



THE DSG NEWS

Down Syndrome Guild of Dallas

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

downsyndromedallas.org

January 2006

DSG Calendar

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Other Events of Interest

February 22-25

13th Annual Inclusion Works!
Conference, Austin, TX

March 3-4

Special Education Law and
Advocacy Boot Camp, Ft. Worth, TX

Keep Current!

Check

www.downsyndromedallas.ORG

**for the most up to date
activity info and to read the
DSG newsletter online.**

www.downsyndromedallas.org

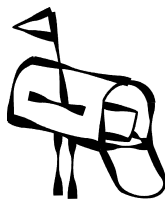


The DSG website has moved!!

Our new site is

www.downsyndromedallas.ORG.

Please be sure to change it in your "Favorites" list and tell your friends and family as well. We're excited about this change to non-profit identity and hope it will resolve our technical problems.



NOTE!

All correspondence should now go to the DSG's physical address, 701 N Central Expwy.

Bldg 5-I,

Richardson, TX 75080.

The PO Box is no longer a valid address.



DSG Board Meeting

Monday, January 9, 2006

7:00 pm

701 North Central Expressway

Bldg 5, Suite I

Richardson, TX 75080

All members are welcome to attend the regular meeting of the DSG board at the DSG office. Directions: From Dallas, take I-75 north and exit Arapaho – exit #25. Go left/west under I-75, then go left/south on the frontage road (or take U-turn lane). Turn right/west into the first driveway after Belle Grove. Look for a sign that says "701 N. Central Expressway." Go to the end of the driveway and it's the last building on the left, across from the bank.

-Submitted by Kelly Theriault



2006 DSG Calendars

Now Available!

The 2006 DSG calendars featuring our cute kids are currently on sale for \$15.00 each. Also available are boxed greeting cards featuring more of our cute kids! 10 cards per box for \$10.00 a box. Call Marissa Easterling at 214-987-4575, the DSG office at 214-276-1374, or visit www.downsyndromedallas.org for more information and to make your purchase.

¡Los Calendarios 2006 de DSG Ahora Disponibles!

Los calendarios 2006 de DSG que representan nuestros lindos niños estan actualmente en venta por \$15.00 cada uno, y presentando tarjetas que representan más de nuestros niños. 10 tarjetas por cada caja por \$10.00 una caja. Llame a Marissa Easterling al 214-987-4575 o visite www.downsyndromedallas.org para más información para comprar.



Mom's Night Out

Sunday, January 22

1:00 - 3:00 pm

Inessa Stewart Antiques & Garden Café

NW Corner of Lovers Lane and Inwood, Dallas, TX

Moms, do you need an afternoon out? Please join us for light munchies for purchase and COMPLIMENTARY mimosas. Please RSVP by Thursday, Jan 18 if you will be joining us by calling Maureen Tignor at 972-691-2458 or emailing her at motig62@comcast.net.

Hope to see you there...and please be sure to invite aunts and grandmothers! The café is on the same corner as Blockbuster and Jack-In-The-Box. Call 214-366-2660 if you need directions.



IEP (Individualized Education Plan) CLINIC

Saturday, January 21, 2006

10:00 am - 12:00 pm

DSG Office, 701 North Central Expwy.

Bldg. 5 - I

Richardson, TX 75080

"Inclusion and Public Schools---All, Some, or a Little---Ways to Make It Part of Your Child's IEP"

Every spring the DSG receives requests from families for assistance in preparing for the ARD (Admission, Review, and Dismissal) meetings. In response to this need, the DSG is hosting an IEP clinic for parents. This year you can be prepared!!

Kelly Drablos, board member and mother of Alana (20 years old with Down syndrome), will present practical advice on the topic and recount personal positive experiences with inclusion in the Allen Independent School District. Ms. Drablos is a practicing real estate attorney, the mother of four, and a long time advocate for inclusion in education. Bring your concerns and questions about this topic and discuss them with other parents.

Please reserve your spot; space is limited. Mail a short note indicating you will attend with your name, address, and phone number, any format will do, to the DSG office at the address indicated above, email your registration to gzarbo2005@sbcglobal.net or call the office with the same specifics at 214-267-1374. This first clinic is free, but we do need to have attendance

verified at least two weeks in advance. Translation will be provided if requested in advance. Registration deadline is January 10th.

February Clinic

Our second clinic will be held Saturday morning, February 18, from 10:00 am – 12:00 pm at the DSG office. Myrna B. Silver, special education attorney, former special educator, and an advocate for children with special needs, will discuss behavior and discipline.

March Clinic

Our third clinic will focus on language and communication. Lynn Campbell, a local private speech therapist with extensive experience working with children with Down syndrome, will speak. The date is Thursday, March 25, again from 10:00 am – 12:00 pm at the DSG office.

All three clinics require reservations two weeks in advance as mentioned above.

Le invitamos a una Charla Informativa para IEP (Plan individual de educación)

El Sábado, 21 de Enero de 2006
De las 10:00a.m. a 12:00 del mediodía
En la Oficina de la Organización de Síndrome de Down (DSG)

Dirección: 701 N. Central Expressway
Edificio 5-I

Richardson, TX 75080

Se tratara de

"Escuelas Públicas y la Inclusión -- Todas, algunas o pocas maneras de hacerlo parte de IEP de su niño."

Cada primavera la Asociación del Síndrome de Down recibe peticio-

nes de familias para asistencia en las preparaciones de las reuniones de ARD (Admisión, Revisión, y Despacho). En respuesta a la necesidad la organización del síndrome de Down llevara a cabo una clínica de IEP para los padres. ¡Este año usted estará preparado!

Kelly Drablos, miembro del comité y madre de Alana (Joven de 20 años con síndrome de Down) presentara consejos prácticos en el tema y recuento personal en experiencias positivas con la inclusión en el distrito Independiente de Allen. La señora Drablos es una Abogado practicante en relación a Bienes y Raíces, madre de cuatro y una defensora de la inclusión en la educación. Traiga sus dudas y preguntas acerca del tema y consúltelo también con otros padres.

