On April 28, 2006, over 300 guests—families, friends, supporters and staff—gathered at the Seaport Hotel in Boston to celebrate the Federation for Children with Special Needs 32 years as a Massachusetts parent center and as a national leader in parent information, resource and training services. In addition to celebrating our mission, this annual Gala Event is also a time for the Federation to acknowledge the contributions of everyone who makes our work possible and to raise additional funds to support that work.

The evening began with a reception in the Plaza Lobby and a silent auction that drew an enthusiastic crowd of interested bidders. A vast array of over 135 unique gifts included autographed sports and collector’s items, concert and theater tickets, as well as gift certificates to the finest area restaurants, hotels, and museums. These items brought in a record high.

In contrast to last year’s various forms of precipitation, the only thing that rained on this year’s Federation conference, held on March 4 at the World Trade Center in Boston, were compliments: “I loved it!”, “Nice Job!”, “Sue Senator [the keynote speaker] was tearful, joyful, [with a] great sense of humor.”

Unusually good weather and Richard Robison, the Executive Director of the Federation, greeted the more than 700 attendees, 37 presenters, and 46 exhibitors. Rich wished everyone a great day, reminded participants to avail themselves of the many free resources and encouraged them to meet the Federation staff and learn about the many Federation projects.

Realizing, “It takes the whole state to do what we need to do [for our children],” Dr. Robison began the day by introducing the many state agency representatives who work in partnership with the Federation, other organizations and parents to provide services for children with special needs. These special guests included Marion

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Visions of Community: The Annual Federation Conference

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Gala 2006

by Jackie McKeon and Brooke Heraty

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Whom Do I Call?

The Federation for Children with Special Needs is home to many parent-run projects that provide information, support and assistance to parents of children with disabilities and their professional partners. Several of the Federation's projects are highlighted below. The sample questions will help callers determine which project to call for help. If your questions and concerns are not addressed below, please call the Federation at 1-800-331-0688 or 617-236-7210 to be connected to a project that can answer your questions and provide the assistance you need.

For questions about:

**HEALTHCARE SERVICES & SUPPORTS**
- We have private health insurance but struggle to pay the deductible, co-payments and other out-of-pocket expenses. Are there other types of health insurance for my child with special health care needs?
- It's difficult for me to attend meetings. Is there another way for me to get information and learn about resources and supports for children and youth with special health needs?
- Is there a way for me to get connected to other families of children with special health needs and learn about the services and supports they have accessed for their children?

**SUPPORT & HELP FROM OTHER FAMILIES**
- I'd like to talk to another parent of a child with a disability. Can you help me?
- I need to contact Early Intervention to have my child evaluated. Do you have the number?
- Where is the nearest support group for...? Can you tell me about other community supports for my child and family?

**Call:**
Mass Family Voices
1-800-331-0688, ext. 210
massfv@fcsn.org
www.massfamilyvoices.org

Massachusetts Family Voices is a state chapter of Family Voices, a national grassroots organization of families and friends speaking on behalf of children and youth with special health care needs. Massachusetts Family Voices is also home to the MA Family-to-Family Health Care Information and Education Center, which provides information to parents around navigating the Massachusetts public benefits system, opportunities to participate in topical conference calls and hosts a statewide listserv where participants can share information, resources and ask questions.

**SPECIAL EDUCATION SERVICES & LEGAL RIGHTS**
- Where can I find out more about state and federal education laws and services?
- What tests will my child receive as part of her evaluation?
- What do I do if I think my child needs more speech therapy?
- What are some of the accommodations for MCAS testing for students with disabilities?

**Call:**
The Parent Training and Information Center (PTI)
Boston, Northeast and Southeast: 1-800-331-0688, or 617-236-7210
Central: 508-798-0531
West: 413-323-0681
www.fcsn.org/pti

The Parent Training and Information Center provides free information, technical assistance, and workshops to Massachusetts families of children with special needs and the professionals who work with them. We believe children benefit most from their education when parents and professionals work together as partners.

**RESIDENTIAL PLACEMENTS**
- My child is in a residential educational setting. What are my rights and my child’s rights?
- My child is involved with the Department of Youth Services. Can you help me understand the juvenile justice system?
- My child is missing from care. Can you help?
- What are the four types of CHINS petitions?

