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**THE DSAGSL 2010 ANNUAL CONFERENCE  
For Families and Professionals**

**Keynote speaker** 9:00-10:30 a.m.

**Exploring the Neurobiology and Treatment of Down Syndrome**

Recent studies have shown the ability to define Down syndrome (DS) related brain phenotypes to similar changes in the brains of mice that genetically model this disorder. We will discuss ongoing studies that link cognitive phenotypes to an increased dose of specific genes and early insights into the mechanisms induced. Importantly, deciphering the pathogenesis of nervous system changes in mice that model DS is providing new approaches for suggesting and testing treatments for children and adults.

***William C. Mobley, MD, PhD** has received numerous honors and awards, among them both the Zenith and Temples Awards for Research in Alzheimer’s Disease from the Alzheimer’s Association, the Cotzias Award from the American Academy of Neurology and the Christian Pueschel Memorial Award for Research in Down Syndrome from the National Down Syndrome Congress.*

*He is a fellow of the Royal College of Physicians, the American College of Neuropsychopharmacology and the American Association for the Advancement of Science. In 2004, Mobley was named a member of the Institute of Medicine of the National Academy of Science.*

*He has published widely, has served on the editorial board of several major professional publications and was editor of the journal Neurobiology of Disease. In addition, he has served on the scientific advisory committees or boards of a long list of national organizations, ranging from the National Association for Autism Research to the Hillblom Foundation. He served on the National Institute of Neurological Disorders (NINDS) from 2003-2007 and was recently named a member of the Committee on Committees of the Society for Neuroscience.*

**CONFERENCE SCHEDULE AND PROGRAM**

# conference schedule

track	session one (10:45-12:00)	session two (1:15-2:30)	session three (2:45-4:00)
birth to three	<p><b>Getting the Most from First Steps</b> Kate Hannon, Program and Community Relations Director The Belle Center</p> <p>Howard Smith, Director Region 1 St. Louis First Steps</p>	<p><b>Your First IEP (Parent Panel)</b> Kim Elias, Facilitator Tanya Hayden Maggie Mackie Julie Missey Janelle Peterson Randa Kay Woods</p>	<p><b>Speech &amp; Language Development</b> Bridgette Barnhart Claudia Orf Melanie San Miguel Speech &amp; Language Pathologists The Belle Center</p>
school age (4-12)	<p><b>What You Didn't Know You Didn't Know... How to Survive Special Education in the Elementary Schools</b> Shelley Biere, Training Facilitator MPACT</p>	<p><b>Developing Literacy Skills- What Can a Parent Do? (3-7 year olds)</b> Mary Sinnett and Julie Williams Learning Program of St. Louis</p>	<p><b>Social Language Development</b> Colleen O'Leary Card, Effective Practice Specialist SSD of St. Louis County</p>
middle/high school	<p><b>Extending Social Opportunities Beyond the School Setting (Panel)</b> Pat Alster, Facilitator/Parent Sue Fleming, Recreation Council of Greater St. Louis Shari Brune, Parent</p>	<p><b>In the Driver's Seat: Middle and High School Opportunities (Panel)</b> Linda Cantrell, Facilitator Sue Fleming, Recreation Council of Greater St. Louis Rhonda Hembree, St. Louis Arc Frank Scarpino, JESS, Inc. Jane Skinner, Life Skills Marilyn Smith, SSD of St. Louis County</p>	<p><b>"Victim No More"- Keeping Our Loved Ones Safe</b> Ray Amanat, President and Founder Amanat's Heroes in Action®</p>
adulthood	<p><b>Roadmap to the Adult System (Panel)</b> Linda Cantrell, Facilitator Linda Baker, Governor's Council on Disabilities Nicole Hunt, Albert Pujols Wellness Center for Adults with Down Syndrome Megan Layton, Self Advocate, St. Louis Life Rob Libera, Lafayette Industries Dana Nichols, St. John's Mercy Medical Center Patrick Wheeler, Missouri Department of Vocational Rehabilitation Services</p>	<p><b>Funding: How to Get It</b> Kadesh Burnett, Educational Coordinator St. Louis Regional Center</p>	<p><b>Guardianship Decisions</b> Lisa Sutherland, Attorney Missouri Protection &amp; Advocacy Services</p>
general #1	<p><b>Dr. Mobley- Ask the Expert</b> William C. Mobley, MD, PhD Keynote Speaker</p>	<p><b>Estate Planning for a Family Member with Special Needs</b> Gerald Zafft, Counsel Stinson Morrison Hecker, LLP</p>	<p><b>Body &amp; Soul: Sharing Life</b> Diana Braun, Self Advocate Welcome Change Productions</p>
general #2	<p><b>Raising the Bar: Improve Cognition and Academic Skills</b> Ellen Doman, Director of Education National Association for Child Development (NACD)</p>	<p><b>Using Visual Supports/Social Stories to Shape Behavior</b> Adrienne Bievenue, Parent Linda Kronmiller, Parent</p>	<p><b>Healthcare Across the Continuum for Children with Down Syndrome</b> Mary Lucido, Social Worker Melissa Sicard, Nurse Practitioner Down Syndrome Center, St. Louis Children's Hospital</p>

