



# B.U.D.S.

Bringing Up Down Syndrome

## Quarterly Newsletter

Volume 11, Issue 1

Fall Issue — September 2005

### From Your Secretary - Jane Conolly



Hi, my name is Jane Conolly and I have been the Secretary for BUDS for 6 years. My husband and I live in Marlton and have two children. Samantha is 12 years old and has Down syndrome. Timothy is 9 years old. My duties as Secretary include attending the organizational meetings and recording the minutes. I maintain the Post office box and the phone mail system. I am also the coordinator for gift baskets. When a child is hospitalized, I am contacted and I send a get well basket filled with goodies from BUDS.

I would like to tell you about Samantha's trips to Lourdes, France, with the American Special Children's Pilgrimage Group. ASCPG is a non-profit organization that sponsors a trip to Lourdes, France, each Easter for special needs children (ages 9-18) and volunteer adult care givers. The group is based in North Jersey.



They just formed groups in South Jersey and the Philadelphia areas. They raise money all year long to take kids to Lourdes. Each child has two caregivers and there is also a doctor and two nurses in the group. My daughter, Samantha, has gone three times in the last four years. She had a wonderful time. Although Samantha's



grandmother is one of the nurses, I would still send her again if my mother decided not to go. The people involved in the group are all volunteers and must pay their own way. They are a wonderful and caring group of people. If you would like more information about Samantha's trips to Lourdes, please call me at 856-985-4756.



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## BUDS Tenth Anniversary Buddy Walk!! Sunday, October 2nd



Well if you didn't know that our annual Buddy Walk is coming, you haven't checked your mailbox lately! BUDS Buddy Walk Committee members have been hard at work planning and creating another fun-filled day for BUDS members, family, friends, professionals, and all other walkers. Our annual Buddy Walk will be held in Washington Lake Park on Sunday, October 2nd, 2005. This year is the tenth year we have held the Buddy Walk and we are expecting this to be the best walk ever! The committee members are bringing back your favorite activities, after all, so many of us enjoy winning those goodies at the chance auction and it wouldn't be a Buddy Walk without hot dogs from Murphy's Market Place and WaWa hoagies! There are also some new ideas being added based on the feedback from walkers. This year, there will be teams at the walk. The committee wants teams to have fun and encourages teams to do things to make themselves stand out at the walk. There will be special recognition of the teams this year based on different categories, so start planning your themes! The committee has also booked some fun and different entertainment this year. Rocket Productions is coming in and taking over the entertainment to keep our party going and make sure that everyone is rockin' the day away.

### Other area Buddy Walks

21 Down—OC  
Boardwalk 9/17

Trisomy 21  
Center at CHOP  
Villanova in PA  
on 10/2

So please be sure and join us on Sunday, October 2nd, at Washington Lake Park. You can download a brochure at our website [www.budssj.org](http://www.budssj.org). Don't forget to lace up those sneakers, grab some chairs, blankets and frisbees (chairs and towels with Buddy Walk logos will be available for sale if you forget them), and come on down to the park to walk for someone you know and/or love that has Down syndrome! ANYONE can be a BUDDY!!!

(We would like to thank all of our committee members and BUDS families for all their help in making this walk a success. We couldn't make it all happen without the help of so many!)



We would like to thank Wal\*Mart and Sam's Clubs for providing sponsorship for our competitive employment instruction. We would also like to thank Maria, Rachel and Laura Williams and Jenn and Joanne McKeown for picking up the checks for BUDS! This was an initiative that was sought out through our Buddy Walk funding.



## Here's What's Happening.....

**Hayride** — Annual Springdale Farms Hayride and Bon Fire Friendraiser, Sunday, October 16th. Please arrive by 4pm, ride starts at 4:30pm promptly! Hotdogs, drinks and dessert provided for all partici-

pants! RSVP by October 12th by calling 856-985-5885 or email Jconolly62@comcast.net.

### General Meeting -

The next general meeting, is scheduled for September 30th from 6:30pm to 8pm at the Little Gym on Route 42

in Turnersville. Adults and older children can socialize while younger kids are in the gym (only children under 12 are permitted in the gym, kids under 3 must have an adult with them). Please call Joanne McKeown at 856-582-8300 to register.

