

DSAM insights

bimonthly newsletter to support people with Down syndrome and their families



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Editor: Kelli Polatty

Art Director: Bill Berry

Contributors: Alyson Edwards, Kathryn Saunders, Sonya Oliver, and Kelli Polatty.

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DSAM

2893 So. Mendenhall, Suite 3
Memphis, TN 38115
901.547.7588 Fax 901.547.7589
email Admin@DSAMemphis.org
www.DSAMemphis.org

From the desk of the Executive Director...

Nine years ago when I got married, my husband and I decided that I would be a stay at home mom. Little did I know how this would change just a few years later when I gave birth to my second child, Stella. At that time I had no idea the things she had in store for my life. She has made my life more beautiful than I could have ever imagined.

I can't believe how quickly the past year has gone by. It has been almost one year since I started in the position of Executive Director for the Down Syndrome Association of Memphis & the Mid-South. What an honor it has been to do this job. I have had the privilege of meeting so many new families and helping them as they start on their journey. I am so thankful to Stella for bringing the world of Down syndrome into my life and so thankful to all of you for allowing me into your lives.

In 2009, DSAM saw some amazing things happen. We welcomed 20 new babies and their families to the Mid-South area. Several staff and board members met with members of Congress to try and make change in legislation that effects people with Down syndrome. We hosted our first local conference with 100 people in attendance. We expanded our Parents and Schools in Partnership program and now have 27 Down Syndrome Specialists in three school districts. The Kids on the Block program reached 25,000 students and teachers in the Mid-South. Once again we hosted the largest disability awareness event in the Mid-South, *STEP UP for Down Syndrome*.

It has been a year to be proud of. None of this would have been possible without your support. I am so appreciative to each of you for continuing to support DSAM in our mission to support and empower people with Down syndrome in the Mid-South. Our door is always open. Please feel free to share your thoughts, comments and concerns. And, thanks again for allowing us to be a part of your lives.

Alyson Edwards
Executive Director



inside DSAM

Board Bio

Chandra M. Evans, PharmD, MS

July 26, 1993. A month earlier, I graduated from high school in North Carolina. Approximately one month later, I would be a freshman Biology major at the University of North Carolina at Greensboro. In four months, on Christmas break, I would be at home with my Dad and my four other siblings anxiously awaiting the return of our precious baby sister who had undergone surgery for no less than 6 hours to repair her heart. I would be my Dad's helpmate in my Mom's stead while she spent the month at Duke University Medical Center as her new baby recovered and became strong enough to come home. We would all receive letters and phone calls from Mama to remind us to do our chores & homework, and be kind to each other while she was nursing our baby sister to perfect health.

Dire warnings from my mother's physician after she had given birth: "She'll love music but she will be an inactive child without much muscle tone" was enough to break anyone's heart. But we are all grateful my Mom and Dad took the chance on giving life to this gift and naming her Chienza (Swahili for 'special'), affectionately known as 'Chi'.

And now jump to 15 years later, in 2008, first day of high school for Chi, as thousands of students bustled through the hallways of my old high school, my mother and I tried to shield Chi from oversized students too excited to notice that she was half their size. I became increasingly frustrated within minutes as I watched Chi who was never nervous.

