

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

January 2011

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

2011 Down Syndrome Guild IEP Clinics *Transitions Across the School Years*

Region 10 Service Center
904 Abrams Road
Richardson, TX 75081
10:00 a.m. to 12:00 p.m.

Transitions Across the School Years Saturday, January 22, 2011

Co-Presented by:

Kristen Adams, Teacher, M.Ed.,
Teacher, KinderFrogs School at Texas
Christian University

Nancy Meadows, Ed. D, Director,
Alice S. Neeley Special Education
Institute at Texas Christian University

This family and educator friendly seminar will focus on transitioning students between school and programs from early childhood through high school. Fears and anxieties about transition will be addressed along with tools and resources to help effectively advocate for children, teens and young adults.

Additional IEP Clinics

Teaching Children Self Help Skills and Increasing Independence

Saturday, February 12, 2011

Co-Presented by:

Kari Zerbe, MA in Early Childhood
Special Education, Educational

Coordinator at The Rise School of Dallas,
Member of DSG Board of Directors
Grace Sunio, OTR, at Children's
Medical Center and The Rise School

Basic adaptive skills are as important to learn as the academic skills that are being taught in the classrooms. Presentation will provide practical advice to enable parents and professionals to teach children skills in the areas of dressing, personal hygiene, eating and toileting. Strategies for overcoming challenges in this developmental area and tools will be given to help begin and then build on that foundation. Participants will walk away with the ability to identify and teach basic self-help skills.

Matching the Behavior Intervention to the Function: Assessing Behavioral Needs and Altering the Way We Think About Behavior

Saturday, March 26, 2011

Co-Presented by:

Laura Seiferd, M. Ed., Instructional
Support Specialist for Plano ISD
Jackie Rymza, M. Ed., Centralized
Structured Classroom teacher in Plano
ISD

This informative seminar will examine behavior objectively and get to the function of the behavior. Social and behavioral skills are keys to success.

The presentation will focus on assessing behavioral needs and, most importantly, on making lasting changes to behavior. Tips to assess and take efficient data on when and why the behaviors are occurring will be presented. Practical intervention ideas to change behavior will be explored.

3rd Annual Kindergarten Round-Up

Saturday, January 29
10:00 a.m. to 12:00 p.m.
Arapaho United Methodist
Church

1400 W. Arapaho Road
Richardson, TX 75080

Parents of children ages 2 to 6 years old are invited to attend this program. A panel of professionals will facilitate a discussion offering important "how to" information regarding the school processes, procedures and rights of your child. Come ready to ask questions and we will provide you with information to help you navigate the transition into the public schools.

RSVP is required to Becky Slakman
at dsged@sbcglobal.net or by calling
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.*

In Memory of Christopher Calabro

From:
Beverly Roberts

Happy Birthday Casey O'Brien

From:
Allison Gannon

In Honor of Judith Warner, Happy Holidays!

From: Jenn and Todd Smith

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.

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

Executive Director Message *by Becky Slakman*

Happy New Year! I hope everyone had a very nice Holiday season. As I write this message, we recently celebrated Thanksgiving. We all have many blessings in our life for which we are thankful. I am very thankful to be a part of an organization that focuses on providing information, resources and programs to individuals with Down syndrome, their families and the community. January marks my 4th year anniversary as the Executive Director of the Down Syndrome Guild of Dallas. An easy topic for discussion in January is always about New Year's Resolutions. Have you made yours? Many times in our life we spend the majority of our time taking care of others. A couple of years ago at a program sponsored by our Options for Adults committee, Dr. George Capone was our featured speaker. His topic was medical issues that individuals with Down syndrome may face throughout their lives. In addition to the very important information he presented that day, at the conclusion of his session he made a statement that has remained with me. He said for the audience to always remember *"that prior to any airplane flight taking off, the flight attendants instruct adult passengers that in case of reduced air pressure occurring in the cabin and the oxygen masks drop down, place the mask over YOUR FACE FIRST and THEN CARE FOR OTHERS AROUND YOU."* If you have room one more resolution to add to your list, I would like to recommend that you make time to take care of yourself!

Over the next few months the Down Syndrome Guild of Dallas offer you ways of taking care of yourself so you will be equipped to navigate effectively through the school and special education systems. Be sure to read through this newsletter to see information on upcoming IEP Clinics and Kindergarten Round Up.

I enjoyed seeing many of you at our recent annual Snackin with Santa event. Reflecting upon 2010, we offered many opportunities for learning and socializing together.

I look forward to seeing you often in 2011!

