best! It will take about five people to fill their shoes, so call us today!

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Insight's Staff

Editor: Simone Wilson
Art Director: Bradley Payne
Contributors: Larry Dodson, Alyson Edwards, Jawanda Mast, Denise Martin, Sonya Oliver, Lauren Powers, Jenness Roth and Darlene Winters.

DSAM INSIGHTS IS FOR INFORMATIONAL PURPOSES ONLY. IT WANTS TO PROVIDE INFORMATION THAT WILL HELP TO BETTER UNDERSTAND DOWN SYNDROME. THE DOWN SYNDROME ASSOCIATION OF MEMPHIS AND THE MID-SOUTH CANNOT GUARANTEE THE ACCURACY OF ANY INFORMATION PRESENTED IN THIS NEWSLETTER.

DSAM

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The Down Syndrome Association of Memphis the Mid-South extends its deepest sympathies to Linda and Rob Taylor in the loss of their infant daughter Ashlee Nicole Taylor; Shawn Patton & Toni McCasslin in the loss of their infant son Jacob Cannon Patton; Charlotte & Joe Perritt in the loss of their adult son Joe Allen Perrit.

(continued from page 1)

We have many great volunteers both family members and non-family members. This fall, however, I'm asking a few of you to step out of your comfort zone and help us with a special effort. We are planning an "Invite your School Board Member and Legislator to the Buddy Walk" outreach. Each year, we send official invitations from our office to these important officials. We typically receive a few responses to our invitations, but the greatest turnout comes from those invitations that were extended through our families, through personal contacts. Every year, our self-advocates have a party and handwrite letters to community leaders and sponsors. Some of our families send this same type of personal invitation. And, the response to these personal notes is amazing. We encourage you to send a note with a Buddy Walk brochure and a photo of your family to our community leaders and personally invite them to the Buddy Walk. It is an unbelievable "Aha" moment for those community leaders who join us at the Buddy Walk because our Buddy Walk is an "Aha" event. So, if you are interested in helping (we have a need for a few people to help in organizing the outreach, too), please let me know.

This is our "Back to School" newsletter so be sure to check out all the good information and tips inside to help make your child's back to school transition a positive one!



Amy Allison

Down Syndrome Specialists: Parents & Schools in Partnership Update

April 2, 2008 was a historic day for the Down Syndrome Association of Memphis and the Mid-South (DSAM). We launched our Parents and Schools in Partnership program. 24 educators and six representatives from the DSAM, including parents and board members, were part of the inaugural meeting at the Crescent Club. Amy Allison, executive director of the Down Syndrome Guild of Kansas City, spoke about creating a Down Syndrome Specialist program with DeSoto County, Memphis City and Shelby County schools. The response was overwhelmingly positive and the education leadership provided DSAM with some great input. Later that day, Allison introduced the program to a group of almost 40 parents. At this stage we are continuing to work with all three school systems and anticipate beginning the program in the fall.

We don't know yet which form the program will take, but we will be publishing an Inclusion Solutions e-newsletter for educators and parents, and we will begin training the specialists. A tentative Down Syndrome Specialist job description is available the DSAM Web site at www.dsamemphis.org.

Each year children with Down syndrome are taught by regular education teachers that have not had the opportunity to receive training in teaching methods that have proven successful for children with Down syndrome. Our goal is to make this information available to teachers through both our programs and the Down Syndrome Specialists within the teacher's school district. Because training topics change every year, we believe that the Down Syndrome Specialist would be able to provide teachers with specific information that may have been presented previously.

In consideration of the school district appointing specialists, we would offer all of our training and conferences at no cost to the specialist from each school district. This Specialist would receive a notebook full of information beneficial to educating children with Down syndrome and other disabilities. We believe that the Specialist would be able to recognize patterns of behavior and/or learning challenges that are common in children with Down syndrome and therefore be able to suggest appropriate interventions. As the horizon changes for children with Down syndrome in the regular education classroom, the school district could feel confident that it is always up to date through its valuable resource: the Down Syndrome Specialist.

Although we know that our parents are experts on their children, we don't recommend that parents of children with Down syndrome consider this position.

Supporting and Empowering People with Down syndrome and their Families.

The Down Syndrome Specialist we hope would be:

- Currently employed by the school system.
- Available to attend conferences and lectures provided by the DSAM. We anticipate two (2) to three (3) conferences/lectures per year.
- Willing to disseminate information to teachers currently teaching children with Down syndrome.
- Willing to act as a resource person for teachers currently teaching children with Down syndrome.
- Available to assist as an interventionist when needed. Our vision is to have someone who can offer advice when an IEP team is at an impasse or needs ideas. The unique blend of being a school district employee as well as someone who has firsthand knowledge of information being offered to parents by DSAM, would allow the specialist to bring IEP teams together in the best interest of the child. Parents would know this person has the support of DSAM. School staff would know this person is an employee of the district.
- Be a contact person for DSAM when important information regarding children with Down syndrome becomes available.

Special thanks Sedgwick CMS for making the luncheon possible and to our hosts for home programs Carol & Jim Greenwald and Bruce & Sheila Siegal, as well as the Tennessee Council on Developmental Disabilities for sponsoring Amy Allison.



Doug Collins of Prudential Collins-Maury Realtors, Brooke Stamps and Laurie Hobson.