Por favor haga su reservación, espacio es limitado. Envíe una nota pequeña indicando que usted estará presente con su nombre, dirección y número de teléfono a la oficina de DSG a la dirección indicada arriba, envíe un correo electrónico a gzarbo2005@sbcglobal.net, o llame a la oficina con las mismas especificaciones al 214-267-1374.

La primera clínica es gratis, pero si necesitamos tener la asistencia confirmada al menos dos semanas en adelanto. Traducción en español será proveída si usted la pide con anticipación. Registracion termina el 10 de Enero.

Charla Informativa en Febrero

Nuestra segunda reunión será el Sábado, 18 de Febrero de las 10:00 de la mañana a las 12 del mediodía en la oficina de DSG. Myrna B. Silver, Abogado de la educación Especial, educadora en el pasado y defensora de los niños con necesidades especiales, discutirá conducta y disciplina.

Charla Informativa en Marzo

Nuestra tercera reunión se enfocara en lenguaje y comunicación. Lynn Campbell, una Terapista Privada en Lenguaje, con una gran experiencia trabajando con niños con SD hablará. La fecha es para el Jueves 25 de Marzo de 10:00 am a 12:00 pm en las oficinas de DSG.

Todas las reuniones requieren reservación dos semanas de antemano como se menciona anteriormente.

-Enviado por Kelly Drablos ☞

13th Annual Inclusion Works! Conference

February 22-25, 2006
Renaissance Austin Hotel
9721 Arboretum Boulevard
Austin, TX

Each year, the Arc of Texas produces the state of Texas' largest conference on inclusive education. More than 1,500 teachers, school administrators, paraprofessionals, and parents gather to share their struggles and success stories. This year's conference is sponsored by The Arc of Texas in partnership with The Access to General Curriculum Network and VSArts Texas

Registration \$170 - professionals,
\$45 - paraprofessionals, parents and students
Hotel \$117/night for single, double, quad or triple
Registration limited to the first 1200 received.

What is Inclusion?

Inclusion IS...

Based in home schools:

- ALL children attend the schools

they would attend even if they weren't eligible for special education services.

Based in age-appropriate, regular classes with support services from special education:

- Children with disabilities participate as members of regular, age-appropriate classes and receive services from special education based on Individual Education Plans (IEPs).

Based on zero-reject:

- Students with disabilities follow the same schedules, use the same facilities, and participate partially or fully in academics, extracurricular, and co-curricular activities alongside students without disabilities.

- Students receive support and encouragement to develop friendships and social relationships with students who don't have disabilities.

- Students with disabilities receive their education and job training in natural community environments.

Based on cooperative learning and peer instruction:

- All teachers are trained to deal with students of all abilities through a unified rather than parallel teacher training system.

- Instructional teams include teachers, special educators, parents, instructional aides, and therapists.

- Students with and without disabilities benefit from peer instruction.

Inclusion is NOT...

- Dumping students with disabilities into regular programs without preparation or support.

- Isolating students with disabilities

in regular schools and classes.

- Ignoring students' individual needs.
- Exposing students to unnecessary hazards or risks.

- Allowing only some kids to be in regular classrooms.

- Requiring students to fit the program, rather than fitting the program to the students.

- Segregating special education classes in separate wings at a regular school.

- Ignoring parents' concerns.

- Placing unreasonable demands on teachers and administrators.

What Inclusive Schools Look Like...

- All children are taught to understand and appreciate human differences.

- Teachers and administrators receive the support necessary to include all students in regular education classrooms.

- Parents' concerns for their children are taken seriously.

- Cooperative learning and peer instruction are strategies used throughout the school.

- "All" means "all," not "all but..."

- Special education is a service, not a place.

- All kids are given the opportunity to develop real friends, not just peer buddies or helpers.

- The entire community honors diversity and supports quality education for all students.

History of the “Inclusion Works!” Program

The Inclusion Works! Project:

The Inclusion Works! program began in 1993 as a five-year grant project funded by the Texas Planning Council for Developmental Disabilities, the Texas Education Agency, and The Arc of Texas. The intent of the project was to promote a statewide systems change in the way Texas schools educate children with disabilities. The Inclusion Works! program exists to increase opportunities for all students to belong and contribute to the school community and to learn, work, and play with their same-age peers in general education settings. Though the grant funding has now ended, The Arc of Texas continues its fervent commitment to being the state’s leader in promoting the practices of inclusive education.

The Legal Impetus for Inclusive Education:

In 1975, the United States Congress passed Public Law 94-142, which is now called the Individuals with Disabilities Education Act (IDEA). This law was designed to assure all students with disabilities the right to receive a “free and appropriate public education.” Part of the language in the IDEA sets a strong precedent for inclusive education, as the following excerpts indicate:

“To the maximum extent appropriate, children with disabilities...are educated with children who are not disabled,” and “special classes, separate schooling, or other removal...from the regular educational environment occurs only when the nature or severity of the disability... is such that education in regular classes with the use of supplementary aids and

services cannot be achieved satisfactorily.”

As Public Law 94-142 was passed, Senator Robert Stafford eloquently articulated the spirit of what the IDEA was intended to accomplish:

“This thing that we do, then, is not only an act of law for equality in education, but an act of LOVE for those extraordinary children wishing only to live ordinary lives.”

For more information, contact The Arc of Texas, 8001 Centre Park Drive, Austin, Texas 78754. Toll-Free: 1-800-252-9729; 512-454-6694; Fax: 512-454-4956. Email: secretary@thearcoftexas.org. Website: www.thearcoftexas.org.



Special Education Law and Advocacy Boot Camp

Friday, March 3, 2006
8:00 am Registration
9:00 am – 4:00 pm Program,
followed by a reception

Saturday, March 4, 2006
8:00 am Registration
9:00 am – 4:30 pm Program
Will Rogers Memorial Center
3401 W. Lancaster,
Fort Worth, Texas 76107

Mark your calendars for this intensive 2-day program on March 3 - 4, 2006, presented by Community Solutions of Ft. Worth.

