

DOWN SYNDROME ASSOCIATION OF CENTRAL KENTUCKY



January
February
2012
volume VI
number I

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*2012 Conference Brochure
included in this issue! See pages 3-6.*



NEWS FROM THE BOARD

PARTY, CONFERENCE, CHANGES AND THE FUTURE

The Down Syndrome Association of Central Kentucky wrapped up 2011 with a fabulous Christmas party at Marriott's Griffin Gate Resort. Nearly 200 family members were in attendance in addition to board officers, directors and advisors! We were thankful for the number of new babies with Down syndrome and we hope that you new families (with children of all ages) felt welcomed! Thanks to all who came - your attendance made this our biggest, best Christmas party ever. Check out the party photos on pages 10-11. Scott Mandl, you and your photography skills are appreciated more than you know. And, as usual, a HUGE round of applause to Allison Kerschbaum, who absolutely knows how to throw a party!

Our second annual Down syndrome conference will be held February 25th, 2012. The full brochure can be found on pages 3-6. Please read it thoroughly and make plans to attend. Also, be sure to tell your child's teachers and therapists about it! The conference is designed so that family members and professionals will learn how to better help our kids reach their full potential. The registration form in this newsletter can be copied but we will certainly mail additional copies to you upon request so that you can pass them out. This year's conference agenda has been carefully planned based on the feedback you gave us last year.

We have had some board changes, too. After a very productive three years, Regina Schmutte has stepped off the Board of Directors and will now serve in an advisory role. (More about Regina in the Board Spotlight section). We are fortunate and excited to have two brand new faces on the board - parent Tonya McPhetridge and marketing expert Rebecca Price!

Jeanne Miller was introduced in the last issue of our newsletter as our new fundraiser. When her efforts are successful, our organization's wish list will include hiring an Educational Coordinator (to further educate physicians, hospital staff, educators and families about Down syndrome and to increase the personal and educational outreach to families and professionals in Central and Eastern Kentucky), to improve our Marketing and Public Relations, and to increase monies available in Erica's Fund. Of course, this is the short list.

During the upcoming year, we will continue to sponsor monthly events for 0-5 group, elementary group and teens and adults. We will continue to throw big parties two or three times a year, in addition to hosting the Down syndrome educational conference. We will continue with our efforts to educate the community about Down syndrome so that everyone will be provided the best support possible. Of course, the day-to-day assistance and communication you receive will continue to be provided by Allison, our Program Coordinator. Basically, we will continue to CELEBRATE, SUPPORT AND EDUCATE.

Everything that DSACK currently does, as well as our visions for the future, is only possible because of the many years of hard work by many dedicated people. Those of us currently serving on the board acknowledge the efforts of those before us.

Wishing all of you a blessed 2012,
Michelle Gilliam, Chairperson

board members

PROGRAM COORDINATOR

Allison Kerschbaum

BOARD OFFICERS

Michelle Gilliam, Chairperson
Tonya McPhetridge, Vice Chairperson
Lee Ann Mullis, Treasurer
April Vernon, Secretary
Hans-Peter Healy, Research Officer
Your Name Here, Board Liaison

ADVISORY COUNCIL

Karen Roof Boudreaux, Parent
Becky Lesch, Parent & Educator
Malkanthie McCormick, M.D. & Parent
John Riley, M.D.
Regina Schmutte, Parent

BOARD DIRECTORS

Susan Hart Bell, M.S., Ph.D., Parent & Professor of Psychology & Coordinator of Child Development, Georgetown College
Traci Brewer, Parent
Meada Hall, M.S., Ed.D. Principle Investigator & Project Director for Community Based Work Transition Programs, UK
Harold Kleinert, Ed.D., Executive Director of HDI
Joanne Luciano, PT, MHS, Kids In Motion, Inc
Samantha Matthews, Special Education Teacher
Matt Moore, Director of Special Education, Jessamine County School District
Rebecca Price, Marketing Director, ABC 36, WTVQ-DT LLC

DSACK Bylaws and financials are open for review, and the Board of Director Meetings are open to our community. Agenda items are determined well in advance.

