

Extra Extra (21) Read All About It

A newsletter from the **OMAHA DOWN SYNDROME PARENTS NETWORK**
Committed to enhancing the lives of individuals & families touched by Down syndrome

Down Syndrome Specialist Program

Down Syndrome Specialists are professional educators who receive training concerning the nature of Down syndrome and related education issues. The Omaha Down Syndrome Parents Network facilitates this program in the Omaha area school districts. The Specialists hold a wide range of full-time positions within their districts/agencies. ODSPN's Education Advocacy Committee hosts three DSS breakfasts each school year. In Spring 2010, Specialists from two school districts led a panel discussion on the use of para-professionals in the classroom. ODSPN provides resource binders as well as regular updates on best practices and adaptive technology.

The Specialists are available for consultation to their district educators and parents of students with Down syndrome. They are not expected to attend every IEP meeting for student with Down syndrome but may be asked to consult should the team need additional resources.

Please be sure to contact your Specialist and introduce yourself. Your DSS can provide information to you and your child's teacher about adapting and modifying the curriculum to ensure a great school year.

ODSPN is grateful for the time and energy spent by the Specialists in their efforts to better support students with Down syndrome, their teachers, and parents.

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Papillion/LaVista	Tammy Voisin	tvoisin@paplv.esu3.org	402-537-6284
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September 2010

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Birthdays

July

Caitlyn Adams
Sean Bethel
Ryan Bisignano
Clair Elizabeth Bruns
Rebekah Cook
Jamie Crozier
Taylor Dabbs
Cole Edwards
Jack Flanery
Devon Freiberg
Ella Haitz
Herley Reichen
Marissa Palacios
Edward Pfeffer
Julian Ramirez
Alex Rohrer
Kayleigh Schoepe
Brady Shannon
Ty Stanley
Brooklyn Tonjes
Jenna Twomey
Benjamin Walz
Trey Yanak

August

Ashlee Archer
Cecelia Bernard
Kaden Boettger
Collin Burch
Daniel Butler
Hunter Connor
Kristin De Leon
Monica Franco
Elisa Gomez
Audrey Goodman
Elizabeth Hernandez
Payton Holling
Steffani Hudson
Morgan Jenkins
Carlos Masias
Timothy McLaren
Dean Okereke
Sarah Placek
Kennedy Rocker
Tracy Sandoval
Jessica Soto

September

Olivia Bargstadt
Jamie Barth
Josie Clark
Bryce Evert
Mary Eyth
Richard Franco
Tyler Gammon
Jacob Gehringer
Chloe Hays
Lane Klein
Cora Kulak
Kalyan Mowrey
Johnny Nielsen
Zakariah Nomad
Sara Posekany
Angela Rogel-Palomares
Bryce Rohrer
Michael Rozmajzl
Brenden Rudiger
Julia Scott
Kennedy Stafford
Wesley Waldron
Clayton Wederquist
Kalyan Wildermuth
Alexandra Wingender

When “They” Say By Kathy Everett, Alpharetta, GA

IEP

Those three little letters instill fear in the hearts of many parents who have a child with a disability. Others have no clue what they mean. In the past 22 years, I have attended hundreds of IEP (Individual Education Plan or Program) meetings. Some were for my own daughter, Jennifer. Sometimes, I provided a hand to hold or a friendly face in the crowd for other parents who needed it. The process of creating an IEP can be long and confrontational, short and cooperative—or anything in-between. The key is for parents to know what to say when “they” say (fill in the blank).

We’ve never done that before.

Well, let’s see how we can figure out how to do it.

She will get more attention in a small group setting.

The average self-contained class has eight students all with significant special needs while the general education classroom has an average of 20 students but statistically only one will have significant special needs.

Your child requires more attention than I can give in my class. I have 20 other students that need my attention.