*If you know of a member with Down syndrome that has been hospitalized or is going to the hospital, please contact us at 856-985-5885.*

### With Gratitude

to the

Township of Washington

For Supporting Efforts to Promote Acceptance of Individuals with Down Syndrome

On the Occasion of the

Tenth Annual Southern Jersey "Buddy Walk"

Washington Lake Park

October 2, 2005

Presented by the Members of

"BUDS" Bringing Up Down Syndrome

An affiliate of the National Down Syndrome Society

## Invitation to All BUDS Families

*Jennifer McKeown has been invited to be the keynote speaker at the annual disabilities forum sponsored by the West Deptford Committee for the*

*Disabled held at the Riverwinds Community Center in West Deptford on October 18, 2005, from 7 to 9 pm. Her presentation will be titled "A Walk*

*in My Shoes". Come out and show your support to Jennifer!*



## Basic Rights Workshop For Your Child's IEP

Saturday, November 5th- Basic Rights Workshop to be presented by Joanne McKeown at 127 Haddon Ave, West Berlin, NJ. The time will be from 9:30 AM to 12:00 PM. There is a ten person minimum and the reservations to attend must be made by October 28, 2005.

Knowledge of Basic Rights will allow parents to attain their child's educational goals through a well planned IEP. Please RSVP to 856-582-8300.



## 2005 National Caregivers Conference – Take Comfort in Knowledge

Presented by The Family Support Center of NJ

Join 1,000 professionals, parents and individuals to learn and discuss new approaches to caregiving issues

### Conference Topics

This annual event will focus on respite, education, family supports and much more. We will host over 30 workshops, informational exhibits and inspirational speakers.

November 3<sup>rd</sup> & 4<sup>th</sup> 2005

Trump Taj Mahal, Atlantic City, NJ

For more information, contact Jaqueline Moskowitz

(800) 372-6510 or (732) 528-8080

Visit [www.fscnj.org](http://www.fscnj.org)

Check out  
[www.cafepress.com/t21club/](http://www.cafepress.com/t21club/)  
for cool clothing  
with Down syndrome related  
expressions!

### Attending a conference regarding your family member with Down syndrome?

Please remember that conference fees and transportation costs to the conference can be paid by BUDS. You must submit an application prior to the conference and be approved. The conference does not have to be advertised through BUDS. If you find a conference that deals with disability issues, you may submit the application to us. Call the BUDS phone number if you need the application form (856-985-5885).

## Here's What's Going On In Other Groups.....

21 Down is a Down syndrome group that services Cape May, Atlantic and Southern Ocean Counties. For more information you can also check out this group at [www.21down.org](http://www.21down.org).



Saturday, October 15th —

Halloween party at the Fishburn's house at 1pm.

Friday, October 21st—Dad's Poker Night at the Fishburn's at 7pm.

Wednesday, November 2nd—General Business Meeting/Financial Planning Seminar with Herb Hinkle & Jack Plunkett at Gloucester County Education Office on Tanyard Road at 7pm.

For more info check out [www.kiids.info](http://www.kiids.info).

## Save the Date....CHOP Trisomy 21 Symposium

Children's Hospital of Philadelphia is holding a Trisomy 21 Workshop on Saturday, March 11th at the hospital. This one day

symposium will provide both the parent and health-care provider with up to date clinical information and therapeutic approaches on select topics applicable to individuals with Trisomy 21. Some of the sessions

include

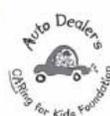
- Adolescent Issues
- Speech Apraxia
- Physical Therapy
- Care Notebook
- Education
- Down Syndrome/ Alzheimer Connection

You can register for the workshop online at [www.cme.chop.edu](http://www.cme.chop.edu)

Sponsored by  
The Trisomy 21 Program at

 The Children's Hospital of Philadelphia®

Hope lives here.



## “What Can I Do to Ensure a Good Transition Plan For My Child?”

The following excerpts are reprinted from the October 2004 issue of The Education Advocate newsletter, a quarterly newsletter of the Department of Education Advocacy of The Arc of New Jersey. The Education Advocate newsletter is only available in electronic format. For more information about The Education Advocate newsletter, or for a free subscription, call or email Joyce Walker with your email contact information. She can be reached at (732) 246-252 ext. 25 or [jwalker@arcnj.org](mailto:jwalker@arcnj.org). Entitle the e-mail “special ed mailing list”.