- Becky Slakman
Executive Director

Cooking Class for Adults with Down syndrome

Saturday, January 22, 2011
10:00am-1:30 pm

**Arapaho United Methodist Church
1400 West Arapaho
Richardson, TX 75080**

(Northeast corner of Coit & Arapaho-
use the east parking lot entrance)

Let's get cooking!! Self advocates 19 and older are invited to join us for a cooking class. Learn creative and healthy cooking techniques, have fun with friends and enjoy the meal you prepare together! Class is led by Jennifer Hood, culinary instructor and Registered Dietitian and her husband Chris. The menu will inspire you to make healthy choices, and recipes will be provided. Please inform us of any dietary restrictions or allergies when you register. Space is limited so participants must RSVP to Neely Holland at 214-267-1374 or dallasdsg@sbcglobal.net.

Teaching by Design

Teaching by Design shows readers how to use the computer to design meaningful educational materials for children and adults with special needs. A synthesis of computer graphics, education, and crafting, this book represents the author's considerable expertise in customizing educational materials for her daughter with multiple disabilities as well as teaching other parents and teachers to create them too.

Full of instructions for designing and adapting materials and strategies for using them--including a time-saving CD-ROM of templates--Teaching by Design is useful to parents and teachers of students of all ages with a wide range of disabilities. Design and customize lotto boards, interactive spelling cards, game pieces, playing cards, matching games, menus, fill-in-the-blank decals, handwriting transparencies, and more, to teach visual perception, math, language, communication, reading, handwriting, and self-help skills.

This book is loaded with illustrations and supportive anecdotal information and is divided into three parts:

- Controlling Variables explains how presentation (media, text, images, and layout) affects learning and how to make appropriate design choices based on your child's needs and preferences
- Graphic Skills provides a mini-tutorial on computer graphics programs including Free-Hand, Illustrator, AppleWorks, Paint Shop Pro, CorelDraw, and Microsoft PowerPoint
- The Recipes include over thirty sets of step-by-step instructions for creating projects, from Interactive Books to Coloring Within the Lines and from Restaurant Menus to Telling-Time

Worksheet. The CD-ROM of graphic templates gives users a headstart in the design process.

With this book, and access to a computer, printer, and office and craft supplies, you can make learning for a child with special needs immeasurably easier, richer, and fun for both of you as you make and use custom adaptive materials for home and school.

For more information on this book and other helpful resources visit www.woodbinehouse.com

Transition Workshop

Transition Workshop for Parents of Children ages 10 and older
Presented by Cindy Pierce,
Transition Consultant

Thursday, February 17, 2011

6:30 p m-8:00 pm

Down Syndrome Guild of Dallas

1702 N. Collins Blvd. Suite 170

Richardson, TX 75080

Do you have a child about to enter high school and you don't know what to expect? Is your child too young for high school but you know the importance of planning ahead and being prepared? Did you attend the transition session at the DSG fall conference and feel like you need more? This workshop is for you! You will learn the laws regarding transition services, help your child identify goals in the areas of further education, employment and independent living; learn how to be an active participant in the development of the IEP, and support your child in the decision-making process. Space is limited so please RSVP to Becky Slakman at 214-267-1374 or email dsged@sbcglobal.net.

Down Syndrome Guild of Dallas Day at the Dallas Stars

Join the Dallas Stars as they team up with the DSG for a great afternoon of hockey!

\$5.00 of every ticket goes back to the DSG to support the programs you love!

Sunday, February 13, 2011

**2:00PM- American Airlines Center
Stars vs. Blue Jackets**

Come early and join us for a party on the plaza featuring slap-shot cage, video games and local band Vocal Trash from 1:15-1:45!

Ticket prices \$20.00 each (\$10.00 off the gate price)
** \$5 dollars of each ticket benefits the Down Syndrome Guild of Dallas.

Order online and print your tickets at home:

Visit <http://stars.nhl.com/DSG>

to purchase tickets!

Password: **stars**

Or save the service charge and order via phone by calling Kyle at 214.387.5582

* This event is open to anyone (not just DSG members) so please invite your family and friends!



Communication and Mental Health

The following is a continuation of our series from *The Guide to Good Health for Teens and Adults* by Brian Chicoine M.D. & Dennis McGuire, Ph.D.

There is an interaction between physical and mental health. This statement is neither new nor is it uniquely true of people with DAS. Physical health problems can have a psychological impact on all people. We may respond to an illness with fear, anger, depressed mood, anxiety and other emotions. In addition, when we don't feel well, we may not function as well physically or mentally. This is also true for people with DS. However, the relationship between physical and mental health can at times be more complicated and more difficult to assess in adults with DS.

