

# THE DSG News

PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED

A P U B L I C A T I O N O F T H E D O W N S Y N D R O M E G U I L D O F D A L L A S

February 2009

Affiliate of the National  
Down Syndrome Congress  
and the National Down  
Syndrome Society

## Screening of *Forgotten Lives*

The Down Syndrome Guild will host a screening of the film, *Forgotten Lives*. This documentary chronicles the horror and abuse perpetuated against Texas' most vulnerable citizens who live in state institutions. In response to the issues raised in this film, concerned citizens formed Community Now!, a state-wide organization to take action to free people with disabilities from institutions. Jeff Garrison-Tate, the Executive Director of Community Now!, will lead the discussion.

This is an important time to be an advocate for people with Down syndrome. Please attend this event to learn more about the issues and how YOU can make a difference in the effort to reform Texas' dependence on state schools and increase opportunities for community-based services.

RSVP to Becky Slakman at (214) 267-1374 or [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net).

**Note:** On February 26, 2009,

the Community Now! coalition is sponsoring a march and rally at the state capitol to urge legislators to provide additional support so that people

with disabilities can live in the community – not institutions. Depending on the level of interest, a bus may be chartered for the day trip from Dallas to Austin.

**Why is it important to see this film? See "This Impacts your Child's Future" on page 7.**

Thursday,  
February 19, 2009  
6:00 pm - gather and socialize  
6:30 pm - screen and discuss  
First Community Bank  
429 Belle Grove  
Richardson, TX 75080  
(across the parking lot from the DSG office)

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## Get Together for Families of Babies with Down syndrome

Sunday, February 15, 2009  
3:00 pm - 5:00 pm  
St. Luke's Episcopal Church  
5923 Royal Lane  
Dallas, TX 75230

**Speaker:** Debbie Clark, L.M.S.W.- A.C.P., Licensed Clinical Social Worker, Children's Medical Center Dallas

**Topic:** Siblings and maintaining balance in the family

We realize that with the birth of your child with Down syndrome, you may have entered a whole new world – one that can be confusing and filled with deep feelings. Please join us for our New Parent Get Together! Come meet other parents, some new – some not so new! Get information, ask questions, and find out how the Down Syndrome Guild of Dallas can be a resource and support for you and your family. We look forward to meeting you and your whole family! For additional information, please call the DSG office at (214) 267-1374.

## GREAT WAY TO HONOR LOVED ONES

# Club 21

*is a Down Syndrome  
Guild program to honor a loved  
one: matching the numeral of  
the important chromosome that  
affects our children.*

To: The Lowe Family  
*In honor of Brittany Lowe  
and family.*

From: Jerry and Susan White

To: Jack and Parker Wood  
*Happy 2<sup>nd</sup> Birthday to Parker  
and Happy Belated 4<sup>th</sup> Birthday  
to Jack!*

From: Elise and Elliot Friou

A gift to the Down Syndrome Guild to honor loved ones is a tangible way to recognize their lives, celebrate birthdays, anniversaries, graduations, new homes, or any number of occasions. A gift in memory of a friend or relative is a thoughtful and caring way to express sympathy while sharing concern for an important cause.

Interested in making a *Club 21* donation? Contact Becky Slakman by e-mail at [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net) or by phone at (214) 267-1374.

## President's Message

*By Kelly Drablos*

2009 is now more than a month old. Our enthusiasm for resolutions is waning and our schedules are filling back up after the post holiday season lull. I hope many of you took the time to attend our first Saturday morning IEP Clinic on January 24<sup>th</sup> and seized the opportunity to learn more about developing an Individualized Education Plan for your student with Down syndrome which embraces inclusion in a meaningful way. Anne Eason and Kathleen Whitbread are speakers with extensive experience and national credentials and it is exciting to have been able to bring them to Texas.

Mark your calendars and do not miss our next two IEP Clinics on March 7<sup>th</sup> and April 4<sup>th</sup>. Regan Roth Fitzgerald, a local behavior education specialist, is presenting on March 7<sup>th</sup> and will discuss "Behavior Intervention Plans," commonly referred to as "BIPs." For those of you who are new to the IEP process, BIPs can be extremely beneficial for students with behavioral difficulties because they develop a methodology for dealing with challenging behaviors

to be implemented consistently by all relevant teaching professionals. BIPs are actual enforceable parts of the pertinent IEPs. Positive intervention strategies are the desired outcome of the process of writing and developing a BIP. Behavior is always a very popular topic for parents and educators alike.