- Learn the system and how to make it work
- Increase cooperation between schools and families
- Create win-win ARDs (Admissions,

Review and Dismissal) and parent-teacher meetings

- Updates, information and background on the Individuals with Disabilities Education Act (IDEA)
- Insights on tests and measurements
- Smart IEPs (Individualized Education Plans)
- Tactics and strategies for effective advocacy

Early Registration (by February 3)

Families \$125 per person
School Professionals \$150 per person
Service Providers \$150 per person

Late Registration (after February 3)

Families \$150 per person
School Professionals \$175 per person
Service Providers \$175 per person

Fees include Continental breakfast and lunch on both days, Friday reception, and two books by Peter and Pamela Wright - *Wrightslaw: IDEA 2004* and *Wrightslaw: From Emotions to Advocacy*, 2nd ed. To register go to www.arcdallas.org/wrightslaw.htm or call 817-871-7392.

Speakers Peter and Pamela Wright are authors and experts on special education law and advocacy. Peter Wright, an attorney representing children with special educational needs, has argued successfully on behalf of these children before the U.S. Supreme Court. Pamela Wright is a psychotherapist whose work with children and families has given her a unique perspective on parent-child-school dynamics, problems and solutions.

Event Sponsors: The Arc of Dallas, The Arc of Greater Tarrant County, Education Service Center Region XI, and Mental Health Mental Retardation of Tarrant County.

Wrightslaw Boot Camp Testimonial

By Laila Kawar

I recently attended the Wrightslaw Special Education Law and Advocacy Boot Camp in Oklahoma presented by Pete and Pam Wright. The conference was great and included information regarding IDEA 1997 and 2004, Tests and Measurements, smart IEP’s, Mediation and Due Process Hearings, No Child Left Behind, Effective Advocacy Strategies, Tips to Resolve Problems with the School and much more! The information presented was concentrated and very helpful.

Three months ago I attended the Special Education Law Conference in Region 10 presented by attorney Jim Walsh and associates regarding the changes in IDEA 2004. The information presented then was very good, but my overall impression was that it was geared more toward schools protecting themselves from litigation. The Wrightslaw conference was child/ parent friendly and included more than just changes in IDEA.

I was very impressed with the focus on positive communication and building relationships between school and parents. The Wrightslaw made it clear that we as parents need to learn as much as possible about the law to be able to effectively advocate for our children, but they also emphasized the importance of building bridges, listening and respecting the school team, and positive negotiation that will lead to problem solving instead of conflict (whenever possible). We will need to work with school personnel for many more years and we need to build and maintain good relationships that will not hurt future negotiations. Their approach reminded me of what I learned during my training

at Partners in Policymaking. Communication is the key to maximize the potential for our children. Of course when we have tried every measure available, and problems are not resolved, we must know about the laws and legal options and choose the path that will ensure our children's success.

At the conference we received two books, *IDEA 2004* and *From Emotions to Advocacy* as gifts. Some of the other Wrightslaw books were offered for sale half-price and I thought that was great. We also received a 12 page handout entitled "10Tips: How to Use IDEA 2004 to Improve Your Child's Special Education". I received permission from Pam and Pete Wright to share this handout with others. If you or someone you know are interested in getting a copy, please email your fax number to me at rashaangel@msn.com and I will send you the information.

Finally, just a reminder, the Wrights are coming to Fort Worth in March 2006. I would highly recommend their conference to everyone; they will have updated information on legal issues. I am planning on attending the conference again. Hope to see as many of you there!

-Submitted by Kelly Theriault ☞



Partners in Education

Partners in Education is a free 3-hour online self-study course for parents of children with disabilities from Partners In Policymaking. The course is designed to teach the skills you need to advocate for your child. You will learn about:

- Laws governing special education and how they protect your child's rights
- Your role in your child's educational experience
- Your child's Individualized Education Program (IEP) and your role in developing the IEP
- How to advocate for your child
- Your rights if you believe your child's educational rights have been violated.

For more information, go to: <http://www.partnersinpolicymaking.com/education/>.

-submitted by Minnie Blackwell ☞

Notable Quote



We tend to think of classroom placement for a child with a disability in an upside down way. We think of moving from a more restrictive to a less restrictive situation. There is this unspoken belief that a student must prove s/he can make it in the less restrictive placement. That is not how it should work. We start with the idea of a regular classroom, regular curriculum, regular home work, well you get the idea. Then slowly decide what adaptation or modifications (restrictions) the student needs to successfully achieve the goals outlined in the IEP.

-Drew Dixon, Director of Intervention Services,
The Arc of Dallas, www.arcdallas.org ☞

Raised to do his best

By Leslie Garcia
November 20, 2005

Adam Bourgeois makes you see the beauty of a job well done.

Every so often – though his sunny disposition keeps it from happening too much – Adam Bourgeois has a little wave of wanting what is beyond his capabilities: To drive. To have his very own car.



Adam Bourgeois, 23, of Plano, works cleaning exercise equipment at the Plano Family YMCA.

Photo: BRANDON THIBODEAUX/DMN

But Adam, born 23 years ago with Down syndrome, knows those are only dreams. So he smiles his sweet smile. He remembers what his parents tell him about doing his best. And he takes pride in what he can do.

If you use exercise equipment at the Plano Family YMCA, you may not see Adam. But you see the results of his work: The meticulously cleaned treadmills and elliptical machines, sprayed and polished during the early afternoon, when the Y is quiet. The dust-free gymnasium floor.

"I fill out a time sheet," Adam says proudly. "The gym's dirty, and I have to clean it. I sweep."

Lisa Edgar, fitness director, says Adam does a very good job.

"We get a lot of compliments on him, people saying the machines are nice and clean."

Adam is not the only young person with disabilities working at the Y. Four others do, too. Their jobs include folding towels, and they take their work seriously. One young man always wears a tie, because his dad wears a tie when he goes to work.