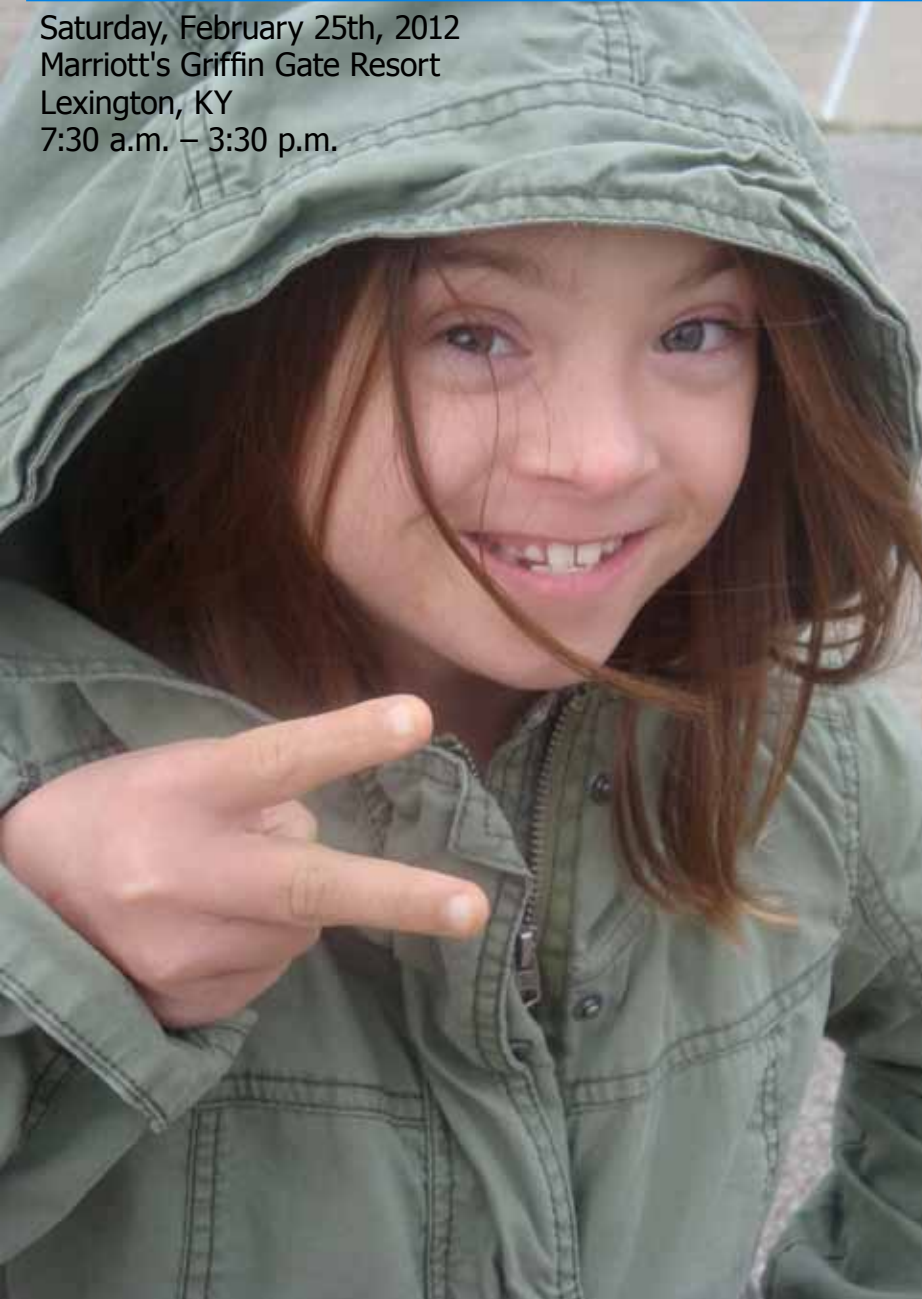
The DSACK Newsletter is published bimonthly by the Down Syndrome Association of Central Kentucky, P.O. Box 910516, Lexington, KY 40591-0516.



Down Syndrome Association Of Central Kentucky *presents*
M O V I N G F O R W A R D
A Conference About Down Syndrome For Parents And Professionals

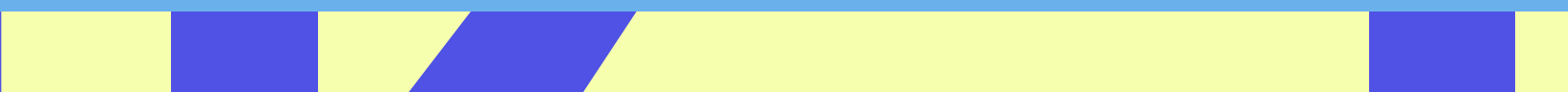


Saturday, February 25th, 2012
 Marriott's Griffin Gate Resort
 Lexington, KY
 7:30 a.m. – 3:30 p.m.



An essential seminar designed for educators, speech language pathologists, school psychologists, students, families and anyone with an interest in people who have Down syndrome.

Every human life is a BEAUTIFUL gift. People with Down syndrome are CAPABLE of living full lives and dreaming big dreams. People with Down syndrome are LOVED beyond your wildest imaginings.





MOVING FORWARD

C O N F E R E N C E S C H E D U L E

Registration and Breakfast – 7:30 -7:55

Welcome and Announcements – 7:55-8:00

Session 1 – 8:00-9:10 “Social Integration Movement: Steps for Fostering Relationships with Typical Peers” by Shaun M. Demeter, Barbara Jackson and Mary A. Molsky. This session will offer practical ways to create and foster more opportunities for one-on-one friendships and social opportunities for individuals with intellectual and developmental disabilities. The presenters will introduce different opportunities available in Fayette County and nationwide (Best Buddies, Kindness Is Power Club, Gummy Bear Club, Spread the Word to End the Word, etc.) for social integration, will discuss the success of these programs and will provide instructions about how to start a program at your own school or organization.

Break – 9:10-9:20

Session 2 – 9:20-10:45 “Hands-On-Math For Your Students and Children Using the Philosophy and Methods of Piaget and Montessori” by Kathy Regan and Jenny Littrell-Hesseldenz. Math develops early and is a critical skill lasting a lifetime making it an important part of all learners’ education. This presentation will have an emphasis on the foundation of math concepts and skills starting with the earliest exercises including exploring patterns and one to one correspondence continuing through techniques for mastering math facts. This session will explore the developmental stages and sensitive periods for learning math with a hands on focus. A discussion of the Mathematical Mind, student assessment, and classroom experiences will be included followed by a “make and take” session of some of the materials which have been included.