I understand and it sounds like you do not have enough support in the class to help with all of your students. Then maybe a paraprofessional is necessary. OR All students need to be challenged and you should not feel like you are the only one who can teach my child. I am sure there are several other children who would love to help out my child. We all know that helping someone else learn reinforces what is being taught. Peer tutoring is a wonderful opportunity for everyone in the class to learn.

He needs to be with other kids that are like him. He will always feel left out and unable to really compete with his peers.

My child needs to be around age-appropriate peers in real life situations to learn how to get along with others in the real world. Research shows that all children benefit from inclusive classrooms.

It isn’t fair to have a child in the class who is learning, to have to teach someone else. It isn’t their responsibility.

We all know that kids learn from kids. Kids build competence by teaching someone else because it reinforces the skills they are learning themselves.

She really needs adaptive PE (or art or music).

I understand my child has limitations, but she will benefit from access to the general curriculum, just like all of the other students do. And in a class like PE (or art or music), just learning to follow directions or changing clothes is a skill my daughter needs for life.

They need to be in adaptive PE so they don’t get hurt.

Don’t you have any other children that ever get hurt? My child needs to learn how to play in social environments. What can I do to help you have the support so that he can safely participate? Let’s work together to plan what support will help him participate safely.

She is so far below grade level, she cannot even. . . .

I understand my child can’t. . . . That is why we have differentiated instruction. The curriculum needs to be modified so that she can continue to progress and learn.

He is not at the level of the other children.

I know he isn’t at the level of the other children. That is why he has an IEP. I don’t expect him to be at the same level as his peers, but I do expect us to use a modified curriculum, where we can identify the supports that are necessary and helpful for him to learn.

We are concerned about her life and/or job skills. That is why she needs to be in this class.

I really appreciate your concern. There are many things I can replicate at home and I can teach my child. But I cannot recreate a high/middle/elementary school environment. My child needs to experience that just like any other child. I will teach my child life skills. I can take my child to the grocery store. I need her to learn how to be around other people.

In communication, one of the most important things to remember is to keep the conversation focused on your child and his needs. It’s what he needs, not what you want for him. It sounds simple, but the key is semantics. Always think about how you phrase a question or statement to encourage the response you want. I never ask if something can be done. I ask how it is going to happen. It is important to be knowledgeable and realistic about what your child can and cannot do. Know the law—but use it sparingly. Honestly, you and the educators want the same thing: for your child to learn in a healthy, caring environment. Soemtimes, we just have differing philosophies of how to accomplish that. Good luck and remember an IEP is not carved in stone. It can be changed.

Kathy Everett is a certified teacher in both general education and special education who directs her own consulting business, Kathy Everett Consulting, to assist parents in navigating school systems. She also has a daughter with Down syndrome. Reprinted from *Down Syndrome News*, Vol 33, No 2, 2010.

Letter from the President

ODSPN is gearing up for the 9th Annual Buddy Walk. It promises to be even bigger and better than last year with a new date, new time and new route! We hope to see you, your family, your friends, your co-workers—everyone at the Walk.

The Buddy Walk is our major fundraiser for the year. It accounts for 95% of our revenue. The Walk allows ODSPN to provide programs (such as the Down Syndrome Specialist program which has over 20 school districts participating in working to provide resources for students with Down syndrome) to our Special Events such as bowling, Parents Night Out, MOMS group, Grandparents group, etc. Last year ODSPN was able to have over 1,200 of our members be a part of at least one of our Special Events. In 2010, over 900 of our members have attended at least one of our Special Events—so we are on target to have even more families attending. ODSPN uses some of the Buddy Walk funding to pay for our Communications Director, Anne Mancini, to do the excellent job that she does in providing information, emails, and organizational skills for ODSPN and our families. Anne is doing the work that 3 volunteer Board members were doing because the needs of our organization and families changed—and that is why Anne was hired. One of our most popular programs, I believe, is sending Birthday Cards to our children with Down syndrome. We took a page from the our friends at the Down Syndrome Guild of Kansas City who had this program in place. We have received so many delightful Thank You cards and emails from our members that the Board believes this is a program worth continuing. ODSPN also provides stipends for families who want to attend a conference or seminar—in 2009 that amounted to 2% of our expense.

