

The CIDSO News

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Highlights from Conference

"A Brighter Tomorrow"

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Submitted by Jean Bates, Christy Bates, Dawn Mattia & Randy Mattia

The Convention began on Thursday night with an ice cream social, where families gathered to get acquainted around a large outdoor multi-purpose fountain, while listening to music and watching children play in the water. On Friday Jean attended the Affiliates in Action meetings with an opportunity to network with forty some affiliate Down syndrome organizations from across the country along with representatives from the national organizations. Jean entered into discussions on Structure of Organizations, Advisory Boards, Participation of Membership, and Self Advocates Roles on the Board. During the day Jean was also given an opportunity to view television and radio PSA (Public Service Announcements) clips of the new NDSC awareness campaign, soon to be launched entitled "We're more alike than different". Please be watching for these they are very well done. One presentation that both Jean and Dawn participated in, was given by a parent and attorney in the Orange County California parent group, who has done

extensive research and development of literacy and math programs for children and adults with Down syndrome. She also took time to explain the "Guiding Principles of Learning" You can look at the results of her research and find some practical learning techniques at www.dsfo.org

Friday night's kick off to the convention began with two dynamite keynote speakers. Viviana Fernandez, Anchor and Producer of CNN EN Espanol, who is a mother of a son with DS and Audrey Wagon, co-founder of the B.E.S.T. Network, which is a network of programs dedicated to promoting people with disabilities in the performing arts. The keynote speeches were followed by an elaborate opening reception for families with wonderful hors d'oeuvres and an opportunity to view the exhibition hall. Saturday began with two wonderful keynote speakers. Karen Gaffney, self advocate opened with a beautifully delivered inspiring speech on her up and coming swim across Lake Tahoe as a fundraiser for NDSC. We also learned more about "The Beach Center on Disability" from founder

and Keynote speaker Ann Turnbull. Ann's dream of taking research out of the hands of researchers and getting it into the hands of the families and individuals who can benefit from it is becoming a reality. Check out www.beachcenter.org and be a part of the virtual community, sharing ideas and best practices.

Then it was on to the workshops! One particular workshop that caught our eye was one given by Susan Peoples, the founder of "Special Offerings" who has been a teacher and clinician for 30 years, and is the mother of a son with Down syndrome. Susan identified an instructional design needed to provide remediation for deficits in short and long term memory, transfer of learning and concept development of skills that are intended for children with DS to achieve academic success. Susan made a promise to us all that in the next 18 months she would be securing 10 million dollars for a self-perpetuating fund to finance the salaries of a minimum of 10 highly experienced and specialized educators in all the basic subjects to come up with

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Revised Procedures for Enrichment/Participation Fund

Please note the newly revised Enrichment/Participation Application which is enclosed. A few clarifications have been made so please read carefully. All applications must be filled out and submitted by the applicant applying. All applications must be sent to CIDSO by the applicant and will be reviewed quarterly. CIDSO will reimburse those applicants that are approved. Thank you for your cooperation in this matter as we seek to support more opportunities in the community for our children.

Homes of Hope Presentation

This past month CIDSO was invited to give two educational presentations on Down syndrome to Homes of Homes employees. CIDSO President, Jean Bates, spoke about health and behavioral related issues in adults with Down syndrome. We applaud the initiative Homes of Hope took on behalf of their residents to learn more about how they can better serve those with Down syndrome in their residences.

Buddy Walk Time!

Saturday, September 29th is the big day! The Buddy Walk Committee has been hard at work planning a fun-filled morning designed to increase awareness for CIDSO and Down syndrome. We are very excited about this year's \$1 raffle which will again feature AirTran tickets along with many other great prizes. We will also have free entertainment including a climbing wall, massage therapists, and lots of fun stuff for the little ones. Team themes are really taking off this year and we are expecting record attendance along with media coverage. Registration starts at 8:00 am and the walk will begin at 9:30 am at Carden Park, 1300 E. Raab Rd, Normal.

The Beatitudes of the Exceptional Child

by *Andre Masse C.S.E.*

Blessed are you who take time to listen to difficult speech for you help us to know that if we persevere we can be understood.

Blessed are you who walk with us in public places and ignore the stares of strangers for in your companionship we find havens of relaxation.

Blessed are you who never bid us to "hurry up" and more blessed you who do not snatch our tasks from our hands to do them for us, for often we need time more than help.

Blessed are you who stand beside us as we enter new and untried ventures for our failures will be outweighed by the times when we surprise ourselves and you.

Blessed are you who ask for our help for our greatest need is to be needed.

Blessed are you when by all these things you assure us that the thing that make us individuals is not in our peculiar muscles, not in our wounded nervous system, not in our difficulties in learning but in the God-given self which no infirmity can confine.

Picnic Turned into Quite the Party!