Break – 10:45-11:00

Session 3 – 11:00-12:30 “Developing Intelligible Oral Speech for Children with Down syndrome” by Jane O’Regan Kleinert, Ph.D, CCC-SLP. This session will focus on the following topics: normal sequence of development of oral speech in children, factors that impede the development of clear oral speech in children (especially children who happen to have Down syndrome), choosing targets and strategies for speech therapy (especially for children who happen to have Down syndrome), taped examples of speech therapy sessions demonstrating targets and strategies and suggestions to reinforce improved oral speech.

Lunch Buffet – 12:30-12:45

Luncheon with presentations by a self-advocate and a panel of DSACK parents -12:45-1:45

Break – 1:45-2:00

Session 4- 2:00-3:30 “Supporting Behavioral and Emotional Issues in Children, Adolescents, and Young Adults with Down Syndrome” by Susan Bell, M.S., Ph.D, Victoria Carr, Ed.D, and Brooke Browning, M.S. This conference presentation will assist parents, teachers, and other professionals in problem-solving some of the behavioral and emotional challenges that affect the lives of most children, adolescents, and young adults but increase in complexity as they involve individuals with Down Syndrome. Too often the behaviors or emotional reactions of these individuals are viewed as linked to their permanent genetic condition, and other, more plausible explanations are ignored. Dr. Bell will provide an overview of a functional assessment and scripted intervention process that examines a host of factors that may be contributing to the troubling behaviors and emotional reactions. Dr. Carr will discuss strategies for inclusive classroom settings, and effective collaboration between teachers, families and other professionals. The presenters will also share case examples, and sample assessment and intervention tools from their most recent book *Addressing Challenging Behaviors in Early Childhood Settings: A Teacher’s Guide*. Brooke Browning will discuss effective strategies for counseling with individuals who have intellectual disabilities as well as emotional concerns.

Adjourn 3:30

Conference Description- This conference will bring together experts in the areas of oral speech, hands-on math, social inclusion programs and behavioral and emotional issues that may occur in people with Down syndrome. Also featured will be a self-advocate and a DSACK parent panel.

**Susan
Hart Bell
M.S.Ph.D.**

Dr. Bell, Professor of Psychology at Georgetown College, is a DSACK board member and parent of a young adult son with Down Syndrome. She is also a former board member of Quest Farm, a residential community for adults with disabilities in Scott County. She holds a Master of Science in Clinical Psychology from Eastern Kentucky University and a Ph. D. in School Psychology from the University of Cincinnati. She has coordinated an interdisciplinary early childhood team of professionals serving preschool children with disabilities in the Raleigh, NC area, directed the Ohio Early Childhood Intervention Project at the University of Cincinnati, and taught at Somerset Community College, University of Cincinnati, and Northern Kentucky University. Dr. Bell's research interests are in the areas of children and technology, cyberbullying, challenging behaviors in early childhood settings, and school psychology. Books co-authored by Dr. Bell include *Designing Preschool Interventions (1999)*, *Challenging Behaviors in Early Childhood Settings: Creating a Place for All Children (2004)* and its companion text, *Addressing Challenging Behavior in Early Childhood Settings: A Teachers Guide (2010)*. Dr. Bell has co-authored several articles on preschool interventions and a book chapter entitled *Enculturation of young children and technology in Technology and Young Children: Bridging the Communication-Generation Gap* by Blake, Winsor, & Allen (2012). Her most recent book chapter, *Internet safety: Proactively protecting young children from internet threats*, coauthored with Peach and Spataru, is in press.

**Brooke K.
Browning
M.S.**

Brooke Browning is currently a school psychology intern with Scott County schools. She is a former DSACK board member who developed the Advocates in Motion teen/young adult group for DSACK in 2008. She attained her Master of Science degree in Educational Psychology from the University of Kentucky and is currently a doctoral candidate in School Psychology. Along with Dr. Tom Prout, she published a book chapter entitled *The effectiveness of psychotherapy with persons with intellectual disabilities* in R. Fletcher's (2011) *Psychotherapy for Individuals with Intellectual Disabilities*. Brooke presented a poster entitled *The effectiveness of psychotherapy for individuals with intellectual disabilities: A meta-analysis* at the National Association for Dual Diagnosis in November, 2010. She is currently completing her dissertation: *Diagnostic overshadowing: School psychologists' attitudes toward adolescents with intellectual disabilities and Down Syndrome*.