The four are part of a program with the Plano Independent School District. That's how Adam got started. And when he graduated from high school, the Y offered him a job.

"A lot of times, sadly, after school ends," kids like Adam stay at home with nothing to do, says Mike Bourgeois, Adam's dad. "It's been a blessing to have the Y step in. This is a godsend."

Adam began working Mondays and Fridays from 2 to 4 p.m. But the Y needed him more, so now he's added Wednesdays.

You can tell he's on-duty by looking at the exercise equipment. See a yellow band on your treadmill? That means it needs to be cleaned. So when you've cooled down and stepped off, Adam will get started.

How many does he tackle in an average workday?

"Lots," he says.

Indeed. The Y has 18 treadmills and 12 elliptical machines, plus a handful of others. Adam starts by pulling on a pair of white gloves in the employees-only room. He takes a spray bottle of cleanser and a towel, and walks his slow, deliberate pace to a machine on the last row. He removes the yellow band, puts it on his wrist and gets to work.

He doesn't talk much, but laughs easily. When he is working, though, he is intent, focused.

You wonder – as he sprays cleanser on the towel, as he wipes handles and

pedals – just what he thinks about. How to spend his paycheck maybe? Deciding the next wrestling DVD he'll buy with it, or the restaurant where he'll do one of his great pleasures, treat his family to dinner?

Is he thinking about his other job, sweeping up at the Cinemark Tinseltown theater in Plano? About playing third base on his Special Olympics baseball team? Or remembering what he learned in his Monday night Bible study?

Or maybe, considering what his parents and employers say about him, he is just intent on his work.

“We raised him as though there were nothing wrong with him,” says his mom, Trudy Bourgeois. “Our philosophy has been, whatever your best is, that's OK with us. Just make sure it's not less than your best. For Adam, this may be his best. For us as parents, it's maybe a little sad, to be honest. But Adam grows in other ways.”

When Adam was young, sometimes people thought his parents were hard on him, Mrs. Bourgeois says.

“We don't accept half-done; we just don't. ... It's important to instill that sense of responsibility and duty because now it's paying off.”

The job gives her son a sense of purpose, of fulfillment, she says. It gives him what others have, the ability to work.

Drew Dixon, a board member of the Down Syndrome Guild, says this type of arrangement works for several reasons.

“It allows him to work and be paid, but he's also with people with and without disabilities. This is the making of a normal community, and 'normal' means a mixture of people.”

Mrs. Bourgeois says she believes that God created people such as Adam to teach the rest of us about life's riches.

“I can't begin to tell you how many times people come up and say, 'I want you to know what an influence your child has on my child.'”

“Adam is a reminder to be humble,” she says, “to not take our gifts for granted.”

- Submitted by Minnie Blackwell. Reprinted with permission of the Dallas Morning News. E-mail lgarcia@dallasnews.com. View this article online at: http://www.dallasnews.com/s/dws/fea/life/stories/DN-NSL_ourtown_1120.ART.State.Edition1_26f93440.html.

Criado para hacer lo mejor

*Por Leslie García
20 de noviembre de 2005*

Adam Bourgeois muestra la belleza de un trabajo bien hecho.

De vez en cuando – aunque su alegre disposición evita que esto ocurra demasiado seguido – Adam Bourgeois tiene la pequeña inquietud de desear aquello que está más allá de sus posibilidades. Manejar. Tener su propio auto



Adam Bourgeois, de 23 años de edad, de Plano, trabaja limpiando equipo para acondicionamiento físico en Plano Family YMCA.

Foto: BRANDON THIBODEAUX/DMN

Pero Adam, nacido con síndrome de Down hace 23 años, sabe que esos son sólo sueños. Así es que sonríe con su dulce sonrisa. El recuerda que sus padres le decían que hiciera lo mejor. Así es que se siente muy orgulloso de hacer lo que puede hacer.

Si usted utiliza equipo de acondicionamiento físico en Plano Family YMCA, puede ser que usted no vea a Adam. Pero usted puede ver los resultados de su trabajo. Las caminadoras y esquiadoras meticulosamente limpiadas, rociadas con atomizadores y pulidas durante las horas tempranas de la tarde, cuando la Y está tranquila. El piso sin polvo del gimnasio.

“Lleno una bitácora de horas,” dice Adam con orgullo. “El gimnasio está sucio y tengo que limpiarlo. Yo barro.”

Lisa Edgar, directora de acondicionamiento dice que Adam hace un muy buen trabajo.

“Recibimos muchas felicitaciones sobre él la gente dice que las máquinas están bien y limpias.”

Adam no es la única persona joven con discapacidad que trabaja en la Y. Otras cuatro personas lo hacen también. Sus trabajos incluyen doblar toallas, y se toman el trabajo muy en serio. Un hombre joven siempre viste de corbata porque su padre también viste de corbata al ir a trabajar.

Los cuatro forman parte de un programa del Plano Independent School District. Así es como empezó Adam. Y cuando el se graduó de la preparatoria, la Y le ofreció un trabajo.

“Tristemente, muchas veces después de terminar la escuela,” los muchachos como Adam se quedan en casa sin nada que hacer, dijo Mike Bourgeois, el padre de Adam. “Ha sido una bendición que la Y haya intervenido. Esto es un regalo de Dios.”

Adam empezó trabajando los Lunes y Viernes de 2 a 4 p.m. Pero la Y lo necesi-

taba más, así es que ahora ha agregado los Miércoles también.

Tu puedes darte cuenta que está trabajando con solo mirar el equipo de acondicionamiento físico. ¿Has visto una banda amarilla en la caminadora? Eso significa que necesita limpieza. Así es que cuando ya hayas terminado y te bajes de ella, Adam empezará con su trabajo.

¿Con cuántas se enfrenta en un día de trabajo promedio?

“Muchas,” dice.