Approxiamtely 45 people came to Fairfiew Park for he CIDSO Picnic. The weather was beautiful and the flies were few. There was something for everyone, from the mud puddles for the little ones to explore to the great food for us grown-ups. Thanks to Judy Bates for coordinating another successful event. Speical thanks to Jason Hahn for leading the water balloon games and to all of you who hit me with the water balloons....just wait unti next year!

Mark the Date:

September 29:

Buddy Walk

October 15:

Board Meeting

December 2:

*Holiday Party and
Annual Meeting*

Disclaimer Policy

The editor of this newsletter writes as a non-professional. CIDSO does not promote any therapy, treatment, institution or professional system, etc. Please discuss specific concerns with your health care professional.

Conference Highlights

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appropriate curriculum for students experiencing developmental delays. Her motto is “inclusion no longer means a child placed in the regular classroom without the benefit of appropriate curriculum”

Jean attended her first “Person Centered Planning” workshop, offered by a mother daughter team and found it very creative and empowering. The concept, which includes family and friends in a brainstorming party, focuses on assets, abilities and future planning at a time of transition in the life of an individual with DS.

Jean also attended a Sexuality Education workshop that focused on strategies for teaching and promoting healthy sexuality and attitudes in those with disabilities. The presenter of this workshop, Terri Couwenhoven, has just written an excellent book on the subject that Jean has purchased and would be willing to share with anyone interested.

Dawn attended another Susan Peoples conference titled “Successful Learning Approaches” which included a lot of common sense approaches to problem solving. For example, if you child lags behind the rest of the class, walking slowly down the hallways at school, the solution may be as simple as making him or her the line leader rather than the caboose. A lot of discussion surrounded medical and health issues that could affect learning such as a thyroid problem, vision problems, and fluctuating hearing loss.

Dawn also attended “Positive Behavior Support” which focused on how to dissect an unwanted behavior to see what is causing it and what the outcome/payoff is for the person behaving badly. We discussed ways to avoid problems that could be caused by environmental issues, how to change the outcomes/payoffs and strategies for rewarding positive behavior. This was presented by a parent of a child with a disability and it was refreshing to listen to the “professional” admit that sometimes you are just going to have behavior problems and sometimes you are not going to handle them well. However, she did encourage us to analyze those situations once order has been restored and we are thinking clearly to develop a game plan for the next time the behavior occurs.

Randy went to a workshop on Assistive Technology, also known as AT. AT is a tool that allows a person to do a task, such that, without the technology, the person could not do the task at the expected performance level. AT promotes Universal Design for Learning (UDL). UDL principles help educators customize their teaching for individual differences and AT tools are uniquely designed to match with individual learning style. With the right tool, a teacher can address multiple learning styles. AT tools provide educators, parents and employers with options. We may associate AT with new and traditional “hardware” (equipment) and overlooking the escalating growth of assistive learning “software.” You might be familiar with Kidspiration www.inspiration.com/productinfo/kidspiration/index.cfm but have you considered Microsoft’s Movie Maker 2.1 (www.microsoft.com/downloads/results). One researcher found Movie Maker 2.1 to be an effective tool for teaching students to learn. Other websites that might spark interest and are helping teachers, parents and students match learning style with individual interests include www.gutenberg.org/wiki/Main_Page and <http://readplease.com/>. If you would like to learn more about assistive technology, including assessment tools and suggestions for including AT tools as part of the IEP you might consider visiting **Wisconsin Assistive Technology Initiative or WATI at www.wati.org**

Christy attended the youth and adult part of the conference. Their kick off had a country western atmosphere, an opportunity to learn line dancing and many great giveaways. The mixer (dance) was held the first night and was led by Radio Disney. All of the workshops Christy attended were led by self advocates who were very knowledgeable about their subjects. Christy attended a kick boxing class, which included healthy tips for staying fit; a sign language class led by a young woman that has signed for Dolly Parton; and a exercise your mind class with puzzles and word games. Christy watched a food demonstration by a young advocate that does a lot of cooking and listened to Craig Blackburn (self advocate and recently engaged) give a Keynote speech on Dreams, Visions and Goals for All. Company D (self advocate dance team) performed and there were Wizard of Kansas skits throughout the weekend. There was of course a dance the second night, complete with beach party theme. Christy had an opportunity to interact with numerous other young adults from around the country. One highlight for Christy was being assigned to sit at a table with Carrie Bergeron, (her husband could not attend) and getting to talk with her.

Seem like a lot? These are just the highlights. If you are interested in learning more about any of these topics and others we would be happy to share information and materials we picked up at the convention. In addition, we have ordered a complete tape of all the workshops and keynote speeches. Just let one of us know if you are interested. And thank you again for providing the financial support which made it possible for us to attend this valuable conference.