On April 4<sup>th</sup>, Julie Liberman, a local speech pathologist, will discuss fun, friendship, play, social skills, and how to develop IEP goals and objectives to assist students with intellectual disabilities in becoming truly included participants in classroom social networks. I still remember a quote from a special educator named Barbara Wilcox from Indiana University, "School is the profound childhood experience." In order for your student to get the most out of their time in school, he or she needs to become as much a part of the school community as possible. Please join us in April and learn how to cultivate appropriate play skills for your child.

Call or e-mail the DSG office and reserve your spot at (214) 267-1374 or [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net).

## Hip-Hop Saturday for Adults with Down syndrome

**S**aturday, February 28, 2009

7:00 pm - 9:00 pm

Studio B

2108 Kidwell Street

Dallas, Texas 75214

*(Studio B is in the heart of the Lakewood neighborhood on Kidwell between Richmond and Prospect; behind Cantina Laredo, Professional Bank, and 7-11 on Abrams Road)*

If you enjoy funky music and the latest hip-hop steps, the *Options for*

*Adults Committee* invites you to come strut your stuff with the dancers from the SMU Division of Dance. Young men and women ages 19 and up are invited to dance your way to fun and friends. In this hip-hop class you will learn some groovy hip-hop moves - no previous dance training is required. RSVP to Becky Slakman at (214) 267-1374 or [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net).

## 2009 DSG IEP Clinics Coming Up

These workshops are designed to provide families with information to be prepared for the annual Individualized Education Plan (IEP) meeting required by school districts for every child who receives special education services. These workshops are **FREE** for Down Syndrome Guild of Dallas members and teachers! Space is limited and **RSVP is required** – (214) 267-1374 or [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net).

### **Behavior Intervention Plans**

*Saturday, March 7, 2009*

*10:00 am - 12:00 pm*

*Region 10 Service Center*

*904 Abrams Road*

*Richardson, TX 75081*

*Regan Roth Fitzgerald*

(M. Ed. BCBA and President Behavior and Education Specialists of Texas, LLC) will speak on how to develop and implement an effective Behavior Intervention Plan (BIP). Attendees will learn about the four main functions of all behaviors and how this

relates to the development of all parts of the BIP from the functional assessment to positive intervention strategies. The speaker will take attendees step by step through the process and have a chance to practice writing techniques and strategies for problem behaviors.

***It's fun to have fun, but you have to know how!***

*Saturday, April 4, 2009*

*10:00 am - 12:00 pm*

*Region 10 Service Center*

*904 Abrams Road*

*Richardson, TX 75081*

*Julie Liberman (M.A.CCC-SLP*

and owner of Speech TX) will present strategies for facilitating friendships.

Topics will include:

- Importance of play
- Typical development of play skills
- Different theories for teaching how to play and improve social skills
- Incorporating these skills into IEP goals and objectives

## 2009 Planners – it's Not Too Late!

This year's calendar has a new look and style. We have a beautiful weekly planner rather than a 12 month wall calendar featuring beautiful photos of Down Syndrome Guild members of all ages. These planners will fit easily in purses and brief cases. Order several daily planners as gifts for your friends, family, teachers, and co-workers. Funds raised will support Down Syndrome Guild programs and services, but more importantly create awareness and portray a positive image of our children and adults for the community.

The cost is \$15 for each planner. To place your order, contact Becky Slakman by phone at (214) 267-1374 or by e-mail at [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net). You can also go to our website at [www.downsyndromedallas.org](http://www.downsyndromedallas.org) to download an order form and fax back to the office or mail at your convenience.

## Faces of the Down Syndrome Guild



◀ 2009 calendar model, Nate Russell, says peek-a-boo. Alex Drake, Dillon Diener, Brayden Zipper, and Jackson Geren enjoy just hanging around with friends as seen in our February 2009 calendar photo.