En efecto. La Y tiene 18 caminadoras y 12 esquiadoras, además de otras máquinas más. Adam inicia sacando del cuarto de empleados un par de guantes blancos. Toma una botella de atomizador de limpiador y una toallita y camina con su paso lento y deliberado hacia una máquina que se encuentra en la última fila. Remueve la banda amarilla, se la pone en la muñeca y se pone a trabajar.

No habla mucho, pero se ríe con facilidad. Sin embargo, cuando está trabajando, lo hace con empeño y concentración.

Te preguntarás – al estar rociando el limpiador en la toalla y al estar frotando los manubrios y los pedales – lo que piensa. ¿Tal vez en cómo gasta su sueldo? ¿El decidir si comprará el siguiente DVD de luchas o el restaurante donde podrá realizar uno de sus máximos placeres, invitar a su familia a comer?

¿Está pensando sobre su otro trabajo, barriendo en los cines Cinemark Tinseltown en Plano? ¿Sobre jugar la tercera base en su equipo de baseball de Olimpiadas Paraolímpicas? ¿O recordar lo que aprendió en su estudio de la Biblia de los lunes por la noche?

O tal vez, considerar lo que sus padres y patrones dicen sobre él, que hace su trabajo con empeño.

“Nosotros los criamos como si no hubiera nada malo con él,” dice su mamá,

Trudy Bourgeois. “Nuestra filosofía ha sido, lo que sea mejor para ti, lo será para nosotros. Sólo asegúrate que no sea menos que lo mejor. Para Adam, esto puede ser lo mejor de sí. Para ser francos, para nosotros como padres, tal vez sea un poco triste. Pero Adam crece de otras maneras.”

Cuando Adam era joven algunas veces la gente pensaba que sus padres eran duros con él, dice Mrs. Bourgeois.

“No aceptamos hacer sólo la mitad, simplemente no lo aceptamos. ... Es importante inspirar ese sentido de responsabilidad y deber porque ahora es cuando está remunerando”

El trabajo le da a su hijo un sentido de propósito, de satisfacción, dice. Le da lo que otros tienen, la capacidad de trabajar.

Drew Dixon, miembro del consejo del Down Syndrome Guild, dice que este tipo de arreglos funcionan por diversas razones.

“Le permite trabajar y que le paguen, pero al mismo tiempo, está con personas con y sin discapacidades. Esto es el hacer una comunidad normal, y ‘normal’ significa una mezcla de personas.”

Mrs. Bourgeois dice que ella cree que Dios creó a personas como Adam para enseñarnos al resto de nosotros las riquezas de la vida.

“No puedo empezar a contarles cuantas veces la gente llega a decirme, ‘Quiero que sepa la gran influencia que su hijo tiene en el mío.’

“Adam es un recordatorio de cómo ser humildes,” dice, “el de no dar por hecho nuestros dones.”

-Enviado por Minnie Blackwell. Reimpreso con permiso de las Dallas Morning News. En línea a: http://www.dallasnews.com/s/dws/fea/life/stories/DN-NSL_ourtown_1120.ART.State.Edition1.26f93440.html. E-mail lgarcia@dallasnews.com.



Perspectives in Parenting - Help for Siblings

By Nancy Lambert Davenport

A question often asked of me as the mother of a child with a disability is “How have your other children coped with their brother’s disability?”

I always have to stop and think. For 27 years we have lived with disability in our house. To us it is normal. When asked a question such as that, I have to put myself mentally in the other person’s household. I have to imagine what he or she might see as a problem and at the same time understand what is considered normal in that household.

Then I usually say that Austin’s siblings are better people because of him. Of that I have no doubt. I mention that they are probably more patient with everyone because of him and more tolerant and maybe more fun. I don’t really know, though, because we have had nothing else.

I know his siblings would resent him one day, and were his strongest advocates the next. As they were growing up, their maturity of insight into human nature, learning methods, patience, and emotional needs was almost frightening; yet they were still kids. They were as embarrassed as they were proud of Austin. When our daughter was in high school she unconsciously tested the merit of continuing to date someone by how the poor guy responded upon meeting Austin. If he didn’t pass the test, we never saw him again.

Professionals have done studies

on helping siblings, and for this I am grateful. In the OPEC Review (Office of Programs for Exceptional Children, South Carolina Department of Education), Thomas H. Powell reported on his research in the article “Brothers and Sisters: A Special Part of Exceptional Families.” Also “Disability Solutions” from year 1997 has some thoughts on helping siblings. Combined with mine, here are several thoughts:

- **Just listen.** Set aside time to listen to their fears, concerns, and hopes. This is harder than it sounds because siblings often feel they need to be strong.

- **Be open and honest.** Answer all questions in a straightforward manner. Talk in a way they can understand.

- **Ask. Don’t assume.** Just by asking “Do you mind if your brother goes along?” implies concern.

- **Limit caretaking responsibilities.** It needs to be a choice most of the time. This does not mean eliminate. A certain amount of helping is natural.

- **Create a library of children’s books on disability.** They can be a great source of information and can help a sibling feel he or she is not alone.

- **Be an example.** Every family member will deal with some frustration. Parents need to set the tone on how to cope.

- **Schedule special time.** Often kids with disabilities take a lot of time. Set aside special time just with the siblings. They need to know they are just as central to family life as their sibling with disabilities.

- **Praise siblings.** Don’t assume. Be liberal with praise when it’s due. Celebrate each child’s accomplishments.

- **Allow and encourage siblings to express their feelings.** Feelings of hate, jealousy, resentment, and even depression are not uncommon. Try to read their cues for when they need special attention. Teach them how to appropriately express their needs for more attention.

- **Don’t expect the siblings to be saints.** Siblings will have disagreements no matter what their ability level.

- **Involve siblings.** If there is agreement from the child with disabilities, invite the sibling to attend planning sessions concerning the life of the sister or brother.

- **Keep laughter and joy.** Write down some of the funny things that happen so you can pull it out when you are low. A family laughter book sends a powerful message of its importance.