The budget that the ODSPN Board approved for 2010 is as follows:

- Buddy Walk 23% of budget (purchase of t-shirts, signage, entertainment at Buddy Walk)
- Parent/Medical Outreach 9% budget (this includes Welcome Bags for new parents at the 10 major area hospitals, Moms group, Grandparents group, New Parent Orientation)
- Special Events 14% of budget (Golf, Parents Night Out, Swimming, bowling, movies, etc.)
- Board Expense 23% of budget (Communications Director salary, Lending Library)
- Website 1% of budget (website changes and associated expenses)
- Communication 21% of budget (postage, printing of Parents Packet, Parents Brochures, birthday gift cards)
- Advocacy 7% of budget (Down Syndrome Specialist program, seminars)
- Member Stipends 2% of budget (stipends for parents to attend training, go to NDSC convention).

ODSPN has more planned for the remainder of 2010 and we will continue to look for events and programs for our members.

Thank you for all of the support you provide to ODSPN through the Buddy Walk. While we continue to look for other ways to increase our revenues, this is our major fundraiser that allows ODSPN to provide for our members.

Congratulations!

Matt Gibbon, former ODSPN Board Member, was honored at the Madonna Schools "Angels For Angels" Celebration and was also featured in an article in the August 13, 2010 edition of The Catholic Voice.

Ayman Sharif, ODSPN Board Member, was featured in an article in the August 15, 2010 edition of the Omaha World Herald. The article profiled Omaha World Herald employees who volunteer in the community.

Marissa Horstman, Troy Kostal, Cassie Lacy, Kelsey Martens, Marshal Rabe and Danielle Alvine appeared in "It's Our School, Too," a play performed at UNO in conjunction with Special Olympics. Over 600 audience members enjoyed the performance.

Nebraska Young Athletes Ryan Bisignano, Addison Adams, Aiden Seipold, Nick Wright, Tommy Schroeder, Josie Clark, Sam VanderVeen, Beth Hamm and Jordan Burtzel took part in the opening ceremonies of the July 2010 USA National Games.



Jake Gehringer and Logan Schneider participate in the Torch Run.

Welcome

Maranda & Cheyenne
BlackEagle
Brielle BlackEagle
& Family

Brenda Sutton
Brian

Julie & John Butler
& Family

Daniel & Patricia Kline
Andrew & Family

Pam & Tony Curtis
Justin & Family

Cindy & David
Wadzinski
Jack

Sandy & Dan Churchich
Debra & Family

Laura & Jeremy Baum
Claire & Family

Anthony Yanak & Robin
Lipshin
Trey & Family

Thank You

Thank you to Dani Archer and Mary Beth Bisignano for staffing a volunteer table at UNO Community Engagement Day on August 25.

Thank you to the over 100 ODSPN members who took the time to fill out the membership survey. The board will use the responses for planning purposes for 2011.

Thank you to Jerome and Sally Linquist for their donation to ODSPN in honor of the 50th Wedding Anniversary of Don and Sandra Dai.

Thank you to Sister Michon Rozmajzl for her donation to ODSPN in honor of Mikey Rozmajzl.

OMAHA DOWN SYNDROME PARENTS NETWORK

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Our mission is to enhance the quality of life for all individuals with Down syndrome by providing resources and support to those individuals, their families, professionals and the community. Our Vision includes:

- Providing access for individuals of all ages and their families to a wide range of opportunities and resources that meet their needs.
- Full participation of the membership, the community and professionals working together to build resources that inform and support one another.
- An effective coalition with the educational community providing a choice of opportunities for high quality education for individuals with Down syndrome.
- A professional community providing services and advice based on current and accurate information available and acting as advocates for family and individuals with Down syndrome.