Snowstorm Interfered with Bar-kays Concert in March: reflections from Larry Dodson and Denise Martin

Everybody was sad that the "Getting Down for Downs with the Bar-kays" concert in March in Memphis? However, this event received a lot of media coverage even before the Bar-kays took the stage, which in turn brought awareness to the Down Syndrome Association of Memphis and the Mid-South (DSAM). Although there was no concert, many families, individuals and the Memphis community still learned about DSAM and its mission. Naturally, DSAM offered to refund the ticket prices, but many chose to give to the good cause. This is why Larry Dodson of the Bar-kays along with his wife, Marie Dodson, and his daughter Precious Dodson, and the entire staff of DSAM consider events like this a labor of LOVE. Thanks Memphis for your heartfelt contribution. We will be back in 2009, from Larry Dodson, DSAM Board Member and Lead Singer, The BarKays.

Denise Martin, BarKays Event Chair and Prudential Realtor, says "At Prudential Collins-Maury Realtors, we had often discussed how we could get more involved in our community. John and Kathy Stamps and Martine Hobson are members of our Prudential family who have beautiful daughters with Down syndrome. The Down syndrome Association seemed like a natural match for us."

Martine Hobson mentioned the Bar-kays fundraising concert in one of our sales meetings. I didn't hesitate to volunteer as chair of the event, and enjoyed involving some of my co-workers too. Although the concert was cancelled, we are still committed to partnering with the DSAM. I know we will have many successful events in the future. A little bit of snow and a cancelled event doesn't mean that you have seen the last of the Prudential Collins-Maury Family!



Marie, Precious and Larry Dodson

inside DSAM



Karen & Rocco Stout



James and Katy Cotton

2008 DSAM Day at the Zoowas a Big Success!

What a day! This year's Zoo Day was a huge success with more than 250 participants, including many friends from the Northeast Mississippi Down Syndrome Society. We want to say a special thanks to the volunteers that helped with the face painting and entertaining, photography, and registration.

Company d: Parents Reflect on their Children's Involvement

According to Darlene Winters, artistic director of Company D, the dance troupe is more than just a dance class. "The success of the Company is a direct reflection of the commitment from the parents," Winters says. Company d recently celebrated its 7th anniversary, and some of the dancers' parents shared their insights.

"The physical, mental, and emotional discipline that is required to be a part of this kind of program has been invaluable to Ben's development," says Elizabeth Sumner, mom of 15-year-old Ben, who has been dancing with Company d for four years. "Ben's involvement in dance has helped him to hone this particular skill, which in turn enhances many other activities he does, not the least of which is his academic and school work. The physical exercise is also important to us, and we believe that Ben is in better-than-average condition for a Down syndrome teen."

The experience translates to all aspects of the dancer's life. "Amanda is a veteran dancer with Company d and it has not only enhanced and fulfilled her life, but it has given me a sense of pride that I cannot put into words," acknowledges Donna Cash, who enjoys seeing her 22-year-old daughter perform with the Company. "Her dream since she was little was to show the world how capable she is and to advocate for others with Down syndrome. Company d has given Amanda the confidence that it takes to be a self-advocate and a public speaker. She is happy, confident, talented and fulfilling her dreams. What more could a mother want for her child?"

An additional benefit is the effect the experience has on the family. "This is not just a thing for the dancers, it involves every family member: Moms, dads, brothers and sisters. The families have bonded and have committed to educating the community with Down syndrome by showcasing these young adults' abilities and focusing on their positive aspects," Cash continues.

These are just a few of the parents who have dedicated their time to making sure the dancers attended weekly classes, rehearsals, performances, camps, and travel engagements. This commitment involves so much more than dropping of a child for practice. Being part of the experience with the dancers makes it so unique for many families. Martine Hobson, whose 22-year-old daughter Laurie dances in the Company knows, "It's real and it's hard, but it's so worth it."

Company d is sponsored by the Down Syndrome Association of the Mid-South and is an outreach and awareness arm of the organization.

AAAHHHH SUMMER

(with thoughts from the Oklshoms Parent Training Center)

Smile and look at your child. See the pluses, the strengths, the fun things you can do together. Make a note of some of those strengths to discuss at your child's IEP meeting.

Unwind, shake off the stress. Take 10 deep breaths and plan to enjoy the summer.

Make some notes about your child's skills—is he/she losing some skills gained during the year? If so, bring those up at an early-in-the-year IEP meeting.

Move into your "community." Let the people at the park, the theater, church, youth programs, swimming pool, etc. have the pleasure of getting to know your child. Social skills are just as critical to success as academic ones!

Encourage your child to try something new: a new game, a new word, a new skill, a new friend. Since the schedule is different and more relaxed old habits might be more easily broken.

Resolve to begin the next school year rested and ready to collaborate and advocate for a truly appropriate educational program for your child. No one wants to think about the next school year now, but now is the perfect time to do a few things that will make the start of a school a little easier.

Start now. Think about child(ren) and how they learn, play, their likes and dislikes. How do you make them behave? What are the things that motivate them?

Utimize your time this summer to sort and review that mountain of papers you got from school last year. File what you need and get rid of the rest. Are you missing anything important? Do you have a copy of the last IEP, assessment, grade card or behavioral plan? Make a note to get copies of missing documents.