I don’t think our family would get even close to 100% on this list. I imagine no family does. But this can be a list to which to aspire.

Life with a sibling with disabilities does not have to be difficult or complicated, but it will probably be unique. We parents need to be creative in designing a life for all our family that allows each child to be his or her best. It’ll be work, but it can be done. No one said parenting is easy.

Contact Nancy Davenport at nancdave@swbell.net.



Parents Have Burden of Proof, Supreme Court Rules

By The Associated Press
Nov. 14, 2005

WASHINGTON - The Supreme Court ruled today that parents who demand better special education programs for their children have the burden of proof in the challenges.

The 6-2 decision, written by retiring Justice Sandra Day O'Connor, said that if parents challenge a program, they have the burden in an administrative hearing of showing that the program is insufficient. If schools bring a complaint, the burden rests with them, O'Connor wrote.

The ruling is a loss for a Maryland family that contested the special education program designed for their son with attention deficit hyperactivity disorder.

The case required the court to interpret the Individuals With Disabilities Act, which does not specifically say whether parents or schools have the burden of proof in disputes.

The family's attorney, William Hurd, unsuccessfully argued that when there are disagreements between schools and parents, education officials have better access to relevant facts and witnesses.

Chief Justice John Roberts had recused himself from the case, because attorneys from his old law firm represented the school district.

Justices Ruth Bader Ginsburg and Stephen Breyer wrote separate dissents. ☞

IEPS and Due Process

Schaffer v. Weast: How Will the Decision Affect YOU?

By Peter W. D. Wright, Esq.
Wrightslaw.com

Edited by Paul Watson, with comments in brackets

On November, 14 2005, the Supreme Court issued their decision in *Schaffer v. Weast*.

The issue in *Schaffer* was whether, in a due process hearing about a disputed IEP, the parent must prove that the school's IEP is not appropriate or the school district must prove that their IEP is appropriate.

Justice Sandra Day O'Connor explained that the Court [resolved] the following question:

"At an administrative hearing assessing the appropriateness of an IEP, which party bears the burden of persuasion?"

Justice O'Connor wrote:

"If parents believe their child's IEP is inappropriate, they may request an "impartial due process hearing." We hold that the burden lies, as it typically does, on the party seeking relief.

States may, if they wish, override the default rule and put the burden always on the school district. Several States have laws or regulations purporting to do so, at least under some circumstances ...

[Note that Texas is not one of those states; in Texas the burden is on the challenging party]...

The burden of proof in an administrative hearing challenging an IEP is

properly placed upon the party seeking relief. In this case, that party is Brian, as represented by his parents. **But the rule applies with equal effect to school districts: If they seek to challenge an IEP, they will in turn bear the burden of persuasion before an ALJ** [administrative law judge]. [Emphasis added; this is the good part of the ruling for us].

Justice O'Connor described the parental rights and safeguards that serve to counter-balance the "natural advantage" of school districts:

"School districts have a "natural advantage" in information and expertise, but Congress addressed this when it obliged schools to safeguard the procedural rights of parents and to share information with them... As noted above, parents have the right to review all records that the school possesses in relation to their child... They also have the right to an "independent educational evaluation of the[ir] child." Ibid. The regulations clarify this entitlement by providing that a "parent has the right to an independent educational evaluation at public expense if the parent disagrees with an evaluation obtained by the public agency." ... IDEA thus ensures parental access to an expert who can evaluate all the materials that the school must make available, and who can give an independent opinion. They are not left to challenge the government without a realistic opportunity to access the necessary evidence, or without an expert with the firepower to match the opposition."

Prior Written Notice

The decision in *Schaffer v. Weast* focused on revisions in IDEA 2004 and "Prior Written Notice" (PWN). These

revisions require that school districts provide "Prior Written Notice" when the school district [refuses, initiates, or changes] "the identification, evaluation, or educational placement of the child, or the provision of a free appropriate public education to the child." See 20 USC §1415(b)(3) (Wrightslaw: IDEA 2004, page 99)

In 2004, Congress added provisions requiring school districts to answer the subject matter of a complaint in writing, and to provide parents with the reasoning behind the disputed action, details about the other options considered and rejected by the IEP team, and a description of all evaluations, reports, and other factors that the school used in coming to its decision... Prior to a hearing, the parties must disclose evaluations and recommendations that they intend to rely upon ...

What Does the Decision Mean to You?

In many jurisdictions, states are already operating under the rule that the [challenging] party has the burden of proof. In these states, the decision should have no significant impact. [Texas falls into this category.]

Residents of these states should not expect to see a change in their due process procedures since the moving party already has the burden. [However,]

Take it or Leave It! When School Districts Draw Lines in the Sand

Many school districts present parents with a unilateral change in the child's [current] IEP (often a reduction of services). If the parents did not consent to the change, the school would respond: "Take it or leave it. Take us to due process."

The parents were in dilemma. They could request a special education due process hearing or they could accept the changed IEP. When the parents did request a due process hearing, Hearing Officers and Administrative Law Judges frequently assumed that the parents were the moving party since they were objecting to a proposed IEP. Thus, the parents had the burden of proving that the new proposed IEP was not appropriate.

The decision in *Schaffer* changed this.

Given this same scenario, if the parents do not consent to the changed IEP, it is clear that the school district must seek a special education due process hearing [Emphasis added].

Justice O'Connor wrote:

"School districts may also seek such hearings. They may do so, for example, if they wish to change an existing IEP but the parents do not consent, or if parents refuse to allow their child to be evaluated."

When the school district seeks to change an IEP and parents do not consent, the school district may not unilaterally change the IEP. The school district must now request a due process hearing, present their evidence first, and prove that their proposed IEP provides the child with a free appropriate education. [Emphasis added]

The 2004 amendments to IDEA require that school districts provide parents with "Prior Written Notice" as a condition of being able to proceed to a due process hearing.