Please keep in mind that between the ages of 3 and 21, a student with a disability receives all (or most) of their services from the school as an *entitlement*. The adult disability system, on the other hand, is a system based on *eligibility*. Remember: transition planning can never begin too early!! This timeline of activities can assist you in preparing for your child’s future.

If your child is between the age 0-5

*Nothing required by law*

*What parents can do:*

- Understand your child’s disability
- Understand your rights in the special education system
- Involve your child in social and community activities
- Register with the Division of Developmental Disabilities
- Encourage language and communication
- Emphasize daily living skills

If your child is between the age 11-13

*Nothing required by law*

*What parents and schools can do:*

- Focus on functional skills
- Field trips/job touring/job shadowing
- Begin research on supported employment, independent living programs, SSI and guardianship issues

If your child is 15 years old

*The Law requires:*

- A statement that both the student and parents have been informed that all rights will transfer to the student once the student reaches age 18

If your child is between the age 17-21

*Nothing required by law*

*What parents, students and schools can do:*

- Continue all activities listed above
- Get a part-time job during the school day
- Re-evaluate curriculum
- Explore post-secondary schooling and apply
- Register for DVRS 2 years prior to graduation

If your child is between the age 6-10

*Nothing required by law*

*What parents can do:*

- Teach your child about their disability
- Help your child identify interests
- Encourage after-school activities
- Assign household chores
- Address social skills & behavioral issues as they arise

If your child is 14 years old

*The Law requires:*

A “statement of transition service needs”

*What parents and schools can do:*

- Conduct assessments (functional, vocational and academic)
- Encourage child to job experience at school
- Contact DVR for technical consultation

If your child is 16 years old

*The Law requires:*

A “statement of needed transition services”

*What parents and schools can do:*

- Job sampling, part-time work
- Interviewing skills, filling out job applications
- Focus on linkages to adult services during IEP meeting
- Get on the list for DDD services



## 2005 NDSS Conference ~ by Mia Bachman

After another incredibly inspirational and valuable learning experience, I return from the National Down Syndrome Society's *Imagine* conference with renewed strength, ideas and passion. I was fortunate to learn from various professionals in areas ranging from recent advances in brain, behavior and genetics to sensory integration and speech intelligibility.

While in Chicago, I had the pleasure of hearing Bridget Brown discuss her feelings about growing up with Down syndrome, her personal challenges and her incredible triumphs. She was the first person in her school district to be included. She and her parents were forced, literally, to bang on doors and demand to "be let in". Bridget stated, "It was those who opened their hearts, minds and doors, which made me a success." She spoke of self-determination and the importance of looking towards the future. She encouraged everyone "to dwell in the possibilities" not the limitations. Bridget believes that self-determination and person centered planning are two tools that helped her realize her dream. She currently advocates on state and federal levels for building caring communities for people with disabilities. After Bridget received her standing ovation, there were few with dry eyes.

Jennifer Rosinia, PhD presented a talk on Sensory Integration and Processing. She pointed out the obvious: All behavior has meaning!!! After Jennifer told us to gather, settle and prepare to learn. She asked us to recognize the various things we do on a daily basis and how much we take for granted. Many of our children have difficulty filtering out the various "noise" in the environment because of their neurological make up. The ability to use this filtering system is an important component of sensory integration.

The definition of **sensory integration is the neurological process that organizes sensation from one's own body and from the environment and makes it possible to use the body effectively within the environment.** The five senses, as well as the vestibular (unconscious movement system within the middle ear) and proprioception (within the muscles and joints) all work together in an elaborate fashion. Initially, there is awareness, then selective attention to that input, followed by giving it a meaning. Organization and execution of a response are the final steps in the process. "Imagine you see a ball coming and you are suppose to kick it. You organize the response: "I know how to do that. I've kicked a ball before." Lastly, the ball is kicked. The inter-related components of this process are complex. For a child who has difficulty with muscle tone, attention, and perceptual problems this process can be very difficult. Jennifer added "The child has a temper tantrum because they are having difficulty with a task, not because they want to be difficult or a pain in the butt." Again, all behavior has meaning.