One reason it can be more difficult to assess the relationship between physical and mental health in adults with DS is because communication challenges are so common. Many people with DS have difficulties with expressive language. They may readily express their feelings nonverbally through a look of sadness, anger or anxiety, or through expressions of joy and exhilaration. However, it may be very difficult for them to verbally communicate the cause or source of their expressed emotions, particularly negative feelings. Caregivers are usually good observers and will often know that something is wrong, but they may not know what or why. Often the only means that an adult with DS has to communicate the presence of a problem is through a change in mood or behavior. This may be especially true if a major problem or stress is involved, such as the loss of an important supervisor at a job or the presence of a physical problem, with pain or discomfort.

When looking at behavior as a communication issue, it may be helpful to consider how "loud" the person's nonverbal or behavioral communication

needs to be for others to "hear" it. Some professionals in the mental health field have discussed what they call a level of "selected deafness" that occurs in one's social environment (Minuchin and Fishman, 1981). For example, if there is a slight change in someone's mood or behavior, others may ignore it. If the problem persists, then the person's behavior may amplify until others "hear" that something is wrong. Not surprisingly, as someone experiences more pain or discomfort (whether physical, mental, emotional, etc.), his behavior may change (such as becoming more agitated or restless) and become more obvious to others.

Once a problem is "heard" by significantly others, the next step is to find the cause or source of the problem. This usually requires digging and detective work on the part of parents, caregivers, and any professional who have been engaged to help solve the problem. At the Adult Down Syndrome center, we look for any clues to look for the source of a change in behavior. We look for physical problems by conducting a thorough physical exam. We also ask about stress in the person's life. We seek out and talk to as many people, in as many settings, as we can to help explain a problem. This may include teachers in schools, staff in residential settings, supervisors at a worksite, etc. In short, we try to gather information from any source to help us find what the person is trying to communicate through a change in their behavior.

Due to the frequency of communication problems, we view any and all behavioral change in adolescents and adults with DS as a possible communication tool. Particularly if the person is non verbal or has limited verbal skills, a behavioral change can be his means of communicating discomfort or a feeling of illness. Even some of our patients with excellent communication skills do not communicate their

discomfort via spoken words or writing. The physical illness affects them mentally and they communicate it through a change in behavior.

In cases like these, we like to think that it is not that our patients are not communicating well; it is that we are not listening correctly. In short, we encourage others to look very carefully at any change in behavior.

Why is this so important? People who may be unable to communicate the presence of a problem, whether or not they have good verbal skills, may be at greater risk for mental health problems. Their inability to communicate a problem may contribute to a condition described by a psychologist as "learned helplessness" (Seligman, 1975). Learned helplessness occurs when people do not get enough experience solving problems they encounter in their daily lives, and as a result, tend to give up rather than try to meet the challenge. In other words, they have literally "learned to be helpless". This, in turn often leads to a state of hopelessness and depression.

Ensuring that people with DS have a means of communicate the need for help, whether verbal or non verbal communication, may go a long way to help to prevent or reduce learned helplessness. Once people learn that they have a responsive environment and that they can communicate successfully when there are problems, this greatly increases the chance that they will use this strategy when faced with future challenges. Taking these differences into account can improve our ability to diagnose health problems and also develop treatment plans.

10 Tips About Placement *by Pat Howey*

My son has been in special education since pre-school. Some years, his material was too hard. Other years, he was with students who could not read or write. There was no support for him in the general education classroom. I feel like I must choose between his mental health and academics.

The school does not seem to have a good placement for my child. Can you suggest any way to change this?

Do Not Put Placement Before the IEP

You must have an appropriate IEP before you can get an appropriate placement. Many parents make the mistake of putting the cart (the placement) before the horse (the IEP).

IDEA requires all IEPs to include present levels of academic achievement and functional performance. (20 U.S.C. 1414(d)(A)(i))

Start by making a grocery list of your child's present levels of educational and functional performance. Without "present levels" there is no foundation on which to build an IEP.

You can list anything that affects your child's ability to function inside and outside of the school setting! Not every child will need functional goals. You will not know that unless you include present levels of functional performance.

The IEP is the Blueprint for Your Child's Program

The IEP is the blueprint the school must use for your child's program. This includes placement. It all begins with present levels of educational and functional performance. The "present levels" in the IEP guarantees that your child gets the right special instruction, related services, modifications, adaptations, accommodations, assistive technology, or any other needed item.

An appropriate IEP answers the following question. "In what setting (placement) can we appropriately put

this IEP into action?" If the school does not have an appropriate placement, it must create one.