Make sure their last IEP is still appropriate to meet your child's needs. If not, make notes of things you want to discuss with the IEP team at the beginning of the school year.

Make your own informal assessment of your child's growth this summer. What can he/she do? How well does he/she do it? Has there been progress since last year? If there appears to be regression in skills during the summer, make sure you note specifics. Think about your child's need for extended school year services next summer.

Enjoy your children. Look at those unique qualities that make them their own person. Are these gifts being enhanced through their school program? Could they be?

Relax and de-stress. Summer is not only time for kids to relax, recreate and recoup. It is the parents' time as well. Take care of yourself so you can take care of your child. Just like the instructions on the airplane—you have to put your mask on before you assist others with their masks!



The Affiliates in Action Conference: Powering Successful Programs

The Affiliates in Action conference (AIA) was in Scottsdale, Arizona in February. Affiliates in Action provides Affiliate leadership a unique opportunity to network and learn from affiliates from around the county. The mission of the Affiliates in Action Conference is to serve and support Down syndrome organizations through collaboration, resource sharing and networking. Lauren Powers, Sonya Oliver, Michael Karst, Alyson Edwards, and Jawanda Mast attended on behalf of the Down Syndrome Association of Memphis and the Mid-South (DSAM). The AIA conference is unique when compared to other conferences in that it focused specifically on helping local Down syndrome support organizations improve their effectiveness.

One of the greatest benefits to DSAM is being exposed to programs that we can implement without having to start from scratch. DSAM is committed to providing programs that fit the needs of our families. All of the affiliates at the conference were very willing to share ideas, forms, and support materials to help other affiliates start a program or service with a minimum upfront effort. We want to share with you some of the programs that fit well with our strategic plan. Using the ideas and materials from the AIA conference, will allow us to turn many of our initiatives into successes for our community. Following are some examples of some of the learning opportunities afforded DSAM leadership.

The Down Syndrome Guild of Kansas City discussed its program, Parents and Schools in Partnership. DSAM has already begun to implement its version of this program using the methods developed and proven in Kansas City. These methods include working proactively with the school systems to develop positive relationships and solutions that will help our students receive the best possible education. We started our Parents and Schools in Partnership program in April with a meeting that included representatives from Memphis City Schools, Shelby County Schools and DeSoto County Schools. We are now well on our way to identifying the pilot group of Down Syndrome Specialists within these school systems.

Another interesting program was the Community Group Plan. A project in which families who share common interests or locations can develop their own specialized or local support groups. The affiliates using this program most often used geographic location to group families, much like DSAM supports the North Mississippi parents' group. However, other affiliates used ethnicity or special interests as the criteria for supporting these community groups. For example, the Atlanta affiliate supports community groups focusing on the growing Latino population.

The Down Syndrome Association of Minnesota has some very successful grandparent programs. The Association realized that some grandparents were struggling to help their grown children through the initial shock and grief of the early days after the diagnosis. As the grand children grew the grandparents faced the issue of not knowing how to handle discipline and other issues. The Association developed a "grandparents pack," started meetings with just the grandparents, who were allowed to pick the topics, and indicated that as more grandparents became involved they became a great help to the organization. They were wonderful volunteers helping with the Buddy Walk and social events, offering clerical support in the office, and getting involved on committees and the board of directors.

The Down Syndrome Association of Greater Cincinnati (DSAGC) supports self-advocate groups on communication skills, relationships and romance, social skills, independence, jobs, and volunteering. One of its programs is called "Lifelong Wellbeing Workshop," for which physicians are invited to discuss "taking charge of your health," weight management, and preventative measures. DSAGC also offers weekend retreats where self-advocates can learn about basic life skills such as cooking, cleaning, personal safety, and home management skills.

Photo: (From left to right)) Jawanda Mast, Alyson Edwards, Lauren Powers, Belinda Karst, Michael Karst, and Sonya Oliver.



Parent, Advocate, and Educator Resources

www.Wrightslaw.org

Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law, education law, and advocacy for children with disabilities.

www.tnstep.org

This site offers a list of classes. **STEP** (Support and Training for Exceptional Parents) is a statewide family-to-family program in Tennessee, established in 1989 by a grant from the U.S. Department of Education. The purpose of STEP is to support families by providing free information, advocacy training, and support services to parents of children eligible to receive special education services under the Individuals with Disabilities Education Act (IDEA) who reside in Tennessee. STEP services are available to any parent or family member of a special education student or a student who may need special help in school (birth through age 22). There is no charge for services to parents. Professionals in the education field are welcome to attend workshops, but there may be a nominal cost for printed materials.

www.communityinclusion.org

The Institute for Community Inclusion supports the rights of children and adults with disabilities to participate in all aspects of the community. As practitioners, researchers, and teachers, we form partnerships with individuals, families and communities. Together we advocate for personal choice, self-determination, and social and economic justice. **FREE DOWNLOADS!**

<http://soeweb.syr.edu/thechp>

The Center on Human Policy (CHP) is a Syracuse University based policy, research and advocacy organization involved in the national movement to insure the rights of people with disabilities. Since its founding, the Center has been involved in the study and promotion of open settings (inclusive community opportunities) for people with disabilities.