What can be done to help the child? Jennifer recommends, "Don't just do something, **STAND THERE!** The first step is to observe the child, identify and recognize the child's cues. Monitor the arousal and attention levels and use sensory strategies to help calm or arouse." In addition, the child has a sensory threshold (how all of the stimuli activates the central nervous system) and sensory modulation (how they deal with a trying situation.) My child for instance, does not like messy food. She use to have a fit when warm toast would melt peanut butter and the two pieces of the bread slid apart. To ease this problem, I would make sure the sandwich cools prior to presenting it to her. We also work on deep breathing when upset. My daughter has difficulty in regulating and modulating the sensory piece during mealtime.

According to Jennifer, the best thing I can do is to modify the relationship between Ava, the sandwich and "other." We regularly work on self-calming, and eye-hand coordination. (IE: readjusting the sandwich to her preference) "Provide the right challenges and look for adaptive responses to indicate you're on the right track. Lastly, gradually increase complexity." Ava is doing much better with her peanut butter and jelly sandwiches, but she is not ready for a turkey club.

Jennifer concluded her talk with the statement "A consistent, predictable, and nurturing environment will provide the best input to the brain."

## 2005 NDSS Conference (Continued)~ by Mia Bachman

I went to a talk presented by Jo Ann Simons, MSW who spoke of Creating a Letter of Intent, or a life-planning document. This twenty-nine-page document is to assist your child or adult with needs in the event of change in care givers. It is a massive, comprehensive packet with very little left out. Jo Ann helped co-author this text, which includes information regarding family, medical, advisors, legal documents, personality traits, preferences, personal care, routines, and a general statement of desires.

In an effort to clarify the importance of the situation, I was asked, "When are you going to die?" The importance of a life-planning document is tremendous and who else knows how your four year old likes her sandwich? Who knows about the vitamin regimen or medical history?

If you are interested in obtaining this document, log on to the Florida Developmental Disabilities Council website. Click on "catalog" under resources and scroll down to "Planning Ahead" You can download this for free. The document is in the middle of the site. Go to <http://fddc.org>

A discussion entitled Positive Behavior Supports. Implications and Uses for Families and Schools presented by Hank Bohanon-Edmonson PhD was interesting. The main point he highlighted was the value of teaching children in a positive, healthy fashion. He discussed a single parent family, with little resources or income who was abusive to the child. For a teacher to "get through" to that child, he would have to scream louder, speak harsher and hit harder. Obviously, those things are not options for educators, so who thinks a trip to the principal's office will affect him? It's ineffective and it inadvertently creates more abuse for the child when he returns home. Hank spoke of reaching out to each child and accentuating the positive. Drawing him in with kindness, support and expressing confidence in the ability to achieve. Everyone wants to feel successful and happy and if an educator is persistent, he may be able to break through to one child and alter his life significantly.

Regarding home life, Hank presented examples of dealing with various situations other than yelling. "Yelling and screaming may be temporarily effective tools, but next time, you have to scream louder." In order to create change, empower the child and cultivate an environment of trust and respect. Ask "WH" questions. Utilize kindness and in many cases, psychological tricks, like reverse psychology. It is unrealistic to tell a child to "do this" and expect it to be done one hundred percent of the time. Kids are not robots, nor should we expect them to follow commands as if they were. The goal is to raise independent thinkers who are positive, empathetic and healthy.

Libby Kumin, PhD, CCC-SLP presented a talk The Goal is Understandable Speech. How Do We Get There? Dr. Kumin spoke of speech intelligibility; how easy or difficult it is for the listener to understand what is being communicated. "Evaluation of speech intelligibility is subjective. Familiar and unfamiliar listeners will have different ratings of intelligibilities."

"There are many factors which effect intelligibility; Things such as muscle tone, the size of the face and jaw, the presence of childhood verbal apraxia, perceptual/speech problems, nonverbal language, message length and content, and environmental stimuli." Dr. Kumin stated that muscle tone in the face improves over time. Some dentists make palate expanders to make the smaller mouth fit the typically sized tongue. Apraxic children can be taught individual sounds and sequencing in order to produce expressive language. Breath support, rate and rhythm of airflow are also apart of intelligibility. There are many exercises to improve feeding difficulties, coordination, expressive language and intelligibility. Dr. Kumin showed a video of five young women with Down syndrome who had severe medical conditions and verbal apraxia as children. These five women sat around a table discussing plans for a party they were going to throw for a friend. These young women were fantastic! I was amazed at their intelligibility, wit and cleverness. It took time, therapy and hard work, but these women had a lot to say and it was music to the ears.