## Study Demonstrates that Inclusion Works *By Nancy Davenport*

Many people think that the jury is still out on whether including children with developmental disabilities in regular classrooms is beneficial. I have heard varied statements on the negative side.

People have said everything from “other kids could catch what the kid with disabilities has” to legitimate concerns from regular education teachers who say “I don’t feel qualified.”

So a study was done.

To learn for themselves about the effectiveness of including kids with disabilities in regular classrooms, the National Down Syndrome Society commissioned a study a few years ago conducted by Gloria Wolpert, EdD. They sought to learn directly from teachers and parents just how it has worked out having kids with differing abilities learn together.

Many teachers in the survey responded that having the kids with disabilities in their classrooms was more rewarding than expected. In addition, the study concluded that teacher preparation was important for success, but, surprisingly, formal training from the school district did not appear to be particularly relevant.

A mixed classroom worked well, the report concluded when:

- There was sufficient support for the classroom teacher
- Students were placed in classes with other students the same age
- Teachers were given more preparation time
- Teachers were given more time to

confer with other teachers, therapists, and parents

In addition, factors which affected success were when teachers:

- Had personality and style which matched the skills of the student
- Were flexible
- Were willing to modify classroom material
- Used hands-on learning tools

“The majority of the teachers who participated in the nationwide study reported that their entire class benefitted from the presence of students with disabilities.”

I think it is important to consider what “beneficial to students” means in the context mentioned above. Just who is benefitted when they talk about that?

Most people immediately assume the reference is to the students with disabilities, and certainly they usually do profit from being in a regular classroom.

The majority of the teachers who participated in the nationwide study reported that their entire class benefitted from the presence of students with disabilities.

This is the same type of gain an artistically talented student might receive from working with a student who is a computer whiz. The benefit is in being exposed to many different kinds of people.

At the same time, almost all the teachers who responded to the survey found teaching students with disabilities

enjoyable, with some calling it the single most interesting and rewarding experience of their careers.

According to the survey, though, the keys apparently to a successful classroom experience with a variety of kids are support and teaching style. Teachers must have help from other teachers and specialists, but they also must be creative.

Without these two, our kids with disabilities will not thrive, and my guess is neither will anyone else in that classroom. We already knew this, but now it has been confirmed.

*Nancy Davenport is editor of The DSG News and can be reached at [nancdave@swbell.net](mailto:nancdave@swbell.net).*

### Dad's Group Happy Hour

Wednesday, February 18  
6:30 pm - 8:30 pm  
The Londoner

14930 Midway Road  
Addison, TX 75001  
phone: (972) 458-2444

Join Down Syndrome Guild dads, Chris McKee and Doug Dureau, for drinks and conversation. Feel free to invite other dads who might enjoy attending. RSVP to Becky Slakman at (214) 267-1374 or [dsged@sbcglobal.net](mailto:dsged@sbcglobal.net). If you are not able to attend this time but would like to be added to the e-mail list for future events, please let Becky know.

## Individualized Education Plan (IEP) Corner

The annual Individualized Education Plan (IEP) meeting is required by school districts for every child who receives special education services.

The most important aspect of a good IEP is that goals and objectives be clearly stated with measureable results. The material below may help parents and teachers understand what it will take to establish and achieve reading goals and objectives.

*Reading First*, a model program from the U.S. Department of Education calls for 90 minutes of instruction per day, 5 days a week, from kindergarten through grade 3.

Children who are not making sufficient progress receive additional instruction.

This model assumes that **reading instruction takes place in general education** classrooms. Children are not allowed to fall behind. They are given the instruction they need when they need it.

"A high-quality reading program that is based on scientifically based research must include instructional content based on the five essential components of reading instruction integrated into a coherent instructional design.

"The design should also consider the allocation of time, including **a protected, uninterrupted block of time for reading instruction of more than 90 minutes per day.**"

### Three Reasons for Reading Failure

Tragically, 75 percent of children who are not proficient readers by the end of third grade will **never** be proficient readers.