**Victoria
Carr
Ed.D**

Dr. Carr, Associate Professor in Early Childhood Education and Human Development at the University of Cincinnati, is Director for the Arlitt Child and Family Research and Education Center. She is Executive Producer for Arlitt Instructional Media, a professional development series of evidence-based instructional techniques for early childhood educators. She holds a Bachelor's Degree in Elementary Education and Learning and Behavioral Disorders, Master's Degree in Gifted Education, and Doctorate in Early Childhood Special Education and has 25 years of experience in Kentucky, Florida, and Ohio as a practitioner and consultant in these fields. Dr. Carr's research is related to teacher instruction to support all learners, curriculum-based assessment, and nature and children. She has published and presented papers with regard to nature and children, challenging behaviors, gifted education, assessment, and other related topics. Books co-authored by Dr. Carr include: *Challenging Behaviors in Early Childhood Settings: Creating a Place for All Children* and its companion text, *Addressing Challenging Behavior in Early Childhood Settings: A Teachers Guide*. Book chapters include: *Children with Gifts and Disabilities* in the *Handbook for Gifted* and a chapter on state funding and professional development for gifted programming in the forthcoming *Debating Issues in American Education*. Her most recent article, *Romancing Nature in Place-Based Head Start Learning Environments* is in press.



**Shaun M.
Demeter**

Shaun M. Demeter holds a Bachelor's Degree in Special Education Teaching and is certified to teach Special Education K-12 and Middle Grades Social Studies. He currently teaches grade 6 Social Studies and co-sponsors The Gummy Bear Club at Beaumont Middle School. Mr. Demeter also designed and is the current administrator for The Gummy Bear website (www.bmsgummybear.org) which includes articles written primarily by students from Beaumont Middle School and has links to YouTube and Twitter pages.

**Barbara
Jackson**

Barbara Jackson is a special education teacher in Fayette County and former Best Buddies President at UK. Best Buddies is a nonprofit organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities. Barbara's sister, Erika, has Down syndrome.

**Jane
O'Regan
Kleinert
PhD,CCC-SLP**

Jane Kleinert is an Assistant Professor in the Division of Communication Sciences and Disorders in the College of Health Sciences at the University of Kentucky. She is a licensed Speech/Language Pathologist with over 35 years of experience specializing in services to children with multiple disabilities, oral feeding disorders and early intervention. Dr. Kleinert's research and grant work focuses on intervention for speech and augmentative communication for students with significant disabilities. Her teaching areas at UK include speech sound disorders, pediatric feeding and motor speech disorders and early intervention. Jane and her husband Harold are life-long Kentuckians and have three adult children. Jane's younger sister, Ruth, has Down syndrome.

**Jenny
Littrell-
Hesseldenz**

Jenny Littrell-Hesseldenz has taught young children at Fayette/Cooperating Nursery School and Kindergarten in Lexington, Kentucky since 2000 where she currently teaches children aged two to six. Before teaching at Co-op, she taught art and science to children of all ages at the Living Arts and Science Center and also taught and coordinated LASC's Urban Ecology and Ecology Outreach Programs to elementary students in Fayette County Public Schools. Ms. Littrell has a bachelor's degree in English Literature from the University of Wisconsin, Madison.

**Mary A.
Molsky**

Mary A. Molsky holds a Master's Degree in Education and currently teaches children who are differently able at Beaumont Middle School in Fayette County, Kentucky. She is also the founder of the original Kindness Is Power Club, The Gummy Bears. The Gummy Bears, created in 2007, has been recognized as an outstanding peer mentoring program. The club has been featured on Kentucky Education Television, Stu's News, The ARC in Kentucky, and The Epilepsy Foundation of Kentucky. Further, the club has been referred to as a model program in two research studies, a Kentucky State Legislative Research Commission and a University of Kentucky Doctoral Research study. This mentoring program whose motto is "Look With Your Heart" started with 12 children and has grown to have more than 100 members at this time.

**Kathy
Regan**

Kathy Regan has more than 30 years of experience as an educator. Kathy began her career as a parent volunteer in her children's Montessori classrooms. She went on to teach at the 3-6 year old level at Providence Montessori School for 20 years before serving as Director of School during her last 10 years of her career at Providence. During this time, she also established the school's toddler program, served as a teacher educator for the Oekos Foundation, and established a Godly Play program in her church community. Kathy is American Montessori Society credentialed at the 3-6 year old level and has a B.A. in Organizational Management from Midway College. Currently she teaches ESL and tutors math and language arts at the elementary level in Madison County.



A HUGE
THANK YOU
to Scott Mandl for
photographing all
of our beautiful kids
with Santa and their
families at the Holiday
Luncheon. You are
sooooo appreciated!

THANK YOU!!

VOLUNTEERS

"DSACK is fortunate to have wonderful volunteers like **Casey Greer** and **Erin Salmons**, who were both helping out at the Christmas Party. Casey is a regular volunteer sitter with the New Parent Group and Erin has volunteered with us in several capacities - the most recent as Volunteer Coordinator for the Buddy Walk! Thanks, ladies. We are so glad that you are part of our community!



SPECIAL THANKS TO YOU!! IN-KIND DONATIONS

Melissa Ball
Malkanthie McCormick
Sam Matthews
Tom and Mary Heilbron
Allison Kerschbaum
Rebecca Price

thank you!



CASEY



ERIN



MOVING FORWARD

A Conference About Down Syndrome For Parents And Professionals

Copy as needed for each attendee or print additional forms at www.dsack.org.

Name _____ Profession/Job Title _____

Organization/School _____ Email address _____ Phone _____

Address (street, city, state, zip) _____

Registration fee : \$35/person, \$50/couple, \$25/college student, with name of school and signature of advisor below.