The national conferences are tremendously valuable to me. I always learn so much, meet the most incredible people and as a bonus, I enjoy a bit of a different city. I would like to thank BUDS for awarding me the grant to attend the conference. It was truly a life changing, wonderful experience. I look forward to many years as being a "student" and a "teacher." Thank you.

Mia Bachman ([miabachman@comcast.net](mailto:miabachman@comcast.net) or 856-795-3526)

## Woodbine House ~ [www.woodbinehouse.com](http://www.woodbinehouse.com)

Visit [www.specialneedslegalplanning.com/](http://www.specialneedslegalplanning.com/) For information regarding a book dealing with Special Needs Planning.

Woodbine House is offering 20% off books dealing with Down syndrome for the months of September and October in honor of Down Syndrome Awareness Month!

Woodbine House is exploring the idea of publishing books FOR teens and adults with Down syndrome. We

are interested in finding out what types of books would be most enjoyed by and useful to teens and adults with Down syndrome, and welcome the input of anyone who lives or works with an individual with Down syndrome aged 12 or older.

As an incentive, we're offering a free Wood-

bine House book for taking this survey. Please choose from the list of books provided at the end of the survey and give us your contact information so we can ship your book to you right away.

[www.woodbinehouse.com/dssurvey/](http://www.woodbinehouse.com/dssurvey/)



# SPAN

Statewide Parent Advocacy Network, Inc.  
35 Halsey Street - 9th Floor, Newark, NJ 07102  
Phone: 973-642-8100 Fax: 973-642-8088  
Toll Free in New Jersey: 1-800-654-SPAN  
E-Mail: [span@spannj.org](mailto:span@spannj.org)

## Train the Trainer ~ SPAN Workshop in October

SAVE THE DATE!

SPAN staff, SPAN Resource Parents, P2P Support Parents, Peer Consultants, and parent leaders are invited to a train the trainer on Wednesday, October 26, from 10-3 at the Ramada Inn in East Windsor, on changes to the Individuals with Disabilities Act and how they impact on monitoring and state accountability, including the development of the State Performance Plan, containing "rigorous and measurable targets" developed by a broad group of stake-

holders. This workshop is sponsored by the NJ Council on Developmental Disabilities Education Task Force, and will be conducted by Diana Autin, Executive Co-Director of the Statewide Parent Advocacy Network and the Region I Parent TA Center, and a member of the NJ DDC Education Task Force.

This workshop is RESTRICTED to people who will agree to conduct at least one workshop for other parents. The expectation for ALL participants is that they

will be part of the effort to spread the word to other parents throughout the state.

Reimbursement for conducting trainings will be provided by the NJ Council on Developmental Disabilities.

More information will follow!

Diana MTK Autin  
Executive Co-Director  
Statewide Parent Advocacy Network  
35 Halsey Street  
Newark, NJ 07102  
973-642-8100 x 105  
[diana.autin@spannj.org](mailto:diana.autin@spannj.org)  
[www.spannj.org/](http://www.spannj.org/)

### Teen and Young Adult Group

If you haven't attended an event or sent in your registration form to be included on the Teen & Young Adult mailing list, you can still do so by emailing [threehens@aol.com](mailto:threehens@aol.com) or calling Nancy Hennefer at (856) 354-0584.

## 29<sup>th</sup> Annual ASAH Conference

*There's More to Me Than What You See"*

Friday, November 4, 2005

Atlantic City Convention Center

Keynote Speaker: Michael Fowlin

ASAH

2125 Route 33

Hamilton Square, NJ 08690

Phone (609) 890-1400

Fax (609) 890-8860

Email: [asahinc@aol.com](mailto:asahinc@aol.com)

ASAH...serving the private special education community since 1974 is a nonprofit, professional organization of over 130 private schools and agencies throughout New Jersey which serve more than 10,000 individuals with special needs. Over 1500 persons including teachers, administrators, directors, parents and those who work with individuals with special needs are expected to attend this year's conference. Online registration available by visiting [www.asah.org](http://www.asah.org). If you have questions, please contact Susan Recce at the ASAH office @ (609) 890-1400 ext. 11.

## New - The Sensory Playhouse, LLC

Because play is the most important part of a child's development - Bridget Cella and Stacey Bittmann have developed a one of a kind facility that will enable all children to explore and learn in a safe and appropriate environment.