Author, Sue Whitney says:

*"I am not aware of any research showing that a research based program will work if it is used by a teacher who is not properly trained, if the teacher-student ratio is wrong, if the required hours per day and week are wrong, or if the program is wrong for the child's stage of reading development."*

Reading programs will not teach your child to read proficiently if:

**"If the reading program is not matched to your child's stage of reading development and is not sufficiently intense to bring his skills to where they need to be for his age and grade, it is worthless for your child.**

1. The program is not appropriate for the child,
2. There are too many students in the reading class,
3. The pace of the instruction is too rapid for children to achieve mastery of skills presented.

### Stages of Reading Development

If the reading program is not matched to your child's **stage of reading development** and is not sufficiently intense to bring his skills to where they need to be for his age and grade, it is worthless for your child.

If the program is not appropriate for your child's reading stage, it will be ineffective for him, even if it works for other children his age.

### Six Qualities of Effective Reading Programs

1. Effective programs are driven by reading research, not ideology.

2. Effective programs emphasize direct, systematic, intensive, and sustained reading.
3. Effective programs require school-wide buy-in before they are adopted.
4. Effective programs are supported by initial professional development and extended follow-up training throughout the school year.
5. When implementing an effective program, the school needs to be committed to the integrity of the program's instructional approach and materials.
6. Effective programs make effective use of instructional time, provide multiple reading opportunities, and employ a variety of reading assessments.

This material is from [WrightsLaw.com](http://WrightsLaw.com). For more information go to their website.

## Rewards Card Reminder

Please remember to use your **Tom Thumb** and **Kroger** Rewards Cards to benefit the Down Syndrome Guild.

**Note:** The **Tom Thumb** Reward Card number is 2768. **Kroger** card holders are now required to present a special barcode upon purchase to designate the DSG as your organization of choice. A letter containing this special barcode and instructions can be found on our website at [www.downsyndromedallas.org](http://www.downsyndromedallas.org).

## In the Community...

### Disability Expo

February 7, 2009  
1:00 pm - 4:00 pm  
Garland Special Events Center

Sponsored by the Arc of Dallas in cooperation with several area school districts, this annual event brings together agencies and service providers for children and adults with cognitive disabilities. For additional information call the Arc of Dallas at (214) 634-9810.

### Inclusion Works! Conference

February 25-28, 2009  
Renaissance Hotel  
Austin, Texas

Sponsored by the Arc of Texas, this annual state-wide meeting is for both parents and educators. Many nationally-renowned experts will give presentations about "best practices" for including students with disabilities in general education classes. To register go to the Arc of Texas website at [www.thearcoftexas.org/conferences](http://www.thearcoftexas.org/conferences).

## New IDEA Regulations Released by U.S. Department of Education

On December 1, the Department of Education (DOE) released new regulations for IDEA Part B that will take effect on December 31, 2008. IDEA (Individuals with Disabilities Education Act) is the federal legislation which requires local school districts to provide special education services. Below is a brief summary of the major changes.

### Parental Consent

If parents revoke consent for services being provided to their child under IDEA:

- the revocation must be in writing
- the school must provide you with written notice (under § 300.503) about their intentions for your child. This written notice may be one way of establishing just when the services should end.
- the school district may not utilize mediation or the due process procedures to challenge your revocation of consent;
- the school is not required to convene an IEP Team or develop an IEP; and
- the school will not be deemed in noncompliance with the IDEA for failure to provide a FAPE to an otherwise eligible child. §300.300(b)(4)

### Representation by Non-Lawyer Advocates

The section on Hearing Rights has been amended to specify that non-lawyer advocates can represent either side (parent or school district) in a due process hearing unless this overrides state law. §300.512(a)(1)

### Compliance Issues

A new monitoring and enforcement section is added, establishing a one-year time frame for school districts to fix any IDEA noncompliance issues. Corrective action must be completed one year from the time the problem was discovered. The current regulations have no specific timeline. §300.600(e)

A State now has 120 days, after submitting its annual performance report (APR) to DOE, to provide a report to the public on school performance. This doubles the current allowable time frame. §300.602(b)(1)(i)(A)

Clarifications were also made in the areas of state monitoring, technical assistance, and enforcement; and allocation of funds.

For the complete analysis of comments and changes to the final regulations see the Federal Register for December 1, 2008 at <http://www.wrightslaw.com/idea/law/FR.v73.n231.pdf>.