Registration includes breakfast, lunch and handouts. *A limited number of registration scholarships available to DSACK families. If you require the registration fee be waived, please contact DSACK @ 859-494-7809 or info@dsack.org.*

Send payment and completed registration form to DSACK, PO Box 910516, Lexington, KY 40591-0516 no later than February 15th. **Early bird registration: deduct \$5 from your registration fee (\$10/couple) if received by February 8th. Mark your check "early bird" in memo section.**

We have reserved a block of rooms at Marriott's Griffin Gate Resort at a reduced rate of \$89 each. Please mention that you are attending this conference in order to receive this rate. A limited number of lodging scholarships are available to DSACK families. If you are a DSACK family living more than 75 miles from Lexington and require assistance paying for lodging the night before the conference, please contact DSACK @ 859-494-7809 or info@dsack.org and a scholarship form will be sent to you.

Cancellations: Due to the cost of providing breakfast and lunch for conference attendees, we are unable to refund registration fees after February 15th, but we will certainly accept your substitution in case you cannot attend.

C O N T I N U I N G E D U C A T I O N C R E D I T S

All attendees will receive Certificates of Completion that reflect actual number of contact hours. This conference qualifies for 6.5 hours continuing education/professional development hours as required by many licensing boards and professional organizations. If your discipline is not listed below, save your course outlines and certificate of completion and contact your own board or organization for specific filing requirements.

- General and Special Education teachers – Submit certificate to your school
- SLPs- Approved for 5.5 hours by KY Board of Speech Language Therapy (math was excluded)
- School Psychologists – Submit certificate to your school
- Early Care and Education - Approved for 6.5 hours by KY CHFS

BIRTHDAYS

Tara and Brandon Wagers welcomed their son **COOPER**, December 1st! "Thanks again for everything. Words cannot express how grateful we are for the warm welcome, the gift cards, and everything else from DSACK!" *Sincerely, Brandon and Tara Wagers*

Happy 14th Birthday, **EMILY FAITH!**
We love you and are so very proud of you! Shine on, beautiful girl!!!
Love, Mama and Daddy

"Amazing **AVA** will be 6 years old and we are so glad she's ours! Happy Birthday to our little girl."

Ava's family

Kent Wallace turned 11 yrs old on November 9th. He enjoyed watching the candles burn on his birthday cake. We had to sing the Happy Birthday song over and over again (about 5 times) as he just loved blowing out his candles. That's why they are almost melted right into the cake!
;o)



Jack will turn 3 on December 30th. Jack is walking and into everything!

HAPPY BIRTHDAY JACK!



celebrate!

NEWS TO USE

The word "self-determination" is heard more and more within conversations about preparing children

and youth well for adulthood. In fact, helping students with disabilities become more self-determining is an increasingly prominent theme of recent policy initiatives, practice recommendations, and conference gatherings. And there are some very good reasons for this heightened emphasis. Numerous research studies have shown a strong link between the development of self-determination and a host of positive outcomes while children are still in school and long after they graduate.

As a parent, you may be wondering what you can do to foster the skills, knowledge, and opportunities that can contribute to self-determination among children and youth with intellectual disabilities and autism. What steps might you take to encourage your child to begin to become more self-determining as they grow up? This guide provides a menu of ideas to draw upon as you consider how best to promote self-determination among your own children with disabilities.

But first, let us provide a little back-ground about how we developed this guide.

Up until now, most of the research on self-determination has focused on what teachers and service providers can do to teach the skills and knowledge that help children become self-determining. Far less attention has focused on the important roles parents can play in encouraging self-determination beyond the school day. We consider parents to be the first and best experts on their children. And so we launched a research project to find out just how parents are nurturing self-determination and to learn about their recommendations for doing this well.

In the spring of 2011, we completed a large-scale survey study involving more than 700 parents of school-age children (ages 5-21) with intellectual disabilities or autism from 34 randomly selected school districts in Wisconsin. As part of this survey, we asked parents to share their own ideas for how parents might help their own children with disabilities develop skills that can enhance self-determination, skills like choice making, goal setting, self-advocacy, and self-management. We received more than one

thousand recommendations! As a project team, we combined and collapsed these strategies into the categories included in this guide.

On the pages that follow, you will find a rich array of ideas generated by parents for parents. This guide is neither exhaustive nor prescriptive. Rather, it simply offers a menu of ideas that can spur and encourage your own efforts. Indeed, we encourage you to draw upon, adapt, and add to the strategies in this guide in ways that best meet the needs of your child and family. Becoming self-determined is an ongoing process for all children and youth, whether or not they have a disability. And so the approaches you take may look different across the age span or depending on the individual strengths and needs of your child. We hope you will find this collection of ideas to be both promising and practical. Enjoy!

Although many different definitions exist, "self-determination" generally refers to having the abilities and opportunities to steer your own life in ways that you choose for yourself and that bring you personal satisfaction. Helping children with intellectual disabilities and autism become more self-determining as they grow up and prepare for adult roles was the focus of this project.