# teen/adult conference schedule

track	teens	adults
<b>Session one</b> (9:00-10:30)	<b>“Victim No More” - Safety Tips &amp; Tools</b> Ray Amanat, President & Founder Amanat’s Heroes in Action®	<b>Cake Decorating Demonstration</b> Sue Thrasher, Head Decorator Celebrating Life Cake Boutique
<b>Session two</b> (10:30-12:00)	<b>Cake Decorating Demonstration</b> Sue Thrasher, Head Decorator Celebrating Life Cake Boutique	<b>“Victim No More” - Safety Tips &amp; Tools</b> Ray Amanat, President & Founder Amanat’s Heroes in Action®
<b>lunch hour (12:00-1:00)</b>		
<b>Session three</b> (1:00-2:30)	<b>Dancing Through Life</b> Christine DeHart	<b>Creative Self-Expression Art!</b> Nathan Larson, Director Turner Center for the Arts
<b>Session 4</b> (2:30-4:00)	<b>Creative Self-Expression Art!</b> Nathan Larson, Director Turner Center for the Arts	<b>Dancing Through Life</b> Christine DeHart

## families and professionals

8:30-9:00 a.m.	<b>Registration</b> (No breakfast provided)
9:00-10:30 a.m.	<b>Keynote Speaker</b>
10:30-10:45 a.m.	Break
10:45 a.m.-12:00 p.m.	<b>Session One</b>
12:00-1:15 p.m.	Lunch
1:15-2:30 p.m.	<b>Session Two</b>
2:30-2:45 p.m.	Break
2:45-4:00 p.m.	<b>Session Three</b>

t/a

teens &amp; adults

all day


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**“Victim No More”- Safety Tips & Tools****Ray Amanat**

Ray’s mission for this workshop is to train everyone on safety, awareness, fitness and to have the will to never give up for a healthier lifestyle! Job safety, safety when living out on your own (for the adults), walking home, taking the bus, mall safety, school safety will be discussed.

**Ray Amanat** is the President/Founder of Amanat’s Heroes in Action® and has been very involved in personal safety awareness and assault prevention for over 25 years. Mr. Amanat is on staff with Florissant Valley Community College in St. Louis and instructs women and children in both courses through the continuing education program. The response to his courses is an indication of how much people are starting to take seriously their personal safety and the safety of their family members. Several major news stations in the St. Louis area have interviewed Ray because of his practical approach to self-defense. Ray has worked with children with special needs in the St. Louis area through the Special School District to help them become more aware. He has worked with the hearing impaired community, and has also instructed students who are visionally impaired. He lectures students in area schools in conjunction with the widely acclaimed D.A.R.E. Program on a regular basis. Ray has dedicated his life to helping men, women, and children increase awareness and develop practical plans for personal safety.

**Cake Decorating Demonstration****Sue Thrasher**

Sue will be demonstrating cake decorating techniques such as making sugar flowers, stacking and filling cake layers, and covering a cake with fondant icing. She will then give the students the opportunity to ice and decorate their individual mini cakes (and of course – eat them!).

**Sue Thrasher** was an art major at UMC and is now a Head Decorator at Celebrating Life Cake Boutique where they do custom-designed occasion cakes and wedding cakes. She is currently building her own cake-decorating business.

**Dancing Thru Life****Christine LaBlaine DeHart**

Christine will be teaching dance/movement to music. This will be a complete dance number to perform that day. She will teach and lead the group. This workshop will show that if you want to dance you can, it comes from inside, and every style is different. The teen group will be doing a country western number using cowboy hats (provided by Christine, and theirs to keep). The adult group will be doing a “Broadway” number to “All that Jazz” and will use canes (provided and theirs to keep).

**Christine DeHart** is the owner of Dancing Thru Life (opened in 2007), a dance studio for adults, teaching tap, ballet, and jazz. Christine trained in St. Louis and at University of Wisconsin in Stevens Point. She owned a children’s dance studio in Wisconsin for 15 years. Christine also was part owner of a Wisconsin theatre production company for 10 years. She has been teaching in area studios since 1992.