This process sounds simple. But, you may have to work hard to get there. You are the best person to do this. You know your child best. You may have to do these three things.

Convince the team that the current IEP is not appropriate.

Guide the team to use the IEP to find the placement.

Negotiate with the school to create a placement if the school does not have the placement your child needs.

A Good Placement Begins With an Appropriate IEP

To make sure the "blueprint" is appropriate you should follow this process.

1. Make lists of your child's strengths and challenges. These lists are your child's present levels of academic achievement and functional performance.
2. Study your lists. They will guide you in teaching the team about what your child needs.
3. You will use your lists to help the team develop an IEP that builds on your child's strengths and corrects his areas of challenge.
4. Use information from the first lists (strengths and challenges) to make a third list. Your list should include the following.
The special education and related services your child needs. Remember that special education means "special instruction."
The adaptations, modifications, and accommodations your child needs in addition to special instruction. These are not substitutes for "special instruction."
5. Use your three lists to help the team create an IEP that prepares your child for:
Further education
Employment
Independent living
6. IDEA obligates the school to prepare

your child for the three things in number five. (20 U.S.C. 1400(d))

7. When you have your three lists, you are ready to ask the team to meet again to change the IEP.
8. A few days before the meeting give each team member a copy of your list.

9. Ask the team to include your lists in the IEP under "Parent Concerns."

10. Remember. You should not look at placement for your child until you complete the IEP!

(Reprinted with permission. Article originated in Wrightslaw E-Newsletter www.wrightslaw.com)

Helping Agencies Serving Richardson (HASR)

The Down Syndrome Guild of Dallas nominated Alan Walne and Herb's Paint and Body at the annual Helping Agencies Serving Richardson (HASR) for their generosity as our partner for the last 4 years as our Golf Tournament Partner. We look forward to many more years of partnering with Herb's Paint and Body!



Mommy & Me Class Infants and Toddlers

Wednesday's, January 11,
2011 to May 18, 2011
10 a.m. to 11:30 a.m.

Aaron Family JCC
7900 Northaven Road
Dallas, TX 75230

No fee for Down Syndrome Guild members.

Age 3 months to 3 years old

The class will be taught by Cynthia Casper, a certified Music Together instructor. Cynthia is a master teacher with a degree in Early Childhood Education, has over 20 years experience teaching preschool children. Mornings will include music, art, free play, movement activities, informal parenting discussions as well as joining together with other toddlers for an outdoor playground experience. Space limited to first 12 families to register. You must commit to entire semester. To register, call or email Becky Slakman at 214-267-1374 or dsged@sbcglobal.net

Sibling Workshop

The Down Syndrome Guild of Dallas
1702 North Collins Blvd., Suite 170
Richardson, TX 75080

Siblings ages 8 -11 years of age
(minimum 6--maximum 12 participants)

Fee: Down Syndrome Guild Members
\$30 for 6 week session; Non-members \$55

Registration deadline: January 15, 2011

Mail your registration payment to the
DSG office or call 214-267-1374 with
your credit card information

PARENT WORKSHOP:

Thursday, January 20, 2010
(required for participation)
7:00 - 8:30 p.m.

SIBLING WORKSHOPS:

Sundays at 3:00 p.m. to 4:30 p.m.

Dates: **January 23, 2011**
 January 30, 2011
 February 6, 2011
 February 13, 2011
 February 20, 2011
 February 27, 2011

PARENT WRAP-UP:

Sunday, February 27, 2011
4:30pm -5:00 p.m.
(after final day of workshop)

Parents are often concerned about the other children in the family. They wonder about the sibling's understanding of Down syndrome, and they are sometimes unsure of how to explain Down syndrome to them. They anticipate what effects having a sibling with Down syndrome will have on their other children's developing personality, and how they will feel about their experience.

The Down Syndrome Guild will be hosting a Sibling Workshop this winter to address these and other issues. We will have a Parent Workshop to kick off the Sibling Workshop. The Sibling Workshop will fun as well as educational and will consist of activities, role play and games

designed for children ages 8 – 11 years of age.

WORKSHOP FACILITATORS:

Debbie Clark, LCSW (Social Worker,
Down Syndrome Clinic)

Becky Slakman, (DSG Executive
Director)

Debbie Clark, LCSW, is a licensed clinical social worker and a licensed marriage and family therapist. She has worked with children and families for 35 years, and has been a staff member in the Down Syndrome Clinic at Children's Medical Center since the clinic opened in 1993. In addition, she has a private counseling practice in Dallas.