"Fostering Self-Determination Among Children and Youth with Disabilities - Ideas for Parents"

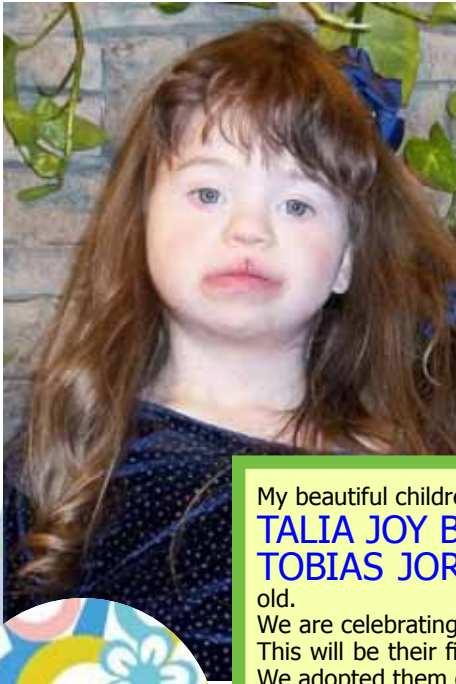
The following information is included in the document: Support decision-making, Encourage problem solving, Promote goal setting and planning, Reinforce self-directed behaviors, Foster responsibility, Promote independence, Support self-awareness and self-knowledge, Encourage self-advocacy and leadership, Support communication, Encourage participation, Foster relationships and social connections, Model important skills and behaviors, Provide reinforcement and feedback, Partner with schools, Hold high expectations and positive attitudes, Connect with others

To access the 44 page document, visit www.waisman.wisc.edu/naturalsupports/ and click on Resources then click Fostering Self Determination.

See reviews by: 1 Carter, Lane, Crnabori, Bruhn, and Oakes (2011); Cobb, Lehman, Newman-Gonchar, and Alwell (2009); Wood, Fowler, Uphold, and Test (2005)

2 Field, Martin, Miller, Ward, and Wehmeyer (1998); Wehmeyer and Field (2007)

CELEBRATIONS



Tarenne Maher
ran her first 5K! She participated in the "Girls on the Run" program at her school throughout the semester. Their race was at Coldstream Park in Lexington on November 19th. There were over 500 girls from the area who participated!



My beautiful children with ds.
TALIA JOY BAKER 9 and
TOBIAS JORDAN BAKER 8 years old.
We are celebrating LIFE with Talia and Tobias! This will be their first CHRISTMAS in a family. We adopted them officially in July and brought them home from Bulgaria in August. Tobias was about to be sent to an institution. Talia had already been in a very bad institution which thankfully was closed down due to journalist who did an undercover story called "The Abandoned Children of Bulgaria".

We are celebrating that for over a month now Talia has stopped rocking and moaning! We are celebrating that just recently (she is 9) she has started taking a sippy cup instead of the baby bottle they handed me the day I picked her up from the group home. We are celebrating that Tobias is in the first grade at school and that he is learning sign language and English words. We are celebrating that now these two kids have access to resources such as DSACK and school and good medical care from doctors who know about ds. We are celebrating Reece's Rainbow and all the help we received from them for the adoptions. I guess that is a little bit more than a quick blurb but we are so blessed to have these children! God is good!

Joyfully Serving Christ, Jamie (Baker) and the Baker Family

NEWS TO USE

Special Olympics Kentucky

For 40 years, Special Olympics Kentucky has been changing the lives of people with intellectual disabilities in the state through the simple tool of sports. Through its statewide, year-round program of sports training and competition, Special Olympics Kentucky provides people with intellectual disabilities of all skill levels the

opportunity to achieve their very best and to experience the joy of their accomplishments. Just having the opportunity to compete and demonstrate their talents is a victory in its own right. Athletes gain confidence and build a positive self-image, plus they learn the value of teamwork, working with a coach and trying to do their best. Special Olympics Kentucky offers 15 official sports and our Spring Season is just around the corner. The spring season offers a variety of sports, which includes Aquatics, Bocce, Gymnastics, Flag Football, and Track & Field. If you are interested in participating or have any questions please call Brittany Abell at 502-695-8222 or e-mail at babell@soky.org.

Down Syndrome Research

Bills have been introduced in both the Senate and the House that would provide an additional six million to the National Institutes of Health (NIH) for increased research into Down Syndrome. NIH would be required to create six centers of excellence for Down Syndrome research and maintain a research plan. The bipartisan Senate bills (S 1840 and S 1841) have been introduced by Senators Sherrod Brown (D-OH) and Susan Collins (R-ME). In the House, Representative Cathy McMorris Rodgers (R-WA) introduced similar bills (HR 2695 and HR 2696) last summer. Asset Development/ABLE Act (this is also very strongly supported by NDSS). It would enable individuals and families to have savings account on behalf of the individual without disqualifying the individual from government benefits (e.g., Medicaid)

The Achieving a Better Life Experience Act (ABLE Act) is expected to be reintroduced on November 15 by Rep. Ander Crenshaw (R-FL) in the House and Sen. Bob Casey (D-PA) in the Senate. The purpose of the legislation is to encourage and assist individuals with disabilities and families to be able to save their own money so that they can maintain health, independence, and quality of life. Opening an ABLE account will provide secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement benefits provided through private insurance, the Medicaid program, the supplemental security income program, the beneficiary's employment, and other sources. A similar bill was close to passage in the last Congress. AUCD strongly supports this legislation.