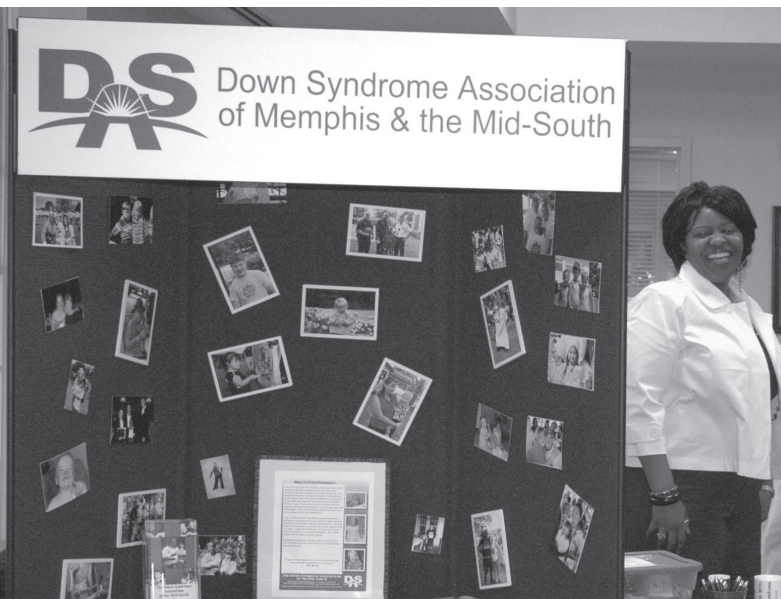
We arrived at her classroom and instantly she retreated almost behind me as the entire class of mainstream students stared at her and she stared back as if she didn't know what to say. We left the classroom after about two minutes, and spent about an hour in the assistant principal's office. When asked how she felt about her new school by the assistant principal, Chi responded, "It's too much". She completely understood what we were trying to do.

I took a later flight back to Memphis so we could arrange a meeting with the Board of Education the following morning and revisit her IEP. The meeting was arranged, I was conferenced in and could sleep better knowing that Chi was not in a mainstream classroom for which she had not been transitioned or prepared.

That day, I committed to myself to not just show up for the changes. I decided I wanted to be a part of the change process. It made me realize how easy most of us forget 'the little people'. It also unveiled how much I didn't know about the politics and technicalities in the education of with children with disabilities. The following week, I called DSAM, was invited to the annual picnic, and the rest is history.

My involvement with this Board is my personal commitment to being a part of the change that shapes the future of our children with disabilities. It is my sincere hope that I will contribute to this sector such that our families will be enlightened, strengthened, and relieved that our organization is in their corner.

Dr. Chandra Evans joined the Board in January 2009 and now serves as the Secretary. She is the daughter of Charles and Shirley Evans and the oldest of their 6 children. Her youngest sibling, Chi, is 16 and lives in Fayetteville, North Carolina with her parents.



Of course there is no formula for success except perhaps an unconditional

Parents & Schools in Partnership: Practical Solutions for Educating Students with Down Syndrome Workshop

Make plans now to join us for this workshop, designed to help you understand how to successfully engage, instruct and enjoy your students with Down syndrome. This workshop will provide an overview of the specific learning needs characteristic of students with Down syndrome. Tips, strategies and solutions relevant to pre-school through high school will be covered.

Attendees will learn:

- How to open the lines of communication
- Ways to promote independence
- Environmental factors which promote success
- Effective home/school partnership techniques
- Various community resources
- Behavior modification strategies
- Alternatives to reward systems
- How to promote friendships
- Effective IEP goals
- Health issues affecting learning

There will be 2 sessions on January 28th, with one session geared toward teachers and one session geared toward parents. All are welcome to either session.

January 28th, 8 am - Session focus for Educators
January 28th, 6 pm - Session focus for Parents

Both sessions will be held at Memphis Educations Association, located at 126 Flicker Street, Memphis.

There is no charge for this event but you must register to DSAM office by January 22nd, 2010. Watch the mail and website for more information about this great workshop.

Inclusion Solutions is a quarterly newsletter, provided to the Down Syndrome Specialists. Would you like to receive Inclusion Solutions?

Email communications@dsamemphis.org with the subject: Subscribe to Inclusion Solutions and we will add you to the distribution list for future issues.

Looking for Mid-South Transportation Resources?

Memphis Area Transit Authority (MATA) Routes and Schedule Information

(901) 274-6282 or www.matatransit.com

Public transportation in the Memphis area. Offers reduced bus rates for people with disabilities during certain hours.

MATAplus

1370 Levee Road
Memphis, TN 38108

(901) 722-7144 or www.matatransit.com

Provides curb-to-curb bus service for people with disabilities. In order to utilize MATAplus service you need to complete an application.