Recently Christine won the title of “Ms. Missouri Senior America 2008”, and placed as 3rd runner up in the National “Ms. Senior Pageant, October 2008 in Atlantic City. She continues to perform with the Missouri Cameo Club 20-30 times a year.

t/a

teens &amp; adults

all day

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**HOPE****Creative Self-Expression Art!****Nathan Larson**

Participants will create cool lo-fi prints using a variety of materials. Using ink, pencil, Styrofoam, paper, colored pencils and pens, we'll create personalized and unique prints. This project is for everyone! It is an easy and fun way to create visually dynamic and legitimate art pieces. Just bring your hands and brain!

**Nathan Larson** is the director for the Turner Center for the Arts. The Turner Center for the Arts is an art studio for people with disabilities located in Maplewood's arts district. It is our belief that every person has the right to, and need for, creative expression. With this in mind, we strive to create a warm, safe, open and freeing environment where creativity can thrive. Instead of focusing on technical prowess, Turner Center encourages artists to be true to their unique vision and realize the full potential of their ideas.

## Getting the Most from First Steps

**Howard Smith & Kate Hannon**

Join Howard Smith, Director of Region 1 of St. Louis Area First Steps, and Kate Hannon, Community Relations Director of The Belle Center, for a discussion of the First Steps Program and resources for meeting the needs of your family. Up to date information will be shared with opportunities to think together about advocating for your child and family with a team of positive attitudes.

**Howard Smith** began working with people with developmental disabilities in 1996 as a case manager for the St. Louis Regional Center. Howard immediately began working with families in First Steps and was the team representative on the Early Childhood Committee. He worked with St. Louis Regional Center until 2004 when he left to work for Special School District as the Lead Family Service Coordinator for the St. Louis County SPOE. Howard held that position for five years until recently being hired by AWS as the Director for First Steps in Region 1.

**Kate Hannon** joined The Belle Center in 1990, and has served in a variety of capacities, including Classroom Teacher, Developmental Therapist, and Executive Director. As Program Director, Kate manages the daily operations and oversees the classroom and therapy supports of children from infancy through kindergarten at The Belle Center preschool program in University City and provides advocacy support to families throughout the St. Louis area.

Before joining Belle, Kate taught emotionally disturbed children through the state of Missouri. She also worked for the Special School District of St. Louis County and the St. Louis Archdiocese. She earned her bachelor's degree in Special Education and Regular Education, K-12 grades, from Fontbonne University. Kate is certified in Early Childhood Special Education and Learning Disabilities.

## What You Didn't Know You Didn't Know... How to Survive Special Education in the Elementary Schools

**Shelley Biere**

Learn tips and strategies for making the elementary years more successful.

**Shelley Biere** is the mother of three children, two of which are on the autism spectrum. Shelley is the training facilitator for MPACT and trains in thirty counties across the north eastern state of Missouri. She provides training to parents of children with disabilities on the special education process. Shelley is also a graduate of Partners in Policymaking. She has her Associates degree in Psychology and is working toward her Bachelors.

### Extending Social Opportunities Beyond the School Setting (Panel)

**Pat Alster**, Parent (Facilitator)

**Shari Brune**, Parent

**Sue Fleming**, Recreation Council of Greater St. Louis

This workshop will be an open discussion with audience participation on what works and what sometimes doesn't work when parents try to organize friendship groups. Come to share your ideas with other parents. Information will also be available on other recreational programs.

The panel will consist of a parent with a teenage daughter and a parent with a teenage son. Sue Fleming, Executive Director from the Recreation Council of Greater St. Louis, will also talk about leisure activities available in the St. Louis area.

### adulthood track

### Roadmap to the Adult System (Panel)

**Linda Cantrell** (facilitator)

**Linda Baker**

**Nicole Hunt**

**Megan Layton**

**Rob Libera**

**Dana Nichols**

**Patrick Wheeler**

Planning to exit the school system is a scary and challenging time when transitioning from an entitlement system into an eligibility adult system. Adults with Down syndrome and their families can become empowered in planning their path and entering the Adult System as informed decision makers accessing adult service providers.

**Linda Cantrell**, M.A.T., is a retired special education teacher from the Special School District of St. Louis County, MO. She has 31 years of experience and focused her career on teaching students with disabilities in community based vocational setting. The last seven years of her career she has served in the capacity of a Transition Facilitator addressing professional activities for secondary staff. In addition, she is the past president of the professional organization Missouri Division on Career Development and Transition. Presently, she is working part time with the University of Kansas, Transition Coalition supporting community transition teams. Linda is a board member of the Down Syndrome Association of Greater St. Louis.