Due Process Complaint Notice

Prior Written Notice is rigidly adhered to in some school districts

and completely disregarded in others. According to the reauthorized IDEA 2004, the parent's Due Process Complaint Notice must provide "a description of the nature of the problem of the child relating to such proposed initiation or change, including facts relating to such problem; and a proposed resolution of the problem to the extent known and available to the party at the time." 20 U.S.C. §1415(b)(7) (*Wrightslaw: IDEA 2004*, page 99)

When the parents provide the due process complaint notice:

"If the local educational agency has not sent a prior written notice to the parent regarding the subject matter contained in the parent's due process complaint notice, such local educational agency shall, within 10 days of receiving the complaint, send to the parent a response that shall include - (aa) an explanation of why the agency proposed or refused to take the action raised in the complaint; (bb) a description of other options that the IEP Team considered and the reasons why those options were rejected; (cc) a description of each evaluation procedure, assessment, record, or report the agency used as the basis for the proposed or refused action; and (dd) a description of the factors that are relevant to the agency's proposal or refusal." 20 USC §1415(c)(2) (*Wrightslaw: IDEA 2004*, page 100)

[Now] assume that a school district changes a child's IEP without obtaining the parent's consent, without a due process hearing, and without an Order from a Hearing Officer or Administrative Law Judge. **In a disagreement with parents, school districts often draw lines in the sand. They may refuse to provide services or they may reduce**

services, without any evaluation or new data that justifies the proposed change in services. In this situation, the school district is required to provide Prior Written Notice [and request due process for the change]. [emphasis added] Many districts fail to do this. After the parent requests a due process hearing, the school district then generates evidence, evaluations, and witnesses to support their earlier decision.

This conflicts with Prior Written Notice [and due process requests] as described by Justice O'Connor and IDEA 2004. PWN, as a pretrial requirement, will receive greater scrutiny in light of the Court's emphasis in *Schaffer* that Congress added provisions requiring school districts to answer the subject matter of a complaint in writing, and to provide parents with the reasoning behind the disputed action, details about the other options considered and rejected by the IEP team, and a description of all evaluations, reports, and other factors that the school used in coming to its decision.

In an attempt to delay or sabotage the process, some districts refuse to release records. Some districts advise parents that they must use an evaluator from the school's "approved list of evaluators." In some jurisdictions, principals refuse to permit the parent's evaluator or expert to observe the child's public school program.

In light of the decision in *Schaffer*, these tactics can be expected to backfire. If litigation does ensue, these tactics may be a sufficient procedural breach to justify a ruling in favor of the parent and child. [emphasis added]

Final Thoughts

In general, what controls outcome is not the facts nor the law. It comes down to one thing: Does the Hearing Officer / Administrative Law Judge (HO / ALJ) want to rule in your favor?

If you can win that battle - and make the decision-maker feel the case in his/her heart and gut and want to rule in your favor - that person will find facts and law to rule in your favor and justify the outcome.

Facts and law get you into the courthouse and onto the playing field, but they do not get you into the end zone. It is the human emotions of the HO / ALJ and your ability to influence their beliefs and emotions that will take you into the end zone, without regard to which side has the burden of proof.

Redistributed with permission. For full text visit: <http://www.wrightslaw.com/law/art/schaffer.impact.pwright.pdf> or <http://www.wrightslaw.com/law/art/schaffer.impact.pwright.htm>. **Note from Pete Wright:** This article may be photocopied and distributed. ☺

Mentally disabled patient [sic] abused at state school

*By Byron Harris / WFAA-TV
November 16, 2005*

The most expensive schools in Texas may have the least recognizable names, but Texas spends \$50 million a year on so-called state schools for people with mental disabilities.

But some residents may actually be hurt, not helped by the institutions.

The possible victims live on the residential campuses of state schools, and the residents aren't always capable of talking about the quality of care they get.

For the last four months, News 8 has been looking into one troubling case of abuse.

It was a shocking and mysterious injury. Hasib Chishty lay in a coma in a hospital bed. His intestine was ruptured and his abdomen severely bruised.

In the last three years, he has undergone four surgeries. More than three years later, neither he nor his family have recovered from what they believe were injuries inflicted by the Denton State School.

"I honestly think they should be put behind bars," said brother Samir Chishty.

Chishty, now 32-years-old, has had a mental handicap his whole life. However, he was physically healthy until his family brought him to the Denton State School in August of 2002 to improve his behavioral and eating skills.

Chishty was assigned to a residential unit called 528 D.

At the school, Chishty went from being a playful resident to a comatose victim.

Kevin Miller, a caregiver at the school, has confessed to victimizing Chishty. However, he also blames a culture of negligence and drug use on the job, which Miller said some supervisors condoned.

"The employees on that shift did either crack, powder cocaine, marijuana, Oxycontin, hydrocodone, valium.....," he said in sworn taped testimony.

Miller was a former drug addict who said he was clean when he began working at Denton State School in 2001. Once he was assigned the night shift, he said he discovered three coworkers were using drugs on duty.

He said he soon joined them.

"We would each take turns going into the bathroom, and you know, snorting," he said.

This is the environment Chishty entered. Like other clients at state schools, he was a full grown adult with a mental disability. He was not always gentle and potentially hard to handle.

"It's a hard job," said Elyse Mitchell, an attorney for Advocacy Inc., which protects the rights of people with disabilities in Texas. "Nobody says it's not a hard job."

On September 26, the client and the confessed drug addicted caregiver collided.

"Most people, they called me fiend because I did all of my share of the drugs within a few minutes, and theirs lasted all day," Miller said. "And then I was begging them to give me some because I was hurting."

As Chishty and other clients settled in for the evening, Miller was hurting and coming down from a drug high. It was when he was in Chishty's room he snapped.

"I almost killed him," he said.

He said he kicked and punched Chishty at least twenty times.

When Chishty's mother arrived for her evening visit, she was shocked to find her son in terrible pain.

"His hand was icy cold," said Farhat

Chishty. "His skin was really pale." This was when the Chishty's said they believe a cover-up had begun.