MATA Travel Training

Betty Anderson
(901)274-2247

Assists individuals in learning how to use public transportation. Information about MATA riders rights.

Delta Human Resource Agency

915 Highway 51 South
Covington, TN 38019

(901)475-1460 or www.deltahra.org

Accessible rural public transportation in Lauderdale, Fayette, Tipton and non-urban Shelby counties.

Operates Monday through Friday from 6:00 a.m. to 6:00 p.m. Round trip \$3.00 (within the same county).

C2W Transportation Services

8598 Highway 51 N. Suite 1
Millington, TN 38053

(901) 872-1807

Must call at least 24 hours ahead of pickup.

BTW Transportation

831 Bullington Ave
Memphis, TN 38106-4652

(901) 774-0808

Ambulance Services, Wheelchair
& Disability Transportation

The Sounds of Sign Language

Kathryn M. Saunders M.A. CCC-SLP
Speech-Language Pathologist
UT Boling Center for Developmental Disabilities
Harwood Center



Language is defined as any system of formalized symbols, signs, sounds, gestures, or the like used or conceived as a means of communicating thought, emotion, etc. It is not merely speaking, but can be gestures, smiles, pictures, sign language, anything that conveys a message or thought.

To hear your child's voice is a truly special occasion and is something to be celebrated. To hear that delightful, charming, soft voice say 'mama,' 'milk,' or even 'no'—some would say there is no sweeter sound. A huge part of what is so beautiful about hearing those first words is that they are paired with meaning. Your child is actually communicating with you—identifying you as mother, asking for milk, or emphatically telling you 'no' to having their hair brushed. Oh, the power behind communication!

So what can be done to bridge the gap for a child who is ready to communicate but not equipped (either by age or development) to verbally 'use their words'? One excellent bridge-builder is sign language. If a child can bring their hands together and imitate body movements, they can begin to learn sign language (paired always with verbal language).

Language is all around us. We want to teach children to communicate and that communication is reciprocal, or the cause and effect interaction of 'you do, you get'. It gives children who are ready to communicate the ability to do so, decreasing frustration and increasing their vocabulary, while providing a strong base for when speech skills begin to catch up with their language abilities.

For those that think the use of sign language may hinder spoken language, multiple studies have proven this theory to be false. My own experience as a speech language pathologist, working in early intervention for seven years, has shown me time and time again that

the sooner you can get a child communicating and building a vocabulary—by whatever means—the better the outcome. Sign language is an excellent weapon for defeating the silence of a non-communicative child.

Of course, every child is an individual, and sign language may not be the right thing for every child. But sign language will not keep your child from speaking. Sign language should always be paired with verbal language.

In the early intervention setting, we are not 'teaching' it as a foreign language or trying to produce little kiddos who are proficient in signing. The goal is to produce the best communicators by the best and earliest means possible without jumping over any developmental steps. Decreasing frustration and increasing vocabulary, while increasing the amount of interaction you are able to have with your child while communicating, is the goal. And that is music to my ears.

Great Things Happen In Inclusive Schools

The week of December 7-11, 2009 marks *Inclusive Schools Week*, an annual event sponsored by the Inclusive Schools Network (ISN) at Education Development Center, Inc. (EDC), which is held each year during the first week in December.

Since its inception in 2001, Inclusive Schools Week has celebrated the progress that schools have made in providing a supportive and quality education to an increasingly diverse student population, including students who are marginalized due to disability, gender, socio-economic status, cultural heritage, language preference and other factors.

The Week also provides an important opportunity for educators, students and parents to discuss what else needs to be done in order to ensure that their schools continue to improve their ability to successfully educate all children.

For more information, or to download a celebration kit to use at your school, visit www.inclusiveschools.org.