**Linda Baker** obtained her MSW degree from St. Louis University and has been an accredited Social Worker since 1980. Her professional social work experiences have been in the area of mental health, home health and the disability/ independent living movement. She received American with Disabilities Act (ADA) training from Disability Rights Education Defense Fund in 1990. It was the only one approved by U.S. Dept. of Justice. She has conducted numerous ADA Title I, Windmills and disability market trainings for major corporations and governmental entities in Missouri and nationally.

As the Missouri Governor's Council's Executive Director she is responsible for managing the various programs and accruing funds for the Missouri Youth Leadership Forum. She sits on various disabilities policy, business advisory committees & boards. Linda promotes the Business Leadership Network development in the state; a business led initiative promoting best employment practices that are inclusive of talented workers with disabilities.

**Nicole Hunt** received her Bachelors degree in Social Work from the University of Mississippi and Master degree in Social Work from St. Louis University. Nicole has been developing her expertise in clinical social work in the hospital-setting at St. Luke's Hospital and Barnes Jewish Hospital since 2005. Originally from Little Rock, Arkansas, Nicole is proud to have made St. Louis her home and to be the Social Worker of the Albert Pujols Wellness Center for Adults with Down Syndrome.

As a social worker at the Center, Nicole meets with clients and family members to complete a psychosocial assessment used to identify individual wellness, social, educational and planning needs. Consultation, supportive counseling, advocacy, information sharing and referrals to community resources will be provided to promote ongoing wellness, socialization and education.

**Megan Layton** My name is Megan Layton and I am 28 years old. I work at the library as a page which is mainly putting the books back on the shelves and putting them in the correct spot. Creative, outgoing, smart, caring and being myself are my strengths. With that I also have weaknesses as well.

I am the daughter of Maureen and Harold Layton. I am not the only one because I have two sisters Ellen and Karen. They have a son as well, and his name is Patrick.

Something to remember, I'm not afraid of saying that I have a disability called Down syndrome. You cannot tell I have it, I am not sick, but it is an extra chromosome that I have in my body, that's it.

One more thing, we are different but we are all the same and that makes us beautiful!

**Rob Libera** has 30 years of domestic and international management experience and was appointed Executive Director of Lafayette Industries in 2004. Rob was educated at Indiana University and St. Louis University, is an alumnus of the Wharton School, University of Pennsylvania, and holds a mini-MBA in non-profit Management from the University of St. Thomas.

As Executive Director, Rob has overseen the growth in employment from 185 employees to over 400 including 363 adults with developmental disabilities at Lafayette's two suburban locations in Manchester and Berkeley. Lafayette Industries is the largest direct employer of adults with developmental disabilities in the State of Missouri. Rob is a Regional Director of the Missouri Association of Sheltered Workshop Managers and is currently President of the St. Louis Coalition of Service Providers.

**Dana Nichols** has a Bachelor of Science degree in Education from the University of Mo-in St. Louis. She has utilized her skills and talents serving individuals with disabilities in the area of employment since 1993 when she first worked with Life Skills Foundation in all capacities of supported employment; assessment, job development, job coaching, and retention services. She also worked as Coordinator of Supported Employment at MERS (Metropolitan Employment & Rehabilitation Services).

The Office of Productive Living Services initiated a partnership with St. John's Mercy Medical Center in 1999 to increase competitive employment opportunities in inclusive setting for consumers living in St. Louis County that are served by Regional Office. Dana was selected to be the coordinator of the grant sponsored project and continues in that role today. She demonstrates her leadership skills by coordinating job matches for 50 + coworkers with developmental disabilities within a variety of departments while working as a liaison between the hospital and eight supported employment agencies in the community. She has presented at Missouri Business Leadership Network events and Supported Employment conferences, participates in the annual Disability Awareness Month at the hospital, serves on business advisory and Special School District committees, and organizes a variety of projects designed to advance the cause of including people with developmental disabilities in the community.

**Patrick A. Wheeler** has always called St. Louis home. He received a Bachelor of Science degree in Psychology and Biology from Xavier University of Louisiana. Subsequent to this he earned a Master's degree in Rehabilitation Counseling Psychology from the University Of Missouri-Columbia. Over the past (17) years he has worked in some capacity with youth that experience a myriad of impeding challenges/conditions to improve their quality of life. For the past eight (8) years he has worked for the Division of Vocational Rehabilitation as a "transition counselor" for St. Louis city and county high schools.

**Dr. Mobley- Ask the Expert**

**William C. Mobley, MD, PhD**

Please see page 1 of this program for information about Dr. Mobley, our keynote speaker.