**Call:**
Parents for Residential Reform (PFRR)
1-800-672-7084 or 617-236-7210, ext. 345
pfrr@fcsn.org
www.pfrr.org

Parents for Residential Reform, funded by the Massachusetts Department of Education, provides support, information, referrals and other information to parents and professionals regarding residential educational settings and more.
From the Executive Director

Thanking Brooke

After nine years and seven successful Galas, Brooke Heraty is retiring from her position as Director of Development at the Federation. Brooke is looking forward to spending more time in pursuit of her two favorite pastimes: spending time with her family and traveling. While we are sad to see her go, she more than deserves a rest. She has done an exquisite job of establishing the Federation’s signature event, which not only is an annual celebration of our mission, but has also provided a solid financial base for our organization.

Brooke began her career at the Federation as a student intern, while pursuing her Masters Degree in Public Policy at Suffolk University. Once she was with us, we could not let her go so we offered her the role of Director of Development.

Aside from her formal training, Brooke’s informal, and perhaps more relevant, training began years earlier with the birth of her son Ryan who has special needs. In addition to her expertise in building financial supports, Brooke knows what it takes to build supports for individuals with special needs, having successfully advocated for her son in the areas of education, healthcare, post secondary education and housing. Brooke willingly and graciously shares this expertise with other families in similar circumstances and with characteristic kindness and graciousness, for many years Brooke represented the needs of young adults with special needs on the Massachusetts Rehabilitation Commission. Brooke’s tireless commitment and spirit of generosity has spurred her efforts to invite everyone she knows, and those beyond, to make a commitment to the Federation along with a generous contribution.

As we say an appreciative farewell to Brooke in her current role, we celebrate her “Spirit of the Federation” and wish her great satisfaction in the next phase of her life. We have all benefited from her dedication and hard work.

From all of us...

Best Wishes, Brooke and Thank You!

Sincerely,

Rich Robison
Community Partnership Awards

Each year, The Federation for Children with Special Needs recognizes individuals who have shown exemplary support of individuals with disabilities and their integration into the community. This year’s awards, presented at the Federation’s annual conference on March 4, went to the following individuals:

**Parent Advocate Award**  
*Presented to Yajaira Blanco*  
Yajaira Blanco is the Manager of Family Services at the Arc of Greater Lawrence. Her work extends well beyond her job requirements. Yajaira often volunteers to start new education programs, attends support groups for parents who have children with disabilities, provides transportation, and organizes parents who desire leadership roles in the community. Yajaira’s passion and energy ensures that parents receive the services, training and advocacy they need to support their children.

**Community Outreach Award**  
*Presented to John and Magi Bush*  
The tragic story of the disappearance of John and Magi Bush’s daughter Molly is well known. Determined that no other family should experience the nightmare of a missing child, they established the "Molly Bish Lifeguard Foundation,” an organization devoted to child safety through education and prevention. The cornerstone of this foundation is the distribution of free child identification kits (over 50,000 to date across New England). An inspiration to all, John and Magi have spoken to hundreds of schools and families throughout the US to educate their audiences about the importance of child identification.

**Exceptional Teacher Award**  
*Presented to Donna Mogavero*  
Donna Mogavero is a dedicated preschool teacher at the Hennessey School in Lawrence. Not only does she make inclusive classrooms a working reality, she also helps ease parents into the transition from early intervention. Ms. Mogavero is an effective teacher who pays close attention to each student, and makes a child with disabilities feel accepted amongst his/her peers. Ms. Mogavero gives all her students a foundation to grow and succeed in society. It is through these multiple and extra efforts that she has made inclusion in the classroom about more than education. It is about curiosity, understanding, and friendship.

**Self-Advocate Award**  
*Presented to Kevin Doherty*  
Kevin Doherty is a Dean's List student of Liberal Arts who also has a reading disability. Kevin was introduced to a text-to-speech computer software program (Kurzweil 3000), when he entered Middlesex Community College. This tool helped Kevin so much he promptly began volunteering to tutor other students and staff in Disability Support Services. Kevin, in an effort to give other students access to this technology, convinced the Special Education Department at his former high school to adopt it. He continues to assist the Northeast Metropolitan Regional Vocational School by presenting demonstrations of the software to the Parent Advisory Council as well as encouraging Northeast students’ use of the program. Kevin further supports his community by teaching swimming lessons to children with and without disabilities.

**Parent Activist Award**  
*Presented to Kathy Ryan*  
Kathy is the proud mother of three children: Owen, age 23, Luke, age 16, and Maggie, age 13. She was one of the first parents in Boston to have a profoundly disabled child in a fully inclusive classroom at the Patrick O’Hearn School in Dorchester. For many years, Kathy has been involved with the Consortium for Children with Special Health Care Needs and with Operation House Call (see separate article), which brings together medical students and families who open their doors to share an up-close-and-personal look at raising a child with special needs in the context of the family. For the past ten years, she has worked for Home First, finding resources to help families take care of their medically complex children in the best place: their homes! Kathy is renowned for her many years of dedicated work with families whose children have developmental and physical issues.