<http://www.inclusion.com>

Inclusion Press creates people-centered resource materials for training events, public schools, high schools, community colleges, universities, human service agencies, health organization, government agencies, families, First Nations organization, nationally and internationally. **FREE DOWNLOADS!**

www.inclusiveschools.org

The official website of National Inclusive Schools Week (usually the first week of December). Classrooms, schools, and communities through the country participate in celebrating diversity in the school environment. This promotes action towards increasing the capacity of the schools and communities to provide a quality education to an increasingly diverse student population, particularly those who have disabilities. **FREE DOWNLOADS!**

www.normemma.com

Website of Norman Kunc & Emma Van der Klift. Professional Development on Disability and Non-Coercive Practices. Helping people work with people, not on them. **FREE DOWNLOADS!**

www.mncdd.org

The Minnesota Governor's Council on Developmental Disabilities features *free access to Parallels In Time: A History of Developmental Disabilities*. **FREE DOWNLOADS AND E-COURSES!**

www.ualberta.ca/~jpdasddc/INDEX.html

Website of the JP DAS Centre for Developmental Disabilities in Alberta, Canada. **FREE DOWNLOADS!**

www.disabilityisnatural.com

Kathie Snow, parent and advocate. **FREE DOWNLOADS!**

<http://tash.org/index.html>

TASH (The Association for Persons with Severe Handicaps) is an international membership association leading the way to inclusive communities through research, education, and advocacy. TASH members are people with disabilities, family members, fellow citizens, advocates, and professionals working together to create change and build capacity so that all people, no matter their perceived level of disability, are included in all aspects of society.

Tackling Back to School Time

by **Jawanda B. Mast**

Back to school is a stressful time for all parents, not just for parents whose children have Down syndrome. However, there are many things you can do to make this time easier on yourself and your child.

- Suggest doing a program for your son or daughter's class. Tell the classmates about Down syndrome and some specific things about your child and how they can be good friends.
- Read a book about Down syndrome or another disability to the class and/or at the library.
- Write a letter about your son or daughter introducing her with her words. Ask if this letter can be sent home with classmates. You will usually need the principal's approval for this. (For these first three, you can inquire about these things at your IEP meeting and have it written into the IEP notes.)
- Volunteer in the classroom if time allows.
- Invite the class to participate in the Buddy Walk—even have a Buddy Walk team for your child.
- Host play dates. You don't have to spend much money. You could do something at the park or in your backyard, a cooking adventure, a craft, or a Friday night at the movies and watch a movie and make popcorn. Check on extracurricular activities in which your child can participate. Ask the sponsor for modifications/accommodations if needed.
- Educate yourself and prepare the teacher. There is a list of books at the bottom of this article that might help your child's teacher with educating your child and other children. These books are helpful for you and the teacher. Make sure you have read the latest information on best practices in education. If you are not up-to-date on what works for children with Down syndrome, it is hard for you to provide support to your child's teacher on how/what to do. There are many resources from newsletters to Web sites.
- Let your school district know that you support the newly created Down Syndrome Specialist Program. If needed, request help from that person.
- Suggest that your child's teacher participate in the RISE (Restructuring for an Inclusive School environment) Conference in September.
- Share our newsletter with the teacher and others who work with your child. Invite them to be added to the DSAM mailing list and educators e-mail list. Most of our activities are open to parents and educators alike. Invite them to join you for a workshop or meeting.
- Don't forget to include the related services professionals (occupational, speech and physical therapist) and paraprofessionals such as classroom assistants in the education process. They will benefit from the information and training as well. Set high expectations for your child's academic achievement, extracurricular activities and behavior.

Call the Down Syndrome Associations office if you need help with any of these items. Some of the resources we offer include:

Everyone Counts

Video and lesson plans aimed at K-5 classroom, which includes education about Down syndrome and includes those with Down syndrome. Appropriate for older preschool children and church groups. Free to inclusive classrooms. This program provides a great opportunity for a parent to do a classroom session. If you aren't comfortable presenting the program, contact DSAM and we'll help you.

Les Passees Kids on the Block (KOTB) & DSAM PARTNERSHIP

We are partnering with LesPasseess Kids on the Block for this educational and awareness puppet program that's taken into local schools. Two troupes feature Ellen Jane Peterson, a puppet with Down syndrome, and children can learn about Down syndrome and about accepting those who are different. One troupe features a self-advocate in the role of Ellen Jane Peterson.

Contact the DSAM office to find out how to bring this program to your school.



Lucia and Marcela DeTuya playing school.



Tavarius and Heather Robinson

Books

The books make great reads and can be a tremendous help to the teachers. Check with the DSAM office on check-out availability. Most of the books can be found at the local bookstore, online and sometimes the local library. We have some books available for you to borrow and read to your child's classroom.

These include:

We'll Paint the Octopus Red – Stephanie Stuve-Bodeen/ Illustrated by Charlotte Fremaux

The Best Worst Brother – Stephanie Stuve-Bodeen/ Illustrated by Pam DeVito

What's Wrong with Timmy?- Maria Shriver

My Friend Isabelle (Comes with Teacher's Guide) Eliza Woloson/ Illustrated by Bryan Gough
and *Teacher's Guide* by Amy Thrasher

My Up and Down and All Around Book – Marjorie W. Pitzer, M.Ed.

I Can, Can You? – Marjorie W. Pitzer, M.Ed.