**Raising the Bar: Improve Cognition and Academic Skills**

**Ellen Doman**

This workshop will help define and describe the components of cognitive and learning skills and explain how to have a positive and real impact on changing and improving those skills. This workshop will be helpful to parents, educators, therapists, and other professionals working with individuals with Down syndrome.

**Ellen R. Doman** is currently the Director of Education for the National Association for Child Development. She holds a Masters Degree in Education with a specialty in curriculum and development. She is a trained Behavior Specialist and Neurodevelopmentalist. She has worked as a Behavioral Specialist for the Department of Mental Health. She has directed three different schools for students with a variety of disabilities. She has directed community living arrangements for disabled adults. She is the former director of United Cerebral Palsy of Philadelphia's suburban children's programs. She was the director of Children's Treatment Centers in North Carolina which provided intensive treatment for children with severe behavioral, attention, and emotional problems. She has worked with children and adults with neurological, behavioral and emotional problems for over forty years.

**Your First IEP (Parent Panel)***Kim Elias (facilitator)**Tanya Hayden**Maggie Mackie**Julie Missey**Janelle Peterson**Randa Kay Woods*

Your child's first IEP (Individualized Education Program) is an important milestone for both parent and child. This workshop is a panel of parents who have been through the IEP process in the last six months. They will share how to prepare, what resources are available, and what to expect.

## school age (4-12) track

**Developing Literacy Skills- What Can a Parent Do? (3-7 year olds)***Mary Sinnett & Julie Williams*

Focusing on ages 3-7 years, this workshop will teach parents a "basic approach" to use with their child to develop literacy skills, based on The Learning Program of Orange County. The presenters will share tips and tools for pre-literacy and early literacy skill development, focusing on empowering parents to use everyday opportunities to help their child learn. This is an evidence-based program, so the presenters will also provide supporting background and information based on 30 years of research conducted by Downsed International located in England.

*Mary Sinnett has her MAT in Special Education from Webster University. She has been in the field of Early Childhood Special Education for the past 9 years as an inclusive classroom teacher and an itinerant teacher supporting children with disabilities in a general education environment. Mary has worked for a non profit agency, the Belle Center, and for Kirkwood School District in St. Louis County. Mary is the lead children's teacher for the Learning Program of St Louis.*

*Julie Williams has a Masters in Healthcare Administration and works as an independent strategy planning consultant for hospitals and healthcare systems across the country. However, she is also a parent of a 7 year old child with Down syndrome. As parents, both she and her husband have been concerned about the academic development of their daughter. So, in conjunction with the Down Syndrome Association of Greater St Louis, she (and others) are working with The Learning Program of Orange County to learn their evidence-based approach and implement it through a pilot project in the St Louis area.*

### In the Driver's Seat: Middle and High School Opportunities (Panel)

**Linda Cantrell** (facilitator)

**Sue Fleming**

**Rhonda Hembree**

**Frank Scarpino**

**Jane Skinner**

**Marilyn Smith**

Middle and High School settings provide opportunities for our youth to become engaged learners. The panel presenters will provide a forum for participants to gain insight into opportunities available in the Greater St. Louis area to develop effective transition plans in the area of employment, education or training and recreational activities.

**Linda Cantrell, M.A.T.**, is a retired special education teacher from the Special School District of St. Louis County, MO. She has 31 years of experience and focused her career on teaching students with disabilities in community based vocational setting. The last seven years of her career she has served in the capacity of a Transition Facilitator addressing professional activities for secondary staff. In addition, she is the past president of the professional organization Missouri Division on Career Development and Transition. Presently, she is working part time with the University of Kansas, Transition Coalition supporting community transition teams. Linda is a board member of the Down Syndrome Association of Greater St. Louis.

**Sue Fleming** is the Executive Director of the Recreation Council of Greater St. Louis, a not-for-profit organization dedicated to promoting and supporting quality leisure opportunities for both children and adults with disabilities. Susan has been with the Recreation Council for over eighteen years and with other organizations serving individuals with developmental disabilities for a total of twenty-nine years. She believes that recreation is for everyone! Susan has developed a number of programs that fully include individuals in their communities and a means of funding, through recreation voucher programs, which allow individuals with developmental disabilities, and their families, to choose recreation opportunities that best meet their interests and support needs.

**Rhonda Hembree, M.S., CTRS**, is the Assistant Director of Leisure Services at St. Louis Arc. She has 18 years in the field of recreation and leisure for people with development disabilities. Since 1950 the St. Louis Arc has reached into the community to help people live their lives to the fullest. Those they support live with their families, in residential homes, even independently. They take part in sports, book clubs, art classes, summer programs, employment, community integration and more. The St. Louis Arc is here to help people and their families achieve and exceed their goals.