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**MATCHING GIFTS**  
**Make Your Contributions Go Further!**

1. Check with your company’s personnel department to see if they have a matching gifts program.
2. Ask for matching gifts forms for all the members of your team.
3. Review the requirements of your matching gifts program carefully—each program has its own policies.
4. Have questions or need more information? Contact Jane Wolfson, Director of Development, at 617-399-8374.

Go to [www.fcsn.org](http://www.fcsn.org) for more ways to give.
Visions of Community, continued from page 1

Freedman-Gurspan from the Massachusetts Department of Mental Health, Jane Tewksbury, Commissioner of the Massachusetts Department of Youth Services, and Elmer Bartels, Commissioner of the Massachusetts Rehabilitation Commission. Marcia Mittnacht, the State Director of Special Education at the Massachusetts Department of Education, was more than an invited guest; she also presented a workshop about the impact of the reauthorization of IDEA 2004.

In addition, the Commissioner of the new Massachusetts Department of Early Education and Care, Ann Reale, shared her department’s goal of helping Massachusetts children and families reach their full potential and congratulated the Federation for all the work it does in bringing the state agencies together. Commissioner Heidi Reed of the Massachusetts Commission for the Deaf and Hard of Hearing complimented the Federation for being a “wonderful, positive part of their work,” and emphasized the importance of partnerships in creating equal access for everyone, as evidenced by the full communication access (sign language interpreters and translation services) that the Federation provided for conference participants. She went on to say the conference was important in helping families understand the variety of resources available to them and that these resources help families create a “shared vision of community.”

Larry Tummino, representing the Department of Mental Retardation, shared that the conference theme, ‘Visions of Community,’ fit his own vision—that people [with developmental disabilities] will be included and visible in their communities. Creating partnerships with families is essential to making this vision a reality.

Commissioner Paul Cote of the Department of Public Health emphasized the importance of having “parents at the table as active participants, teaching and showing [the Department] what we are doing.”

While it was an honor for Rich Robison to introduce the keynote speaker Susan Senator, Sue echoed that it was an honor for her to be invited. She mentioned how she “stumbled” on the Federation when her son was three and it felt like she had found the “promised land.” Sue’s son has autism and she would make books for him so he’d know what to expect when they went to family gatherings, or other places. She took that one step further and used her skills and talents as a journalist to write a book. Stressing the “power of family stories” and how they “can and are changing the world” Sue wrote Making Peace with Autism: One Family’s Story of the Struggle, Discovery and Unexpected Gifts. Sue gave a sad, funny and overall inspirational keynote address about her family’s experiences and shared strategies that, despite our children’s differing needs and diagnoses, can help us all survive each day and recognize and appreciate each of our children’s unique gifts.

The morning session concluded with some hopeful words from Dr. Troy Justesen, the Former Deputy Assistant Secretary at the Office of Special Education and Rehabilitative Services and Acting Director of the Office of Special Education Programs at the U.S. Department of Education. Dr. Justesen, while not a parent, is a person with a disability. He shared his experiences growing up. When he was in high school, he only ate in the school cafeteria with his classmates two times because the building was not accessible. He spoke about how the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) are “the foundation on which my future is based.” He noted that the people doing the policy work in Washington D.C. are either “parents [of children with disabilities] or people with disabilities. It’s their passion to build on the successes that are already in place.” He looks forward to a day when “disability is part of the fabric of life” and no one will have to “worry about opportunities to work, opportunities to be happy, and opportunities to be independent.”

If you missed the conference, and would like more information about the workshops and speakers visit http://www.fcsn.org/conference/workshops.html. Many of the workshop handouts can be downloaded from the Federation website.
Frequently Asked Questions about IEP Annual Goals

From The Parent Training and Information Project (PTI)

What are annual goals?
According to federal and state laws, each child who is eligible for special education and related services must have an Individualized Education Program (IEP). In Massachusetts the IEP must include measurable annual goals and short-term objectives and/or benchmarks to meet your child's educational needs resulting from the disability and to enable your child to progress in the general curriculum, i.e., to help your child be part of and learn what all children of the same age are learning.