Congratulations to **Emily Brewer** for making the "A" honor roll. Emily has been on the honor roll every semester since 4th grade. Keep up the hard work, Emily!



Last year Sydney practiced cheerleading with her sisters Saige and Laynie but didn't compete. This year Sydney is hitting the stage with them. I don't know who is the most proud, my husband and I or herself.

GO SYD!



TROY LOVICH
and **BLAIR OSBORNE** all dressed up and ready to go to the Jesus Prom!



MAKING CONNECTIONS

DSACK BOARD SPOTLIGHTS

Regina

When I asked Regina if she wanted to write a farewell letter for the newsletter, she declined. So, I told her I'd be happy to write something in her honor, but, here I sit. The newsletter deadline is today and, because I want this to be perfect for her, I have procrastinated. Afraid I won't do her justice.



After three extremely productive years as an officer of the board and chair of the Buddy Walk, Regina is stepping down from both positions. Three years is a long time to serve in both of those capacities and she now has professional obligations to which she needs to attend. She will serve in an advisory role for BW 2012 and will be able to commit a very small amount of her time to that role.

Many of you know her and understand when I say that there is nobody like her and she can't be replaced. It would be impossible to replace Regina Schmutte. I have never met anyone so full of energy or love. She loves and is passionate about your children even if she has never met them and it doesn't matter if they are babies or adults. She is always quick to offer help in whatever way is needed. Have a waiver question? Need help setting up your personal Buddy Walk team? How about a presentation for your child's school or scout troop? Does the DSACK website or Facebook page need updating? Is there family who needs a visit in the hospital?

Soon after her son, Bobby, was born, Regina stated that she wanted to become a board member and be in charge of the Buddy Walk. *What? Are you crazy?* She was adamant and came up with a written plan for the Buddy Walk. She was certain that she could reduce costs and increase profit without compromising the fun part of the celebration. *Really? Are you for real?* Yes, Regina was for real. She took risks, made some big, big changes and brought us all along for the ride. It was fabulous. The Buddy Walk was more fun than ever. The profits soared as did the number of walkers and individual teams. Yes, there are many people to

credit for the great fun and the increase in numbers, but without Regina's vision, energy and work-ethic, I know it would not have happened so quickly.

Regina, there is nobody like you. You cannot be replaced. On behalf of everyone affiliated with The Down Syndrome Association of Central Kentucky, THANK YOU. WE APPRECIATE YOU. You are beautiful, extremely capable and loved more than you know.

Respectfully submitted by Michelle Gilliam



Tonya Hello, my name is Tonya McPhetridge. I am joining the board in the capacity of Vice Chair. I look forward to serving our community in every aspect that I can. I live in East Bernstadt, KY with my husband, Travis, and two daughters, Kylie, age 3, who has DS, and Jaden, age 2.

Harold

Harold Kleinert, executive director of the University of Kentucky's Human Development Institute (HDI), has been elected to serve as an at-large member on the national board of directors of the Association of University Centers on Disabilities (AUCD).



HDI is UK's Center for Excellence in Developmental Disabilities. Since its inception, the institute has worked to improve the lives of individuals with disabilities. Promoting independence, productivity, and inclusion throughout life for persons with disabilities and their families requires leadership and the courage to be creative innovators.

The AUCD is a membership organization that supports and promotes a national network of university-based interdisciplinary programs, including 67 centers for excellence.

"This is a great honor and will provide another venue for Dr. Kleinert's leadership, knowledge, and enthusiasm to positively impact the field of developmental disabilities at a national level," said Kathy Sheppard-Jones, HDI training director and adjunct assistant professor in the UK Rehabilitation Counseling program.

UKNOW, University of Kentucky News, November 22, 2011

2011 HOLIDAY LUNCHEON

WOW, WOW, WOW!!!

What an elegant luncheon. We all thoroughly enjoyed seeing friends, eating great food, relaxing in the beauty of the atmosphere and seeing Santa and Mrs. Claus! Thank you for a wonderful Christmas Luncheon!

Love, Sam, Karen, Maria and Anna Juett

P.S. DSACK is a gift to us!





Every human life is a *beautiful* gift. People with Down syndrome are *capable* of living full lives and dreaming big dreams. People with Down syndrome are *loved* beyond your wildest imaginings.

be inspired!

Ground Gained

I noticed him right away. He was sitting quietly in a big overstuffed chair, reading a book. I had wandered into the children's book section of a huge bookstore looking to pick up a 'young adult' book for a friend.

The image of a child curled up in a big chair reading a book is a cozy one to me and it always evokes a smile. This time it did more than that. I teared up. The little boy had Down syndrome and he was just quietly sitting reading, pages turning slowly, concentration on his face, words touching his lips with movement. It's been a long time waiting for this. Waiting to see a child, like him, reading in a place like this.

There really is little more to today's blog than this image. Nothing happened. No one said anything. I never saw his mom or his dad, though I glanced around at the other adults in the area and wondered. I saw several other children, some running and restless, others quiet and entranced. But

I couldn't detect who belonged to him. It was as if he was put there, by the store, as decoration, as a symbol of the power of words and the ability of all to enjoy.