**Frank Scarpino** performed as a Moolah Shrine clown for fifteen years enjoying his role as a clown with numerous engagements for children with Down syndrome. When Frank retired in 2001 from SBC (Southwestern Bell Company with thirty two years) he pursued his love for interacting with children and worked two years at Adult Vocational Services.(Service Provider for people with disabilities). His job duties included job coaching, work site supervisor, and work experience supervisor at Fox High School. He was offered a position at JESS in 2007 and presently supervises the SWEP (Summer Work Experience Program) for St. Louis County. Frank interviews Special School District High School students and matches their abilities and talents in summer employment in the business community.

## 2

session two

1:15-2:30


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**Jane Skinner** is a Corporate Job Marketer in the Employment Services Department at Life Skills. Life Skills is an organization that provides services for teens and adults with developmental disabilities. Her primary role at Life Skills is to develop partnerships with corporations and businesses that lead to employment opportunities for people with developmental disabilities. In addition to working in the area of social service employment, her background includes retail management, apparel buying and marketing. She came to Life Skills from Corporate Express Promotional Marketing where she was a Senior Marketing Account Manager for over seven years. She has a Bachelor of Science degree from Southeast Missouri State University. She and her husband Mike are the parents of two young children, their son Evan, 7 and daughter Rylie, 5. Rylie has Down syndrome.

**Marilyn Smith** has been an administrator and teacher for Special School District of St. Louis County, Missouri for twenty three years. She is currently the Effective Practice Specialist for Transition and a Transition Liaison for the state of Missouri. Marilyn has presented at conferences on a wide range of transition topics, locally, state, and nationally. She has co-authored a self determination training manual for professionals.

## adulthood #1 track

**Funding: How to Get It****Kadesh Burnett**

The focus of this presentation will be to offer insight related to

- a. Funding options (Community Support Waiver, Comprehensive Waiver, Autism Waiver, and Sara Lopez waiver
- b. Medicaid Eligibility
- c. Service coordinator/ consumer/family communication through Person Centered Planning process.

**Kadesh Barnea Burnett** is currently employed at the St Louis Regional Office as the Eastern District Education Coordinator. In her role as the Education Coordinator she has the awesome responsibility of training staff, service providers and community members on guided divisional principles, philosophies and values related to meeting the needs of Missourians that have varying physical and cognitive abilities. She completed her undergraduate studies at Missouri Western State University, where she earned a BS in Health and Exercise Science and is currently pursuing her Masters of Arts in Nonprofit Administration from Lindenwood University.

## Estate Planning for a Family Member with Special Needs

**Gerald Zafft**

This workshop will cover various types of estate planning issues confronting families with a special needs child and the the options available to them. There will be a considerable amount of time devoted to special needs trusts, including the Midwest Special Needs Trust, and other options. There will also be time left open for questions and discussion.

**Gerald J. Zafft** is of counsel to Stinson Morrison Hecker LLP, one of the country's largest law firms with offices throughout the Midwest as well as Phoenix and Washington, D.C. Mr. Zafft, who is with the St. Louis office, concentrates his practice in Estate Planning, Corporations, Tax and Mergers and Acquisitions. In his practice, Mr. Zafft works mostly with closely held businesses and the entrepreneur owners. He advises them on all aspects of legal matters which confront businesses today, from administrative law to zoning.

Mr. Zafft has had considerable experience in estate planning for families with a member with a disability. This experience has led to the creation of the Midwest Special Needs Trust (previously known as the Missouri Family Trust), of which Mr. Zafft is the prime author. The Midwest Special Needs Trust is a nationally recognized innovative approach which permits a family to provide for their loved one's benefit, without jeopardizing his or her eligibility for government entitlement funding. He has been a member of the Board of Trustees of the Midwest Special Needs Trust since its inception in 1989, and served three terms as President.

Mr. Zafft received his Bachelor of Arts and Juris Doctor degrees from Washington University in St. Louis in 1957 and 1959, respectively, and his Masters of Law (in Taxation) degree from New York University in 1967.

## Using Visual Supports/Social Stories to Shape Behavior

**Adrienne Bievenue & Linda Kronmiller**

This workshop will discuss the behaviors commonly associated with students with Down syndrome, their possible causes and offer suggestions, tools and resources for parents and educators to use in and out of the classroom. Time will be given for discussion of specific behaviors that have challenged parents and educators.