Math and Literacy Educational Resources

Teaching children and teens with Down syndrome literacy and math skills can be challenging. The Down Syndrome Foundation of Orange County created the Learning Program to help parents and educators help their loved ones. Effective teaching strategies and customized materials are available for download and/or purchase at the DSFOC website. The Learning Program complements formal instruction in literacy and math with occupational and speech therapy components.

The guiding principles of the program are:

- Assume Your Child is Able
- Make Learning Fun
- Success is Key
- Teach ... Don't Test
- Model ... Don't Correct
- Let Child Set Pace
- Balance Learning Time and Play Time
- Don't Let Guilt Get in the Way

Visit www.dsfo.org/learning_program_registration.php to register to access free online materials

New to the ODSPN Lending Library. Email info@odspn.org to borrow these or other titles.

My Social Stories Book (2002). Gary, Carol and Abbie Leigh White. Jessica Publishers. Great book to use for individuals who want to read how to act appropriately in social settings. Some pictures, but good for parents to use to start the conversations.

The New Social Story Book (2010). Gray, Carol. Future Horizons. Great book with over 150 social stories that teach everyday social skills such as What is a mistake?, Thanking People For What They Do For You, etc. Written for children on the Autism Spectrum, but applicable to any individual with a developmental disability.

Playing It Right! Social Skills Activities for Parents and Teachers of Young Children with Autism Spectrum Disorders, Including Asperger Syndrome and Autism (2006). Bareket, Rachael. Autism Asperger Publishing Co. Very easy-to-use book for teaching with both visual and written cues how to "When Do I Need to Wait?" And "Don't Interrupt." Useful for any child with a developmental disability.

The Social Skills Picture Book for High School and Beyond (2006). Baker, Jed. Future Horizons Inc. Excellent book for individuals of any disability and age, with visual and written cues on "How to ask for help," "Don't tell others what to do unless they are hurting you or others."

Talking Together: Social Stories that Clarify Daily Routines and Explain Social Rules (2009). Natural Learning Concepts. Social Rules—Having A Conversation—Dealing With Bullies—Stranger Danger Easy-to-follow stories with pictures, words, and questions after each story to reinforce the social story with the individual.

Managing My Money: Banking and Budgeting Basics (2010). Hale, Natalie. Woodbine House. Great money-management book for anyone with a developmental disability. Divided into 3 sections- keeping money records, keeping a budget, and managing a checking account- with great examples. There is also a CD so that additional forms can be printed.

The Little King and his Marshmallow Kingdom (2010). Rotella III, Louis. Ata Boy Productions, Inc. Story of King Louie and his marshmallow kingdom. Story talks about differences and similarities that all children have. Good for children 4 – 10 years of age.

Stuttering and Down Syndrome

Imagine you are trying to plan what to say in a foreign language—one where you know only a few words. You are likely to have long pauses when you are thinking of words, may take a long time to respond, might start to speak and then forget the word, or perhaps repeat a word a number of times while you are trying to plan your sentence. You may, in fact, appear disfluent.

Fluency depends on an equal balance between demands on the language system and the abilities of the individual to meet these demands.

For a person with Down syndrome, wanting to convey messages through a system that does not always work perfectly may lead to word repetition; long pauses, sometimes in unusual places; rushing of words; emphasis on the wrong word or part of a word; and/or struggling to find the right speech sounds.

To help a person with Down syndrome develop fluency, work to decrease the demands and increase communication.

Decreasing demands can be as simple as slowing down your own speech, avoiding finishing sentences, avoiding too many long or complicated words or sentences, and providing positive encouragement for the message rather than the style of delivery.

Increasing communication can be through expanding vocabulary, encouraging sign language and other adaptive communication aids (this reduces the pressure on the speaker and allows them several avenues to communication); encouraging the development of good social and communication skills (when to speak, looking at people, etc.) and/or working with a speech therapist. It is important to be encouraging and let the speaker know that what he or she says has value and that others want to listen!

Visit the Stuttering Foundation at www.stutteringhelp.org