But to me he was a symbol of so much more. He was a symbol of where we are now, a symbol of where we have come from, a symbol of ability, of independence, of ground gained. Rushes of emotion ran through me. I didn't know what to do with them. I was born into a time of hopelessness and rejection. A time where children with differences weren't expected to learn, didn't expect to be taught. A time where children with differences didn't have homes - they were placed in them. A time where children with differences didn't read in overstuffed chairs - they sat in bare walled wards.

I wondered what words touched his lips and made them move. What the story was that he was reading.

And I wondered if he realized that his story, the one that brought him here to the bookstore, to curl up and read, was more fantastic, more unexpected, more thrilling than any word on any page of any book that I've read thus far in my life.

I saw a child, sitting in a chair, in a bookstore ... reading.

Imagine that.

Posted by Dave Hingsburger, Monday, April 07, 2008

Down Syndrome Association Of Central Kentucky

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calendar

0-5 PARENT GROUP & PLAYGROUP

Tonya McPhetridge is now the leader of this group. She will be in charge of scheduling topics and speakers. If you have any questions or suggestions, please contact her @ fizzie190@windstream.net or 606-224-6776 or 606-843-0368.

January 14th, 2012 - "Parents Teaching Parents" 10:00a.m. - 12:00 noon at DSACK Office, 340 Legion Drive # 6, Lexington, 40504 - Come and share books, resources, ideas and toys that have helped your child OR come with questions and topics that you would like to discuss with others who are a little further along on the journey. Please submit topics for discussion to Tonya at least 1 week prior so each topic will be allotted enough time. (Submit topics you want to learn more about AND/OR those about which you have something to share!)

No February meeting! Please register for the DSACK Conference on February 25th, instead!

March 19th, 2012 - Gymboree Play & Music - 1:00p.m. - 2:30 p.m. Our group will have a private party at Gymboree, 4383 Old Harrodsburg Rd, Suite 145, Lexington, 40513. This will be great fun for infants, toddlers and preschoolers. You and your child must wear socks to the party. RSVP to Tonya at least 1 week prior.

In case of inclement weather, an email will be sent out the morning of the meeting to confirm or cancel the meeting. If you do not receive an email, contact Tonya@606-224-6776 that morning.

ELEMENTARY GROUP

January 21, 2012 - Join us at Joyland Bowling Lanes in Lexington on Paris Pike to enjoy an afternoon of fun! We will be reserving lanes with ball ramps & bumpers, and any open lanes will be available. DSACK will cover the cost of 2 games and shoe rentals for 1 child. Please encourage peers and siblings to attend this event! We will meet from 1p.m.-3p.m. **RSVP to Samantha.d.matthews@gmail.com**

February 11, 2012 - Join us from 11a.m.-1p.m. at the DSACK office for a Valentine's Party! Invitations, cake, punch, and crafts will be provided. Please bring a list of classmates, friends, and teachers that you would like to make Valentine's for. Volunteers will be assisting children, so parents are encouraged to enjoy snacks in the back of the office :) **RSVP to Samantha.d.matthews@gmail.com**

March 10, 2012 - Meet at Build-A-Bear in Fayette mall from 11a.m.-1p.m. to build a bear! (choose from a selection of 3) DSACK will cover the cost of 1 bear. Parents will have the option of purchasing accessories and a 10% discount card can be used. **RSVP to Samantha.d.matthews@gmail.com**.

submissions

Submission deadline is Monday, February 13th and can be sent to Allison Kerschbaum at dsack.org@gmail.com.

Send DSACK pictures of your family member to be included in the newsletter. Digital photos only.

Do you... Have an interest in placing an add in our newsletter? Know someone who might like to receive our newsletter? If so, please contact Allison Kerschbaum at (859) 494-7809 or dsack.org@gmail.com.

Let's get the word out about DSACK and our loved ones with Down syndrome who are beautiful, capable and loved!

TEEN & ADULT GROUP (Advocates In Motion), Ages 13 Years and Older

The contact person for this group is **Karen Osborne**, Blair's mom, kτοςborne@bellsouth.net or 859-707-1300 Families will now have the opportunity to lead a monthly event so to sign up for this, please contact Karen! All events will be funded by DSACK, but will need to stay within the budget. We will consider splitting AIM into 2 groups (one for teens and one for adults) as attendance and family participation increase.

January 15th, 2012 - Bowling from 2:00 p.m. - 4:00 p.m. @ Southland Bowling Lanes, 205 Southland Drive in Lexington. Cost of bowling and snacks for individuals with Down syndrome will be covered by DSACK. Hostess: Julia Steinman

February - Valentine Dinner is being planned! Watch your email or, if no email access, call Karen for details.

March 3rd, 2012 - Party at the McCormick's home, 4848 Pleasant Grove Rd. in Lexington, 2:00 p.m. Come for food and fun! Hostess: Megan McCormick
If you would like to host a monthly event, just call Karen or Allison (859-494-7809) with details and DSACK will take care of the communication and cost of the event.

In case of inclement weather, an email will be sent out the morning of the meeting to confirm or cancel the meeting. If you do not receive an email, contact Karen @859-707-1300 that morning.

SOMETHING FOR EVERYONE

Register for the DSACK Conference **February 25th, 2012**. Registration brochure included in this Newsletter, pages 3-6.

thank you to our sponsor!