**Adrienne Bievenue** has been involved in advocating and supporting families whose children have Down syndrome since her son, Russell, was born 11 years ago. She has played an active role in the DSAGSL's Education Committee, is currently the leader of the St. Charles Community Group and is an MPACT Parent Mentor.

**Linda Kronmiller** is a graduate of the Parents As Partners program and has been actively involved with issues relating to Down syndrome both educationally as well as legislatively. Her son, Eric, has been the main character of many "social stories" that Linda has created. She is currently a representative of the DSAGSL on the newly formed Governmental Affairs Committee of Missouri.

**Speech & Language Development**

**Bridgette Barnhart**

**Claudia Orf**

**Melanie San Miguel**

This workshop will focus on providing ideas for helping the young child with Down syndrome realize his/her full potential in Speech and Language Development. The workshop will include tips and strategies for families and educators on how to incorporate skill building activities into daily routines at home and school.

**Bridgette Barnhart** is a Speech/Language Pathologist with the Belle Center in St. Louis. Bridgette has extensive experience working with many persons with Down Syndrome in homes, schools, and clinics, while also growing up with her youngest brother who has Down syndrome.

**Claudia Orf** has been a practicing speech-language pathologist for 19 years. She graduated from St. Louis University with her Masters in Communication Disorders, Speech Language Pathology. Claudia is a full time provider and is currently working with children who have Down syndrome across all ages and in a variety of settings including home, childcare centers and schools.

**Melanie San Miguel** graduated from the University of Missouri-Columbia with a degree in speech pathology in May 2008. She has worked as a speech-pathologist with The Belle Center for a year and a half. During her time with Belle, she has worked with children of various ages (18 months to 16 years old) and with various diagnoses including: Autism, Down syndrome, language delay, Apraxia of Speech, cerebral palsy, speech delay, Velo-Cardio-Facial Syndrome, Rubinstein-Taybi Syndrome.

**Social Language Development**

**Colleen O'Leary Card**

Children with Down syndrome have both strengths and challenges in the development of communication skills. While they generally have the desire to communicate and interact with others, young children with Down syndrome often demonstrate ineffective communication skills, due to unintelligible speech, a gap between their receptive and expressive language skills, and social-communication deficits. Behavior problems are sometimes related to frustration in not being understood. This conference session will provide parents and educators with practical tools to promote the social communication development of school-aged children with Down syndrome which can be applied in the home and in school settings. The relationship between communication and behavior, and practical solutions to challenging behavior, will also be discussed.

**Colleen O'Leary Card** is an Effective Practice Specialist (EPS) in the area of autism for Special School District of St. Louis County. Colleen is a licensed speech-language pathologist with more than 20 years experience working with children and adults with severe communication disorders in a variety of settings (home-based therapy, clinical, private sector, and public schools). Colleen has spent the majority of her career specializing in the area of autism spectrum disorders (ASD), providing person-centered intervention to both children and adults with ASD and their families. Colleen has extensive experience working with a wide-range of individuals with ASD, ranging from students with limited speech- using signed speech and augmentative communication and visual supports to facilitate verbal language- to supporting individuals with socio-communication challenges including high functioning autism/Asperger's. Throughout her career, Colleen has provided training and consultation locally and nationally to parents and professionals on effective supports for individuals with ASD and related disorders. In 1998, she was an invited presenter at an international conference on Asperger's Syndrome in Dublin, Ireland.

## **“Victim No More”- Keeping Our Loved Ones Safe**

**Ray Amanat**

**Mission Statement:** *To enable everyone to be safe physically, mentally, and emotionally so that we can empower them to grow and become successful in life.*

Come and join Ray Amanat (The Servant of Safety) and founder of Heroes in Action® and learn how to work with your kids on specific life skills in regards to their personal safety. This program demonstrates how to teach assertive social skills through role play to aid in character development. Ray’s curriculum is designed to encourage kids from all learning levels to make healthy choices as they grow to become successful adults. You, as parents, are your child’s first “Heroes in Action”, so don’t miss this opportunity to work with Ray in helping your child grow to be a Hero in Action as well.

**Ray Amanat** is the President/Founder of Amanat’s Heroes in Action® and has been very involved in personal safety awareness and assault prevention for over 25 years. Mr. Amanat is on staff with Florissant Valley Community College in St. Louis and instructs women and children in both courses through the continuing education program. The response to his courses is an indication of how much people are starting to take seriously their personal safety and the safety of their family members. Several major news stations in the St. Louis area have interviewed Ray because of his practical approach to self-defense. Ray has worked with children with special needs in the St. Louis area through the Special School District to help them become more aware. He has worked with the hearing impaired community, and has also instructed students who are visionally impaired. He lectures students in area schools in conjunction with the widely acclaimed D.A.R.E. Program on a regular basis. Ray has dedicated his life to helping men, women, and children increase awareness and develop practical plans for personal safety.