First, the school would not admit he was hurt and that night the staff wouldn't wake up the on-call physician.

Chishty wasn't transferred to a hospital for more than a day, even though his condition worsened.

As Chishty fought for his life from a hospital bed, the school declined to investigate the incident and said he had been injured by a seatbelt in a van.

"There was a dramatic change in this patient's condition overnight, and the only explanation that this family is given for many months is that maybe it was a seat belt that caused this abdominal injury, which is clearly preposterous," said Kelly Reddel, the family's attorney.

As a result of the beating, Chishty was nearly paralyzed and confined to a wheelchair.

He can't eat or drink, which was two of the few pleasures he ever had.

"I could never imagine," said sister Yusra Chishty. "I couldn't believe it for a long time."

The Department of Aging and Disability Services, which runs the school, won't talk about the case because it's in court. "We're against any kind of abuse and neglect," said Don Rogers, with the department.

The department said employees like Miller are tested for drugs when they are hired and later if they are suspected of drug use.

DADS abuse cases are investigated by another state agency. In 2004, nearly nine out of ten charges of abuse were

determined to be unfounded.

Miller's supervisor was transferred to another department and declined to talk to News 8.

However, Miller said in 2002 there was a pattern of patient mistreatment at Denton where caregivers used rubber gloves to abuse patients.

"But if you have like rubber gloves on, you can grab, like if they have a hairy back or something, you can grab the hair and you can pretty much grab a great deal of it," Miller said.

According to the Miller, metal serving spoons became fearsome weapons used to whack patients on the head.

"This is the tip of the iceberg of some of the examples of abuse here," Miller said on the taped testimony.

Mitchell examined records at the Denton State School for a three month period that included Chishty's case.

"The abuse incidents were to me the most serious because those would typically involve an injury," she said.

She found 20 confirmed incidents of neglect, 12 confirmed incidents of abuse and 50 medication errors. "If there were people who were working with the residents and using recreational drugs, I think that would be highly inappropriate," Mitchell said.

Three years after the incident, the state of Texas no longer maintains Chishty was injured by a seat belt. Just two months ago, his mother got a letter from the state admitting her son had been abused.

But the court case over the abuse is not resolved. Miller has been indicted by a Denton County grand jury and

charged with reckless bodily injury to a disabled person [sic].

As for the Denton State School where the incident occurred, Advocacy Inc, which inspects all state schools, said Denton is one of the best in the state.

-Submitted by Minnie Blackwell. © 2005 Dallas Morning News. Story available on-line: <http://www.wfaa.com/topstories/>.



Down Syndrome Awareness Postage Stamp

The U.S. Postal Service is again considering the adoption of a Down Syndrome Awareness postage stamp.

Congress members John Hostettler (R-IN), John Langevin (D-RI) and Pete Sessions (R-TX), as well as Senator Richard Durbin (D-IL) have introduced resolutions (House Congressional Resolution 42; Senate Congressional Resolution 48) supporting the stamp.

If you would like to join this effort, please send a letter describing why you believe Down syndrome awareness is important to you and your family to:

Dr. C. Douglas Lewis
Chairperson
Citizen's Stamp Advisory Committee
c/o Stamp Development
U.S. Postal Service
1735 North Lynn Street, Room 5013
Arlington, VA 22209-5013

-Submitted by Kelly Theriault



FREE Dental Care for Children with Special Needs

By Joanna Spahis, RN,
CNS, APNG, Clinical Nurse Specialist,
Down Syndrome Clinic, Children's
Medical Center, Dallas

Did you know there is a program to cover the cost of dental care for children with special needs, including Down syndrome? The Humanitarian Foundation, Grottoes of North America has been helping children with special needs with the cost of their dental treatment since 1970.

The Dental Care for Children with Special Needs Program has a unique partnership with qualified dentists throughout the United States and Canada. The program was designed to help eligible children to receive the best dental care possible.

Since its inception, children have been treated at several national treatment centers, including Children's Medical Center in Dallas. Through the extension program, a child can also be treated in his/her community by a local dentist and/or hospital. Parents select the dentist of their choice and the program works directly with the dental office to process the claim and issue payment.

Dental services are provided to children up to the age of 18 years with any of the following conditions: developmental delay/mental disability (including children with Down syndrome), cerebral palsy, muscular dystrophy, and recipients of organ transplants. The child's developmental age must be at least 2 years below his/her chronological age. Evidence of this must be provided by a note from a physician or results of developmental testing, such as that done for a child's ARD (school program).

For more information, contact Lisa Ortiz in the dental clinic at Children's Medical Center of Dallas, 214-456-8833, or visit www.scgrotto.com.

Newsletter Delivery Timing

The DSG's goal regarding newsletter delivery is that every member receives their newsletter by the first of the month. Yet we know that newsletters often arrive after the first, sometimes as much as 7 days after. We have not been able to determine a pattern of delivery, either by zip code or city.

With our non-profit mailing permit, the time it takes to mail an item is significantly longer than first class mail, and timing of delivery can even vary at the same location from month to month. We attempt to strike a balance between the deadline for submissions to the newsletter and getting it into members' mailboxes close to the first of the month.

The current newsletter submission deadline is the 7th of the month prior to publishing. For example, if you want an item in the March newsletter, you must submit it by February 7. Moving that deadline up any further will reduce the number of items we can list, especially from other organizations.

Other ways we've tried to address the problem is by putting events in the newsletter for 2-3 months before they occur, and we send out event reminders by email, and post all of our events and a copy of the newsletter on our website.

If you are uncertain regarding the details of a DSG event or just want to re-confirm the time and location, check our website at www.downsyndromedallas.org, or call the DSG office at 214-267-1374. If you don't have a computer at home, you can access the internet on a computer at any public library.

We regret any inconvenience the delivery timing may have may have caused DSG members. We welcome additional suggestions to improve the situation.

- Submitted by Kelly Theriault and Patty Bates-Ballard

Snackin' With Santa Photos