Some Thoughts on Seclusion and Restraint

by Bev Adcock

The issues of restraining and/or secluding children with disabilities who have serious behavior problems is a hot topic right now. After several people died while being restrained or secluded, Congress, as well as many State legislatures, are struggling to come up with laws that protect everyone. Eventually, this is expected to become part of federal law. Until then, schools and parents need to proceed very carefully. This issue affects everyone.

Here in Tennessee one school district actually built wooden boxes, drilled air holes in the top, put children inside them and padlocked them in. This may have been a one-time occurrence – although the fact that they had time to build boxes makes that unlikely – but it turned into a full-time placement for those children. It accomplished nothing except to needlessly punish children even before they had a behavior and allow staff to ignore their responsibility to teach. It is nothing less than child abuse.

Seclusion itself isn't bad. Getting away from everything to a quiet place where you can calm down and pull yourself together is something we do for ourselves when we are upset. Used correctly, it can be an effective part of a behavior plan.

Usually a child is removed from class if he is aggressive (hurting himself or others or throwing things) or uncontrollably screaming and it disrupts class for more than a few minutes. Short outbursts or minor or one-time hitting, kicking, etc. should be handled by other methods. For example, you might move a child to the hallway for a few minutes and then return him to class once he is calm.

If the out-of-control behavior is serious or goes on longer than a few minutes, more needs to be done. Seclusion shouldn't be punishment or a way for adults to escape a frustrating situation. So how do you decide when

it is OK and when it isn't? First, there is a difference in "seclusion" versus "time out" or "cool down." Seclusion usually means a place where the child is locked in and left alone. Time out and cool down rooms are usually not locked and while the child may be alone, staff are nearby and make frequent visual checks to be sure the child is OK. Tennessee has very strict definitions for locked rooms that include the size, materials, doors, windows and locks as well as how often staff must check on the child. If seclusion, time out or cool down is suggested as a way to deal with behaviors, find out exactly what they mean. Removing a child and keeping them away from everyone else should always be the last resort. After the first time it happens, the IEP Team needs to meet and come up with a better plan for addressing the behavior.

The first rule of behavior management is that the child must be protected from harm. No child should ever be locked up. Locks are a substitute for having staff with

the child and allow staff to walk away and stop trying to resolve the problem. Leaving a child who is out-of-control locked up alone is a recipe for disaster. He could hurt himself or have a seizure because he is so agitated. Children locked in seclusion rooms have been seriously injured and some have died.

Because of the possibility of danger to the child, staff must always be either with the child or close by making frequent visual checks. That way if the child hurts himself or has a seizure, staff can quickly intervene.

Some children need an adult to help them get calm. Others may need to be alone, but staff still need to keep a close eye on them.

Restraint, or holding a child down, should only be used if it is the only way to keep him from hurting himself or others. Never lie on top of a child or hold them in a way that will restrict their breathing. If a child tells you he can't breathe, left him go immediately. Children have died while being restrained.

Any time you have a behavior plan for a child, make sure you understand everything, including how and when

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different parts of it will be used. If time out/cool down will be used, be sure you ask and understand:

- What is meant by “time out/cool down/seclusion”?
- When would time out/cool down be used (for which exact behaviors)?
- How often or how long would the behavior have to happen before time out/cool down is used? How severe would the behavior have to be?
- Where would time out/cool down take place (location of room, size of room, etc.)?
- Has the room been set up so ensure the child’s safety?
- How long would the child be in there at a time? How many times a day?
- Where will staff be? How frequently will they check on the child? (Visual checks should be done at one-minute intervals.)
- How will staff decide if using cool down is helping?
- What criteria will be used to decide when the child will return to class?
- Most important: What methods are being used to prevent the behavior from occurring in the first place?
- Never agree to have a child locked in.

As a general rule, if anything in the plan would be unacceptable for a nondisabled child or for someone to do to you if you got mad, it is NOT a good idea. However, if a child is attacking others and needs to be alone to get calm, staff may need to temporarily hold the door closed. This is better than using a lock as it keeps staff close and focused on calming the child down.