## **Guardianship Decisions**

**Lisa Sutherland**

The purpose of this presentation is to provide individuals with information to make informed decisions regarding guardianship. What are the guardianship options? What alternatives to guardianship are available? How does one access the alternatives?

The presentation will also describe the legal process for obtaining guardianship and restoration.

**Lisa Sutherland** attended the University of Missouri-Kansas City School of Law. Ms. Sutherland obtained her J.D. in May 2000. She began her law career at the Office of the Attorney General as an Assistant Attorney General. In 2003, Ms. Sutherland took a position with Missouri Protection and Advocacy Services (MO P&A). MO P&A is a non-profit legal office. Ms. Sutherland provides free legal and advocacy services for individuals with disabilities.

## 3

session three

2:45-4:00


 moving forward  
with  
**HOPE**
**Body & Soul: Sharing Life****Diana Braun**

Diana Braun and Kathy Conour bucked the system and lived interdependently for 39 years. Their film – Body & Soul: Diana & Kathy – provides visual representation of not only how they do it, but also how they have continued to lobby for the rights of others with disabilities. Body & Soul received the AAIDD annual media award, was the co-recipient of the TASH Award and was the Best of the Fest at Superfest. Diana and Kathy also received the John Deere Distinguished Citizens of the Year Award. Diana's discussion revolves around how they do what they do, and inspires and provides information for others on how to seek a similar independent path. Specific topics covered will include lobbying for rights and why having "money follow the person" is so crucial, self-advocacy and empowerment, and how to work and include people with disabilities in the community.

**Diana Braun** As an 8 year old child, Diana Braun found herself living in a state run nursing home in Freeport, Illinois. Taken away from an abusive family, Diana and her brothers and sisters were scattered. At 12 she was sent to the Dixon Developmental Center. At 19 Diana left Dixon, a state run institution. She vowed to one day close those institutions and has devoted her life to doing just that. Diagnosed with Down syndrome, Diana drives, cooks, maintains her home and attends the Blessed Sacrament Church and attends an annual retreat for people with disabilities.

Diana's activist commitments have led her to be president of People First, a self-advocates group and a member of the Illinois Council on Developmental Disabilities. Currently she serves on the board of the Illinois Arc, an organization involved in advocacy for people with intellectual disabilities. Illinois is one of the states that still has a large number of people living in institutions, so Diana has her hands full with her advocacy work. Diana and her housemate and activist friend of 43 years, Kathy Conour traveled to present at conferences and visit elected representatives. In February of 2005 they went to Washington and met with the offices of Senators Obama and Dirksen. Their particular focus is reform of Medicare, trying to make money follow the person instead of institutions. Kathy passed away in September 2009 and Diana continues to speak about obtaining and maintaining independence.

## Healthcare Across the Continuum for Children with Down Syndrome

**Mary Lucido & Melissa Sicard**

At this workshop we will be discussing various health topics that are associated with children that have Down syndrome. We will leave time at the end for a question and answer session.

**Mary Lucido, LCSW** received her Masters in Social Work and is a Licensed Clinical Social Worker at the Down Syndrome Center, St. Louis Children's Hospital. Mary has been involved in hospital social work since 1981. She has been at Children's Hospital since 2003, and has been with the Down Syndrome Center since 2005.

Mary is part of the center's team that meets to provide your child and family with comprehensive services and coordination of medical services. She links families to quality information and support opportunities. She advocates for the children and family's needs within various agencies in the community. She has been fortunate to meet and see the good work that is done by the Down Syndrome Association volunteers that attend the clinic and meet with the families. Mary has spoken and provided written information as part of the training process for New Parent Volunteers at the Down Syndrome Association of Greater St. Louis.

**Melissa Anne Sicard, CPNP** is a Pediatric Nurse Practitioner employed at Washington University School of Medicine –Genetics Division. She, along with her collaborative physician, Dr. Dorothy Grange, coordinate and manage the care for children with Down syndrome at the Down Syndrome Center located at St. Louis Children's Hospital. Prior to her current position, she was a Registered Nurse in the Pediatric Emergency Department at St. John's Mercy Medical Center.

Melissa received both her Bachelors and Masters in Nursing at University of Missouri-St. Louis. She graduated Magna Cum-Laude and is a member of the Golden Key Honor Society. Born and raised in St. Louis, Missouri, Melissa now lives in Chesterfield with her twelve year old daughter, Gabriela Elizabeth and two dogs Lola and Jimmy.