Books you may be able to borrow but we encourage you to purchase for yourself and your school:

Classroom Communication Skills in Children with Down Syndrome – Libby Kumin, Ph.D, CCC-SLP

Teaching Math to People with Down Syndrome and other Hands On Learners - Book 1 (Book 2, CD's and tool box to be released summer 08) – DeAnna Horstmeir, Ph.D.

Teaching Reading to Children with Down Syndrome – Patricia Oelwein, M.Ed.

Fine Motor Skills in Children with Down Syndrome – Maryanne Bruni, BSC OT (C)

Gross Motor Skills in Children with Down Syndrome – Patricia C. Winders, P.T.

Negotiating the Special Education Maze: A Guide for Parents and Teachers - Fourth Edition, Winifred Anderson, Stephen Chitwood, Deidre Hayden & Cheri Takemoto

Back To School Speech and Language Tips

By Lauren S. Powers, M.A. CCC-SLP

The summer is almost over and it is time to start thinking about going back to school! The beginning of school can be an exciting time as well as a busy time. Here is a list of tips to help make the transition back to school a little easier.

The summer is almost over and it is time to start thinking about going back to school! The beginning of school can be an exciting time as well as a busy time. Here is a list of tips to help make the transition back to school a little easier.

- Turn "back to school" shopping into a speech and language activity. This is a perfect time to increase your child's vocabulary regarding objects that he will use everyday. This is also a great time to work on following multi-step directions such as "Go get a box of crayons, a pencil, and some glue."
- Answering questions regarding object function can be addressed as well. An example is "For what do you use a pencil?" or "What do you use to write?"
- For children who have difficulty transitioning to new places or new routines, ask the school if you can bring your child to the school for a tour. If this is a new school, tour the entire school and discuss what your child will do in each room (ex. "The library is where you will go to read books. We are always quiet in the library.") If possible, take pictures of the school and

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the school personnel to review the rooms and people. This is also a great time to practice saying the names your child will need in her daily activities.

- If it is possible to find out who the new teacher is before registration, show your child her classroom and discuss who her teacher will be. Discuss the way your child will arrive and leave the school. Remember, safety first.
- Dust off your child's IEP. Review the goals that your child will be working on during the school year. If your child has made progress in some of the areas, make sure the therapists are aware of that progress. If the goals are written with terms and language that is not familiar to you, ask for an explanation. If you have any questions, don't hesitate to ask. The therapist should be more than happy to explain why specific goals were chosen and how they fit into the future plans for your child.
- Incorporate an activity notebook. The beginning of the school year is a great time to begin an activity notebook to be completed at home. Ask the therapist to send home activities, work sheets, word lists so that you can help your child carry over the work he does in school.
- Stay involved with your child's therapist. The more you communication with the therapist the better. Some therapists may not have time to write in a notebook every time your child is seen; however, try to find out what would work for your child's therapist and work together as a team. Ask your therapist if e-mail is easier for her. Don't expect a long note, but the note should let you know how your child is doing and what needs to be addressed next.
- Incorporate a social journal. A journal is also a great way to incorporate language activities for your child. If your child has any pragmatic (social language) or conversational goals, ask your therapist if you can send a weekly journal. Fill it with pictures and entries describing the fun things that your child participated in that week. Include things such as going to the zoo or having a special visitor. Some parents simply e-mail pictures to the therapist and the children really enjoy discussing that particular activity.

These are just a few suggestions. Remember that every activity can be turned into a speech and language activity. Simple acts such as getting dressed can target clothing items, colors, body parts, prepositions, and temporal concepts (first/last).

Respite and Personal Assistance

If you are receiving services through the Medicaid Waiver, you may request a list of respite service providers for your area from your DMRS case manager.

(DMRS) Department of Mental Retardation Services

West TN Regional Office- Intake Section

11293 Memphis-Arlington Rd.

P.O. Box 586, Arlington, TN 38002-0586

(901) 745-7200/ <http://state.tn.us/dmrs/index.html>

Contact Shawn Davis for referral/application process @

1- 866-372-5709 The Medicaid Waiver offers funding for a variety of services. Medicaid Waiver is not the same as traditional Medicaid. For a person to be eligible for DMRS

Services he/she must have a diagnosis of mental retardation, with an overall IQ of 70 or less, before the age of 18. If you need further assistance in applying for DMRS services please contact the Community Advocate at the Arc of the Mid South. 901-507-8568

****Do not use the application form listed on the web-site as it has not been updated. Call 866-372-5709**

SRVS Family Support Program

3592 Knight Arnold Rd.

Memphis, TN 38118

901-869-9291 901-869-9203/ <http://www.srvs.org>

Limited support is available to individuals who are unable to meet their needs through other agencies, organizations or funding sources.

The Arc of the Mid South

3485 Poplar Ave Ste 210 Memphis, TN 38111

(901)327-2473 www.arcmidsouth.net

email: msarc@arcmidsouth.net

Family Support Services including in-home respite care, weekend retreats, summer camps, and personal assistance.

TN Voices for Children

1-800-670-9882/ www.tnvoices.org

Respite care and respite care training. Eligibility: under age of 18 (or 22 if still in school), have a diagnosis of emotional disturbance or mental illness, and have TennCare. Cannot be receiving adoption assistance.

Raymond Skinner Center

712 Tanglewood, Memphis, TN 38103

(901) 272-2528/ <http://www.cityofmemphis.org>

(search for "Raymond Skinner Center")

Day Program for ages 22 and up. After school program for ages 5-21.