For more information, contact the DSG office at 214-267-1374 or dsged@sbcglobal.net

Dad's Group Happy Hour

Wednesday, January 12, 2010
6:30 pm - 8:30 pm
The Londoner

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

Join co-chairs, Chris McKee and Doug Dureau, for drinks and conversation. Feel free to invite other Down Syndrome Guild dads who might enjoy attending. RSVP to Becky Slakman at (214) 267-1374 or via e-mail at dsged@sbcglobal.net. Not able to join this time, but would like to be added to the list to receive information for future events? Let Becky know that as well.

Budget Shortfall Forces Big Cuts for Disabled

by Emily Ramshaw, the Texas Tribune

Barbara Cullison waited eight years and eight months to get community-based care for her profoundly autistic daughter Audrey through a popular Medicaid waiver program designed to keep people with disabilities out of institutions. Now, Audrey and thousands of other Texans with disabilities fear losing their services because of budget cuts demanded of state agencies.

Advocates say the Department of Aging and Disability Services' baseline budget request eliminates financing for more than 13,000 people — the majority of them waiting to receive so-called Medicaid waiver services in private homes, group homes or other community settings. Agency officials say an "unknown number" of people already receiving the services could lose them.

Lawmakers would have to approve another \$317 million off of the agency's budget wish list — called "exceptional items" — to keep the services intact, a pipe dream when the state is facing an estimated \$21 billion shortfall and has asked agencies to submit options for cutting their budgets another 10 percent.

"If this goes away, what are we going to do?" asked Cullison, whose daughter just came off of the waiting list for community services in September. "I need that safety net, need to know [that] when I can't take care of her anymore, there's a place for her that's set, that's paid for. After nine years, I thought I didn't have to worry about this anymore."

Agency officials acknowledge their hands are tied. Their current budget proposal means thousands of people sitting on lengthy waiting lists for community-based care likely won't get it — and some people who already get services will probably lose them.

The community cuts aren't the only threatened services at the disability agency. Officials there already approved

cutting reimbursement rates paid to care providers in the community and at private institutional settings, saving tens of millions of dollars. They're saving another \$2 million through "utilization review": revisiting high-cost community care plans to "make sure that all recipients are receiving the services they need," agency spokeswoman Cecilia Fedorov said, "not more or less."

"We've got some lawmakers telling us there will be some services lost, but we'll end up okay. There are others telling us that nothing's safe," said Amy Mizcles, director of governmental affairs for the Arc of Texas. "The reality is, if funding is not restored for those exceptional items, 13,000 people will lose their waivers."

What's not clear is if lawmakers can make these service cuts without risking losing federal funding. Federal health care reform requires states to maintain coverage at the same level it was when the Affordable Care Act became law in late March. Stephanie Goodman, spokeswoman for the Health and Human Services Commission, said the agency is asking the Centers for Medicare and Medicaid Services how that requirement will be interpreted, especially when it comes to people who have Medicaid waivers to receive care in the community.

Meanwhile, parents who rely on these community-based services for their disabled children are hoping their families won't be called up for utilization review. Joe Nester, who has a 29-year-old daughter and a 27-year-old son who receive Medicaid waiver care at home, said his kids have undergone the review process twice — and have narrowly avoided cuts in services both times.

"For the kids, it would've been a significant backward step, not to mention our quality of life would've become so much worse," said Nester, of San Antonio. "They need to try to find revenue somewhere else, and not cut services to families who need it."

Quarterly Meeting for Families of Adults with Down syndrome

Margot Wheeler, Texas Department of Assistive and Rehabilitative Services (DARS)

Thursday, January 13, 2011

6:30 pm- 8:00 pm

Down Syndrome Guild of Dallas

1702 N. Collins Blvd. #170

Richardson, TX 75080

One of the greatest challenges faced by adults with Down syndrome is how to stay involved and productive in the community after completing school. One of the ways to accomplish this goal is through employment. Adults with Down syndrome are more than capable of being successfully employed, but sometimes need support. Margot Wheeler, the Down Syndrome Guild of Dallas's liaison with DARS will present information that will benefit anyone who is, will be or wants to be receiving employment services through the Texas Department of Rehabilitative Services (DARS). New changes and programs will be discussed, so even if you are familiar with DARS, this session may still present you with new information. Please RSVP to Neely Holland at dallasdsg@sbcglobal.net or 214-267-1374.

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RICHARDSON, TX 75080

Return Service Requested

(214) 267-1374

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CALL (214) 456-2357

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DOWN SYNDROME GUILD OF DALLAS



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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.

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Down Syndrome Guild Calendar of Events

January 22
Adult Cooking Class

January 22
IEP Clinic

January 23
Sibling Workshop

January 29
Kindergarten Round-Up