## Special Thanks

Thank you to the following school organizations that have financially supported the Down Syndrome Guild of Dallas in recent months:

- Highland Village Elementary School Student Council
- Plano East High School Golden Girls
- Jesuit College Preparatory Booster Club

## This Impacts your Child's Future!

There is currently a heated debated in Texas about the condition of our "state schools," which are not schools but large institutions that house people with developmental disabilities. On December 1, 2008, the U. S. Department of Justice released a scathing report about the horrific conditions in the Texas state schools and threatened litigation if changes are not made. The report includes allegations of abuse, neglect, mismanagement and violations of civil rights.

***This issue affects every one who has a child or family member with Down syndrome because decisions will be made by the 81<sup>st</sup> Texas Legislature about how to spend funds for services for adults and children with developmental disabilities – now and in the future!***

There are currently 50,000 people on waiting lists to receive services in the community through a Medicaid waiver program with the average wait of 8-10 years. Our state currently spends over 2 ½ times the amount of money to institutionalize a person with a disability than it spends to support an individual in a community-based setting (i.e., the home of a relative or a small group home). State schools are the only entitlement program for people with developmental disabilities, forcing many families to place their loved ones in institutions because they can no longer wait for supports and services in the community.

For the first time in Texas history, we have legislators who are willing to

reform the current system, which favors funding institutions over community-based care. Representative Patrick Rose

**“***This issue affects every one who has a child or family member with Down syndrome because decisions will be made by the 81<sup>st</sup> Texas Legislature about how to spend funds for services for adults and children with developmental disabilities – now and in the future!***”**

and Senator Rodney Ellis have proposed legislation that includes the following ideas:

1. Fully fund the waiting lists for Texans with disabilities in part through funds saved through the consolidation and closure of state institutions
2. Consolidate Medicaid waivers with a system that determines services based on needs rather than type of disability
3. Develop additional accountability measures for private providers of services to ensure that community services and supports are provided at the highest standards.

For additional information on this topic, go to "In the news" section on our home page, [www.downsyndromedallas.org](http://www.downsyndromedallas.org), and click on the article *The ARC of Texas Responds...*

***Take action! Plan to attend the screening of "Forgotten Lives." See page 1.***

## ...and Around the State

**Blazing the Trail with Transition - 2009 Annual Texas Transition Conference**

February 23-25, 2009  
Doubletree Hotel  
Austin, Texas

The Texas Transition Conference is an annual three-day conference that equips individuals with transition information in the hopes of improving outcomes for postsecondary opportunities for youth with disabilities. Key note speakers are internationally recognized experts with topics including: *Transitioning to the University, Student-Directed IEP Meetings, and the State of Transition in Texas* among others. For more information contact Cheryl Grenwelge, TTC Coordinator - (979) 458-1593 or see the TTC website at <http://ttc.tamu.edu/>.

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DOWN SYNDROME GUILD OF DALLAS

*This month on the DSG Calendar, Wyatt, Nate, and Samuel show us what friends are for.*



MISSION STATEMENT: THE DOWN SYNDROME GUILD OF DALLAS PROVIDES ACCURATE AND CURRENT INFORMATION, RESOURCES AND SUPPORT FOR PEOPLE WITH DOWN SYNDROME, THEIR FAMILIES AND THE COMMUNITY.

ARE YOU MOVING? DON'T FORGET TO PROVIDE US WITH YOUR CHANGE OF ADDRESS BY CALLING THE OFFICE OR BY E-MAIL AT [DALLASDSG@SBCGLOBAL.NET](mailto:DALLASDSG@SBCGLOBAL.NET).

THE PUBLICATION OF *THE DSG NEWS* IS MADE POSSIBLE BY THE GENEROSITY OF THE CHARLES H. PHIPPS FAMILY FOUNDATION.

## Down Syndrome Guild Calendar of Events

### February

Mom's Escape - *Visit the website for details about the February outing.*

### February 15

New Parent Get Together

### February 18

Happy Hour for DADS Group

### February 19

Screening of *Forgotten Lives*

### February 26

Community Now! Rally in Austin

### March 7

IEP Clinic – Behavior Intervention Plans