Tennessee Respite Coalition

PO Box 90433, Nashville, TN 37209

1-888-579-3754/ www.tnrespite.org info@tnrespite.org

Memphis Respite Voucher Program

(901) 522-0090

Contact: Tammy DeNiro at Tammy.deniro@tnrespite.org

Respite care funding for people with developmental disabilities or mental illness.

Comprehensive Counseling Network

2150 Whitney Ave, Memphis, TN 38127

(901)354-7367/ <http://www.ccnmemphis.org>

Free short term respite (10-12 week) for children ages 2-15. Usually consists of 3 hrs of community outings per week. Must have a mental health (DSM IV) diagnosis. Available to Shelby County residents only.

United Cerebral Palsy

(serves individuals with all disabilities)

4189 Leroy Ave, Memphis, TN 38108

(901) 761-4277/ www.ucpmemphis.org

Saturday respite for children ages 5-17. Personal assistance for all ages.

Support Solutions

518 Pecan Grove, Bolivar, TN

901-383-9193

60 day respite for individuals with maladaptive behaviors.

Must be receiving Medicaid Waiver services.



Special thanks to Robin Henson (far left) for pulling together Dress Down for Down Syndrome at Independence Middle School in Senatobia, MS. Robin is aunt to Cohen Perkins who has Down syndrome. She led this effort to honor Cohen, raise money and to promote awareness. The school raised \$1,000 for the Down Syndrome Association of the Mid-South. From left to right: Robin Henson, Becky Bradley, Sarah Perkins, Cohen Perkins, Barry Perkins, Sarah Perkins (Cohen's grandmother).



Thanks to Fiona Hawks and her parents, Maureen and Edmund for encourages us and sharing their vision with our families at the DSAM's 1st Tapping the Potential Spring Luncheon.

mark your calendar

Times Square Video Contest

Celebrate the Buddy Walk's 14th anniversary by entering the Times Square Video Contest. The video, which showcases individuals with Down syndrome from all over the world, will air on the Panasonic News Corporation Astrovision screen in Times Square on September 28, 2008 at 10:30 a.m. The New York City Buddy Walk™ will immediately follow the video at the Great Hill in Central Park.

Each year, the National Down Syndrome Society (NDSS) receives thousands of photo submissions for the Contest. Because the Buddy Walk™ promotes acceptance and inclusion of individuals with Down syndrome, the winning photographs feature children, teens and adults with Down syndrome working, playing and learning with friends and family. Please limit photos to no more than three per individual with Down syndrome. If more than three pictures are received, only the first three will be considered. For more information visit www.buddywalk.org

Submission deadline is July 18, 2008. Families will only be notified if their photo was accepted. Unfortunately NDSS is unable to return any photos that were submitted for the contest. For additional questions about the contest, contact timessquarevideo@ndss.org or call (877) 526.0270.



Stella Edwards and Baby Brother Miles, one of the photos featured on 2007 Times Square Awareness Video



With Sheldon and the Chick-Fil-La Cow is from left to right Morgan Tibbens, Toni McCullough, Drew Maxey and Sadie Stafford

Y'all Come and Join Us for the North Mississippi Down Syndrome Awareness Picnic

The Down Syndrome Association of Memphis and the Mid-South (DSAM) presents the 4th Annual North Mississippi Down Syndrome Awareness Picnic on Saturday, **September 6, 2008 from 11 a.m. to 2 p.m.** at Goodman Oaks Church of Christ in Southaven (1700 Goodman Road East).



Family Fun at the Picnic.

This event is for everyone, not just our Mississippi families. So bring your blanket or lawn chairs and join us for a fun day filled with food, moon bounces, music and fellowship. We will announce the month of October as "Down Syndrome Awareness Month." Last year more than 200 people attended the picnic, including teachers, school administrators, local mayors and Mississippi state representatives. The event has been a great success during the past three years because of the many volunteers and donors who make the picnic possible, and because of everybody who attends the event. The picnic's goal is to promote awareness and celebrate the abilities of individuals with Down

syndrome. Lunch will be served at 11:30 a.m. and presentations begin at 12:30 p.m.

If you are interested in helping with the event and for more information contact Sonya Oliver at 662.342.0545 or 901.647.4275 or e-mail oliversonya@bellsouth.net.



American Buddies Singing the National Anthem

DSAM 2008 Buddy Walk

Mark your calendars! Our 2008 Buddy Walk will be another great event!

The Down Syndrome Association of Memphis and the Mid-South (DSAM) celebrates its 11th annual Buddy Walk on **Sunday, October 19** from noon to 4 p.m. at the Memphis Botanic Garden. Last year close to 4,000 Mid-Southerners participated in our 10th Anniversary Buddy Walk. This year's event promises to be even bigger and more fun. News Channel 3 meteorologist Jim Jagers is back as emcee and the Radio Disney Party Patrol will be on hand too. Make sure you get a good seat for our Stars on the Main stage. Prizes will be awarded to the largest Buddy Walk teams and individuals raising the most pledge dollars, and there will be a great prize for the self-advocate that raises the most pledge dollars. Remember, it's never too early to start your Buddy Walk team. Gather family, friends and co-workers to walk as a team at the Buddy Walk and support a buddy with Down syndrome. Create a team name and show your "Buddy Spirit" by designing signs and banners with your team name for the day of the walk.