Bridget and Stacey

have lots of experience with sensory needs and have selected equipment and activities that will stimulate all of the five senses. You and your child will be able to explore by touching, tasting, smelling, seeing and hearing an ever-changing variety of different types of

manipulative devices and toys.

It is their hope to create a stimulating and comforting environment for parents, care-givers and their children to come to reconnect and enjoy each other while learning and playing. [www.thesensoryplayhouse.com](http://www.thesensoryplayhouse.com)

To have future BUDS Newsletters emailed to you in PDF format instead of traditional hard-copy mailing, please email Lin Rubright at [buds.newsletter@comcast.net](mailto:buds.newsletter@comcast.net) with the email address to which you wish your future Newsletters sent. Thank you.

## New Directions

New Directions is a free publication "offering information and inspiration to individuals with disabilities and their families as they direct their own supports and services. For a free subscription to New Directions, a publication produced under contract from the New Jersey Developmental Disabilities Council (DDC), send your name and address to:

Editor: Brenda Considine

CCS Communications

PO Bow 384

Hopewell, NJ 08525

Phone/fax: (609) 466-0694

Or email your request to: [consid@comcast.net](mailto:consid@comcast.net)

## IDEA and What It NOW Means to Your Child's IEP

The following excerpts are reprinted from the January 2005 issue of IDEA NOW, a publication produced under contract from the New Jersey Developmental Disabilities Council (DDC). We have selected excerpts pertaining to changes in IEP's for inclusion in this issue of our newsletter. For the complete article and/or more information about the IDEA NOW publication, or for a free subscription, send your name and address to:

IDEA NOW c/o  
NJ Council on Developmental Disabilities  
PO Box 700  
Trenton, NJ 08625  
Or email your request to: [susan.richmond@njddc.org](mailto:susan.richmond@njddc.org)

### **“A New IDEA Congress, President OK Major Changes to IDEA**

On December 3, 2004, President Bush signed the Individuals with Disabilities Education Improvement Act of 2004. The nation's new special education law has changes that will affect how services are delivered to students with disabilities.

Some of the most critical changes affecting children with disabilities and their families center on the IEP process, due process and the discipline provisions. How these changes affect children and their families will depend, in part, on how the U.S. Department of Education interprets them through policies and regulations and how they are implemented at the state, district and school level.....

### **IEP's**

Consistent with No Child Left Behind, **special education and related services** must be based on peer-reviewed research to the extent possible. *Advocacy Tip: Parents can question the IEP members about the research-basis of each aspect of the specific program of instruction proposed for a student.*

**Short-term objectives** are no longer required, except for the very small percentage of children with significant cognitive disabilities who are taking alternate assessments aligned with alternate achievement standards (less than 1%). *Advocacy Tip: Parents can still request that the IEP specify short-term objectives. Short-term objectives help parents and teachers measure student's progress in achieving annual goals and provide a guide to the intervening steps that should be taken toward achieving those goals.*

**IEP progress reports** must still describe the progress a child is making toward meeting the annual goals, but there is no longer the requirement that the report reference “the extent to which the progress is sufficient to attain the goal by the end of the year.”

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**Transition.** IDEA 2004 eliminates the requirements that an IEP tie a student's course of study to a statement of the student's transition service needs beginning at age 14 and identify the interagency responsibilities or linkages needed to provide transition services. The new law focuses instead on establishing specific, appropriate, measurable post-secondary goals when the student turns 16 and identifying the services the student will need to achieve those goals. *Advocacy Tip: Parents can request transition planning at age 14 in terms of course selection and interest identification to ensure that there is a basis for goal-setting and service selection prior to age 16. They can also request that a statement of interagency responsibilities and any needed linkages be included.*

**IEP attendance and participation.** IDEA 2004 expressly permits IEP team members to be excused from attendance if their area is not being discussed (if the parent and the school district agree); expressly allows alternate means of meeting participation (e.g. conference calls); and allows consolidation of reevaluation meetings and other IEP meetings. *Advocacy Tip: Parents who want to preserve the cross-fertilization of ideas and the interdisciplinary nature of IEP meetings can request that all team members be present throughout the meeting. Parents can also take advantage of the opportunity to meet by telephone on the event they are unable to attend in person.*

**Pilot program for multi-year IEPs.** Up to 15 states will be allowed to let local school districts offer, with parental consent, a multi-year IEP, not to exceed 3 years. The new IEPs will contain multi-year goals. The federally required elements of the multi-year IEPs are not as inclusive as for annual IEPs, however, state may include these as required elements in the multi-year IEPs. *Advocacy Tip: Parents in states with a multi-year IEP option who want a traditional annual IEP should not feel pressured to agree to a multi-year IEP.*

**Pilot program for paperwork reduction.** Waivers of statutory and regulatory requirements, for a period not to exceed 4 years, may be granted to 15 states proposing to reduce excessive paperwork and non-instructional time burdens.