Be careful about using cool down with children who prefer to be alone and will act out so they can go to the cool down room. For students who prefer to be alone, find a different approach.

The set up of the cool down room depends on a child’s needs. If a child bangs his head or throws himself against walls or floors, these should be padded. On the other

hand, if the child’s out-of-control behavior is screaming, the physical design of the room may not be as critical. Ask to see the room and think in terms of what the child does when out of control and what helps them calm down. Don’t ask for things a child doesn’t need. The room should be empty so there is nothing to throw and nothing to do. The child should only be there until they are calm enough to return to class.

Even in the best-run programs, sometimes children who are out of control get hurt. They may scoot themselves across the floor during a tantrum and get rug burns. They may scratch or bite themselves. They may bruise or cut themselves when they fall against walls, floor or furniture. If a child is injured, ask lots of questions but don’t assume it was the fault of staff. On the other hand, make sure it wasn’t abuse. Regardless of the cause, focus on making sure it won’t happen again. Work with the parents to plan how to prevent any future harm by changing staff, providing staff with more training, changing the location or adding some safety precautions. Parents should be informed about any incidents and included in discussions about how to address the behavior.

Check frequently on how the elements in the behavior plan are working and change them if they are not effective. There must be documentation on when and why the child is in time out/cool down so the IEP Team can see how often it occurs and if the frequency is going down. Cool down can be a useful tool, but it should not be the only method used for out-of-control behaviors.

It is possible to improve the behavior of any child. But it requires a thoughtful, planned approach with a behavior plan that clearly spells out what needs to happen. Prevention should always be the biggest part of any behavior plan with the child’s safety as the number one priority.

Bev Adcock is co-owner of Possibilities, Inc., a company that provides training and consultation to parents and school districts on special education. She has been a classroom teacher, principal and surrogate parent and served on a Special Education Advisory Committee for a school district. She is co-author of 9 books and training curriculum and is a Behavior Consultant to parents and school districts.

Share Messages with Holiday Spirit

A great way to help build stronger relationships and awareness with the medical field is to send holiday cards to all of the medical professionals you interact with. Include your personal message and let them know how much you appreciate their support.

Upcoming December Activities

DSAM Holiday Party

December 12, 2009 from 5:00-8:00pm
Germantown United Methodist Church (Owings Life Center), 2323 West Street, Germantown

The DSAM Annual Holiday Party and Dinner is just around the corner! You are invited to join us as we ring in the holidays with a visit from Santa, gifts for the children, crafts, dancing and a puppet show.

There is no charge for this event, but please RSVP to the DSAM office by December 8, 2009.

Thanks to Audrey and Mary Aubrey Landrum for coordinating the holiday party again this year. Please contact them if you are interested in volunteering at 901.488.2068, 901.756.9037 or jlandru1@comcast.net.

DSAM Holiday Mom's Night Out

December 1, 2009 at 6:30pm

Join us for this popular event at the home of Martine and Laurie Hobson, 1954 Corbin Rd., Germantown. Please bring an appetizer or dessert and a wrapped gift for the gift exchange! RSVP to the DSAM office at 547-7588 or sonyaoliver@dsamemphis.org.



BWW & DSAM

The Second Annual Buffalo Wild Wings Golf Tournament, held August 21st at Stonebridge, was a success! BWW employees from the Wolfchase location were on hand to sign up teams, serve drinks and food, and coordinate the after-party, where door prizes and silent auction winners were announced. The event raised \$5,000, benefitting the Down Syndrome Association of Memphis & the Mid-South. A huge thank you to BWW and their employees for all of their hard work and efforts to help raise awareness and support DSAM.

donations

Donations 9/1/09 – 10/31/09

STEP UP for Down Syndrome

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Mills, Kelli, Emlyn & Jeb Polatty

In honor of Kelsey Schumacher
The Hanks Gang

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2893 So. Mendenhall Rd. Suite 3
Memphis, TN 38115

901.547.7588 fax 901.547.7589

www.DSAMemphis.org

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