To get the latest Buddy Walk updates check the DSAM Web site, www.dsamemphis.org, or watch for details in the Buddy Walk edition of the newsletter and the Buddy Walk brochure, both scheduled to arrive in your mailbox in August. You will be able to register online, starting in July, at <http://buddywalk.kintera.org/dsam>



Mckinnon Fratta and Kristen Gilbert enjoying 2007 Buddy Walk.

DSAM Needs:

- Gift cards from Target, Kroger, Office Depot, Starbucks, etc. We use the gift cards to purchase items for the office and to give as gifts to volunteers/speakers/etc.
- A new copy machine
- File cabinets that can be locked.

Kids on the Block Puppet Partnership Needs:

- Funds for a new Ellen Jane Peterson puppet for our partnership with Les Passees Kids on the Block (KOTB). COST: \$850. The current puppet is more than 20 years old and in poor condition. This is a burden on the puppeteer (Amanda Cash). This puppet must be purchased from the national KOTB organization. The puppets are hand made and built to last.
- A sponsor for Amanda's Troupe one day, two performances, one school. COST: \$150
- New puppeteers for the KOTB Program. These are paid positions. Puppeteers need to be able to work during school hours on one or two days per week.
- A volunteer to provide transportation for one of our self-advocates who puppeteers. Mileage reimbursement is available. If you are interested, please contact Jawanda Mast at the DSAM office at 901.547.7588.

mark your calendar

July

National Down Syndrome Congress 36th Annual Convention

July 11 through 13, 2008

Boston, Massachusetts

For more information visit www.ndscenter.org or call 1-800.232.6372 or 770.604.9500. Stipends will be available to assist participants. Please watch the DSAM newsletter and Web site for up-to-date information or contact the DSAM office at 901.547.7588.

Christmas in July!

July 22, 2008 from 5 to 9 p.m.

Clubhouse of Devonshire Gardens

3128 Devonshire Way, Germantown

Christmas might still be five months away but it's time for Santa to start thinking about stuffing that sack and looking around at what goodies will slip down the chimney most easily. Get a jump-start on your Christmas shopping. Join DSAM for shopping, food, beverages, door prizes & more. For more information and to RSVP e-mail Alyson Edwards at dsamevents@bellsouth.net or call 901.547.7588.

The F.I.R.M. (Family Information and Resource Meetings)

July 25, 2008 from 6:30 to 8:30 p.m.

Faith Christian Church

4965 Willow Road, Memphis

What to do? This meeting will explore options, such as housing, employment, and support for adults with disabilities.

There is no charge to attend this event, but registration is required. To RSVP please contact the DSAM at 901.547.7588. Refreshments will be served, no childcare available.

August

Basic STEP (Support and Training for Exceptional Parents) Workshop

Tuesday, August 5

6:00 – 9:00 p.m.

DSAM Office

Workshop designed to support families by providing free information, advocacy training, and support services to parents of children eligible to receive special education services through the public school system under the Individuals with Disabilities Education Act (IDEA) who reside in Tennessee. There is no charge but registration is required by contacting DSAM office by Mon. August 4 at noon.

New Parent BBQ

August 16, 2008 at 6 p.m.

At the home of Kelli and Mills Polatty

3462 Northwood Drive, Memphis

This gathering is for babies who are one year old or younger, their siblings and their parents. It is a great opportunity to meet other parents. Gifts for babies and parents are provided.

Please RSVP by August 13, 2008 to Kelli and Mills, 901.324.4234 or kbpolatty@hotmail.com.

September

North Mississippi Down Syndrome Awareness Picnic

September 6, 2008 from 11 a.m. to 3 p.m.

Goodman Oaks Church of Christ

1700 Goodman Road (Southaven)

For more information contact Sonya Oliver at 662.342.0545 or e-mail oliversonya@bellsouth.net.

Transition 101

September 18, 2008 from 10 a.m. to noon

DSAM office

2893 Mendenhall, Suite 3, Memphis

This workshop is designed to assist families in preparing for transition from early intervention to the school system. It is appropriate and a must for families with children ages two and up and for professionals. The work-

shop is free but you must register by calling the DSAM office at 901.547.7588.

Sept 28 & 29 – Events to be announced featuring Bridget and Nancy Brown (see back cover for more details).

RISE Beyond Access Conference

September 30, 2008

Cook Convention Center

255 N. Main Street, Memphis

For more information visit www.rise.memphis.edu and check the DSAM's Web site www.dsamemphis.org for updates.

October

National Down Syndrome Awareness Month

Buddy Walk Shirt Pick-Up Party

October 10, 2008 from 4 to 7 p.m.

DSAM office

2893 Mendenhall, Suite 3, Memphis

11th Annual Buddy Walk of the Mid-South

October 19, 2008 from noon to 4 p.m.

Memphis Botanic Garden

750 Cherry Road, Memphis

The F.I.R.M. (Family Information and Resource Meetings)

October 23, 2008 from 6:30 to 8:30 p.m.

Faith Christian Church

4965 Willow Road, Memphis

At this meeting you will have a chance to observe a mock IEP meeting.

There is no charge to attend the event, but registration is required. To RSVP please contact the DSAM at 901.547.7588. Refreshments will be served, no childcare available.