**IEP team transition.** Parents of a child transitioning from Part C services (early childhood) to Part B services (school-age) can request that an invitation to the initial IEP meeting be sent to representatives of the Part C system to assist with a smooth transition of services.

**Transition between school districts.** A new provision will help parents of transferring students know what they can expect from their new schools. Services comparable to those described in the IEP in effect before a child's transfer must be provided by the new school district until the previous IEP is adopted, or a new IEP is developed, adopted and implemented.

To have future BUDS Newsletters emailed to you in PDF format instead of traditional hard-copy mailing, please email Lin Rubright at [buds.newsletter@comcast.net](mailto:buds.newsletter@comcast.net) with the email address to which you wish your future Newsletters sent.  
Thank you.

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## Upcoming Events

Bereavement support group for families who have experienced the loss of a baby or a young child; Third Wednesday of every month, 10-12, at NJ Dental School, 110 Bergen Street, Room B 839, Newark. Contact Jan Hader, LSW, 800-545-7437, or Gladys Martinez, LSW, 973-972-5458.

### SEPTEMBER, 2005

September 27, 2-3:30 p.m., Supporting one another in the behavior change process. Featuring Sharon Lohrmann & Linda Barbara. Register online at <http://www.tash.org.teleconferences/pbs/index.htm>. \$25.

September 27, 6:30-8:30 p.m., LRC South, Sewell. Creating a Make Sense IEP featuring Bonni Rubin-Sugarman, Director of Special Services in Haddonfield. Sponsored by NJ Coalition for Inclusive Education. Contact 732-613-0400 for more information. \$15 fee includes materials & refreshments.

September 27, 6:30-8:30 p.m., Cape May Court House. Atlantic County Family Support Organization Family Support Group Meeting on Legal Services featuring Liz Cunningham, Esq. Contact Andrea Burleigh, 609-485-0575 x 105. Refreshments, babysitting, transportation available.

September 28, 6 p.m., 315 North 6<sup>th</sup> Street, Newark. Essex County Child Welfare Planning Council meeting re: child welfare reform. Refreshments provided. Contact Kevin Waters, 609-947-8924.

September 28, 7 p.m., RWJ Hamilton Center for Health & Wellness. The Journey of Parenting a Child with Autism, featuring Christina Adams, author of A Real Boy. \$15. Call 800-483-7436. Sponsored by Friends' Health Connection. On-line at [infor@friendshealthconnection.org](mailto:infor@friendshealthconnection.org).

September 28, 7-8:30 p.m. How to Prepare for an IEP, Gloucester Township Branch Library, Blackwood. Hosted by Family Support Organization. Call Sue Doherty-Funke at 856-662-2600.

September 29 & 30. Essential Lifestyle Planning: Foundational Person Centered Thinking Skills. Boggs Center, New Brunswick. Free. Register at 732-235-9325 or <http://rwjms.umdj.edu/boggscenter>.

September 28, JFK Johnson Rehab Center for Head Injury, Hartwyck at Oak Tree, Great Room, 2048 Oak Tree Road, Edison. Navigating the School System Following a Brain Injury. RSVP Rene Carfi, Staff liaison to Children & Adolescents Committee of the Brain Injury Association of NJ, at 732-738-1002 or [rcarfi@bianj.org](mailto:rcarfi@bianj.org). Free.

September 29 and every Thursday through December 1 (except no workshop on 10/13 or 11/24), 8-9 p.m., Choosing a College Workshop for HS Students, presented by W. Bergen Center for Children and Youth. \$275 for the series. Register by 9/16. Contact Dorianne Brown at 201-934-1160 x 7314 for more information.

September 29, American Academy of Pediatrics-NJ Chapter School Health Conference.