DSAM University of Memphis Tailgate Party

Saturday, October 25

UM vs. Southern Miss

Kick-off: 7:05 p.m. Liberty Bowl Stadium

Tailgate BBQ begins at 5:00 p.m. and is hosted by Mills & Kelli Polatty and Martine and Laurie Hobson. Location/details to be announced.

Game tickets are \$5 per person. Tickets and reservations for the game and tailgate may be reserved through the DSAM office. There is no charge for the tailgate party. Donations will be accepted.

November

Lunch & Learn

November 18, 2008 from 11:30 a.m. to 1 p.m.

Old Venice Pizza Company

368 Perkins Ext, Memphis

"What can the Boling center do for you?" is the afternoon's topic.

For more information and to RSVP e-mail Alyson Edwards at dsamevents@bellsouth.net or call 901.547.7588.

December

DSAM Holiday Party

December 6, 2008 from 4 p.m. to 7 p.m.

Germantown United Methodist Church (Owings Life Enrichment Center)

2323 West St., Germantown

There is no charge to attend the DSAM Holiday Party, but please RSVP by December 1, 2008 by contacting the DSAM.

DSAM Holiday Mom's Night Out

Location: Martine and Laurie Hobson's Home, 1954 Corbin,

Germantown, TN 38139. Bring a kitchen gift worth \$10 or less and your favorite appetizer or dessert to share.

Some dates and times may be subject to change. Check www.dsamemphis.org for the most up to date information. Unless otherwise noted, all RSVP's and questions should be directed to DSAM at 901.547.7588 or dsamevents@bellsouth.net

MEMORIALS

In memory of Delmo Bramuchi for Company d

Cathy Bramuchi
Ned Bramuchi
Max & Barbara Bramuchi
Edgar & Barbara Currier
Kenneth & Ana Foerster
Mary J. Haggitt
Kathy Howell
J. Carl Johnson
Janience Kennon
Jennie Pogue
Alan & Ruth Richards
Warren & Kathleen Riggs
Daniel & Patricia Smith
Judy Wright
Minnie C. Young

In memory of Les Brewer & Red Wilkerson

Hope & Andy Mouhot

In memory of Justin VanTassel Hill

The Down Syndrome
Association of the Mid-South

In memory of Bob and Catherine Hyde

By Blair & Jo Gilbert

In memory of Jacob Cannon Patton

Ann Caldwell
First Methodist-Hope Sunday
School
First United Methodist Church
David & Marilyn Seagrave
Anne Sellers
Chad & Kim Stewart
Ted Turner

In memory of Joe Allen Perritt

Carol Greenwald

In memory of Margaret Quick for Company d

Ruth Bramuchi
Kathy Howell

In memory of Lori Siegal

Jonathan, Jawanda and
Rachel Mast

In memory of David Thomas

Carlton & Jana Leist

HONORARIUMS

In honor of the Bar-Kays

Jonathan, Jawanda &
Rachel Mast
Memphis Charitable
Foundation

In honor of Larry, Marie & Precious Dodson

Jonathan, Jawanda &
Rachel Mast

In honor of Janie Holland

Shelley & Brandon Wann

In honor of Emma Karst

Mark & Jackie Sholl

In honor of Walker Morris III

Walker & Jane Morris

In honor of David & Pat Smith

Hope & Andy Mouhot

In honor of Mr. & Mrs. Don Thomas

Carlton & Jana Leist

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Pennie Barclay
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Bob's Appraisal Service

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ogize if we inadvertently
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or email
dsam1@bellsouth.net.

Bridget and Nancy Brown featured at RISE Conference and other DSAM Events

The Down Syndrome Association of Memphis and the Mid-South (DSAM) is excited to partner with the University of Memphis RISE (Restructuring for Inclusive School Environments) Beyond Access Conference, on **Thursday, September 30** at the Cook Convention Center. The 2008 Conference will feature Dr. Tom Buggiey, chair of the Siskin Children's Institute of Excellence at UT Chattanooga. Response to Intervention (RtI) and its implications for all teachers will be the focus of the conference. All session presentations will focus on (RtI) and the implementation of tiered-levels of support in the general and/or special education classrooms.



As a part of its sponsorship of the conference, the DSAM we will host **Bridget and Nancy Brown as session speakers. Their workshop title is "Honey, I Blew Up the Curriculum"**. On Sunday evening September 28 and Monday September 29, Nancy and Bridget will be featured in events for self-advocates and parents who may be unable to attend the RISE Conference. More details to come!

Bridget Brown (www.butterfliesforchange.org) is a successful young woman who captures the attention of everyone she meets. She was the first person with a disability included in her school district. She now helps individuals with disabilities learn how to advocate for themselves. Bridget helps people share their dreams and design bright futures. She is a student representative for the TOTAL transition program in Illinois and she a well-known public speaker. Nancy Brown, Bridget's mother has a background in social work and more than 25 years of experience working with people with disabilities. She is an inclusion consultant for Project Choices and runs her own consulting organization called Pathfinders. **DSAM will offer registration reimbursement stipends for parents and a limited number of stipends for teachers of students with Down syndrome. Please contact DSAM for information on using this resource.** Information about cost and program will be available soon at www.rise.memphis.edu or at the DSAM Web site www.dsamemphis.org

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Memphis, TN 38115

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