September 30, 8:30-4:15, Brookdale Community College, 765 Newman Springs Road, Student Life Center, Lincroft. Alliance of Information & Referral Services of NJ Annual Statewide Conference. \$50 as a SPAN staff person (SPAN is a member organization). Contact 908-454-7000 x 131 Deborah Meade or Steve Nagel, 888-908-4636 x 200 for more information.

**OCTOBER, 2005**

October 1 and for seven consecutive Saturdays, 10 am – 12:30 p.m., Lawrenceville. Free Family education course, Visions for Tomorrow, for caregivers and family members of children and adolescents with emotional, behavioral, and/or brain disorders. FREE. Call 609-799-8994.

October 6, 8-4:30, Valley Regency in Clifton. Youth Consultation Service Institute for Infant & Preschool Mental Health presents its 3<sup>rd</sup> Annual Conference, What Infants, Children & Families Need to Thrive: Lessons from Children in Birth and Foster Families. \$75. Call 973-395-5500 or go to [www.ycs.org](http://www.ycs.org) for more information. SPAN will pay for at least one staff member to attend.

October 8, Rider University, 2083 Lawrenceville Road, Lawrenceville, Science & Technology Center. Loving your Kids: Can It Keep Them Safe? Workshops on bullying, getting along, the internet, gangs, and social skills for kids with special needs. \$15. Checks to PEI Kids. Register by September 30. Contact 609-695-3739 for more information or to register.

October 11, 2-3:30 p.m. What Families need to know about behavior problems and positive behavior support: Demanding quality supports for our sons & daughters. Featuring Sue Swenson of National ARC & Nancy Weiss of TASH. Register online at <http://www.tash.org/teleconferences/pbs/index.htm>. \$25.

October 11, 7:30 p.m., Coleman Elementary School Library, 100 Pinelynn Road, Glen Rock. Math Disabilities & Coping Strategies for Elementary School Students, presented by the Special Services Advisory Council of Glen Rock. Featuring Dr. Teresa Montai, Associate Program of Learning Disabilities at FDU. Free.

October 14, 2-3:30 pm. Advocating to eliminate the use of aversives, seclusion, and the inappropriate use of restraint. Featuring Pat Amos of the Family Alliance of NJ, Jane Hudson, Pat Hunt, and Jamie Ruppman of TASH. Register online at <http://www.tash.org/teleconferences/pbs/index.htm>. \$25.

October 15, 9 am to 2 pm, Collingswood Community Center. Public Policy Advocacy training and the New IDEA. Featuring Peg Kinsell. \$15. Register by October 7. Call Dianne Malley at 856-858-5675 or email at [dis-licpa@aol.com](mailto:dis-licpa@aol.com).

October 18, 19 & November 29: Essential Lifestyle Planning II: Process Facilitation and Plan Writing. 9:30 am – 3:30 p.m. each day. Boggs Center, New Brunswick. Free. Register at 732-235-9325 or <http://rwjms.umdj.edu/boggscenter>.

October 19, Transition from School to Adult Life, 7-8:30 p.m. Merchantsville, NJ Sponsored by Family Support Organization. Contact Sue Doherty-Funke, 856-662-2600.

October 20. Expanding Partnerships in Systems of Care: Substance Abuse and Mental Health Working Together. Register at [http://gucchd.georgetown.edu/programs/ta\\_center/tacalls.html](http://gucchd.georgetown.edu/programs/ta_center/tacalls.html).

October 24, 7:30 p.m. Education Funding. Hosted by Cando Parents, Harrison School Building, Gray Road, Caldwell. Contact Pam Donovan at 908-403-5789.

October 26, 9:30-3 p.m. Ramada in E. Windsor. Train the trainer on the changes to federal and state accountability and monitoring under IDEA 2005 for parent leaders, advocates, and SPAN staff and volunteers ONLY. Lunch will be provided.

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# **B.U.D.S**

**Bringing Up Down Syndrome**

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***The information contained in this newsletter is provided as  
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of the editor, or endorsed by the support group.***

## **BUDS UPCOMING EVENTS**

Friday, September 30th—Little Gym in Turnersville

Sunday, October 2- Buddy Walk

Sunday, October 16- Hayride at Springdale Farms— 4 PM

Saturday, December 10- Santa breakfast at St Rose of Lima

January- Family swim party-details to follow

February- Adult Potluck-details to follow

March- Family bowling-details to follow

May- Family miniature golf-details to follow