Who develops the goals?
Goals are written at a meeting of the IEP Team. Team members include: you (the child's parents or guardians); at least one regular and one special education teacher; an individual qualified to interpret evaluation results; individuals knowledgeable about the general curriculum, a representative of the district who can commit resources, your child (if s/he is age 16–22, or younger if appropriate), and others who know or have expertise about the child.

What information is necessary to develop goals?
Development of meaningful educational goals relies on up-to-date information about your child's strengths and needs. This information is included on the IEP in the section entitled Present Levels of Educational Performance. Your child's present levels of educational performance are determined by the results of her/his evaluations, schoolwork, and observations. This information is collected from many sources—including you—and must be accurate, complete and comprehensive.

In the Present Levels of Performance section, the Team describes the effect of your child’s disability on his/her performance in all areas of education including academics (reading, math, etc.) and other, non-academic areas (socialization, behavior, daily life activities, mobility, extracurricular activities, etc.). Your student’s knowledge and skills are compared to what students of the same age are required to know and do, according to developmental standards and the curriculum frameworks. Based on this comparison, your student's skill weakness in a given area is defined.

How should annual goals be written?
The IEP Goals are not lesson plans or restatements of the curriculum content. Annual goals are statements in the IEP that describe outcomes, e.g., what your child can reasonably be expected to accomplish in one year’s time in his/her special education program and in participation in the life of the school.

Goals are written to develop skills in reading, math, social skills, travel training, behavior, and more, so that your student is able to access, participate in, and make progress in the general curriculum.

It is important to write measurable annual goals that will help your student build skills. Ask yourself, “In one year’s time, remembering my child’s vision for the future, what skill would make the greatest difference?” True skill-building goals will lead to more and more independence in various environments and throughout the school day.

What does a well-written annual goal include?
A well-written annual goal will clearly describe:
- TARGET BEHAVIOR—The skill or behavior in need of change
- Condition—Circumstances under which the target behavior is to occur
- Criteria—Acceptable level of performance of the target behavior

It should be easy for you to imagine what it will “look like” when your child reaches each goal. Below are examples of measurable annual goals with corresponding objectives or benchmarks, developed collaboratively by the Federation for Children with Special Needs and the Massachusetts Department of Education.

**Example 1**
Current Performance Level: Nadia is able to write three to four sentence paragraphs. All of her sentences are written using the subject/verb/object format and include little or no detail. Nadia had difficulty writing introductory and conclusion sentences. She also has difficulty remaining on topic throughout her paragraph. Nadia is skilled at spelling and punctuation, which are at grade level. Her paragraphs usually score 30 to 35/50 on the district writing rubric.

**Measurable annual goal:**
Nadia will WRITE A SIX SENTENCE PARAGRAPH using four types of sentences scoring 45/50 on the district writing rubric.

**Objectives:**
- Given a list of sentences, Nadia will accurately label the four types of sentences.
- Nadia will be able to write acceptable examples of the four types of sentences when asked.
- Given a sample paragraph, Nadia will be able to consistently label correctly the components of a paragraph.
- Given a topic, Nadia will be able to write a paragraph using three out of the four types of sentences.

**What are objectives and benchmarks?**
Each goal must have written objectives or benchmarks. These are statements that describe observable steps or milestones your child is expected to accomplish within a specified period of time. They both demonstrate progress toward the goal.

**Objectives** break the Measurable Annual Goal into discrete components that are short-term, measurable, intermediate steps.
**Benchmarks** break the Measurable Annual Goal into major milestones that your student is expected to reach within a specified period of time.

**Which are better, objectives or benchmarks?**
One is not better than the other. Objectives fit some goal areas better than benchmarks, and benchmarks fit other goal areas better than objectives.

**Are objectives or benchmarks required to be included in every IEP?**
Yes. Although IDEA 2004 requires that IEPs must include a description of benchmarks, or short-term objectives only for children who take alternate assessments aligned to alternate achievement standards, Massachusetts state law still requires that all IEPs include either objectives or benchmarks.

**What kind of goals should be written?**
IDEA 2004 specifically states that an IEP must include both academic and functional goals. Ask yourself, “What skill would make the biggest difference for my child?”

Possible goal areas include academic, behavioral/social/emotional, physical, orientation and mobility, travel training, communication, assistive technology, non-academic activities, extra-curricular activities, vocational preparation, post-secondary preparation, self-advocacy training, IEP participation training, independent living/life skills, etc.

**Can my child’s goals address what will happen after high school?**
Yes, your child’s IEP must address “Transition” beginning with the first IEP to be in effect when your child is 16 (or younger if determined appropriate) and then updated annually thereafter. These goals must be based on age-appropriate transition evaluations.

**Example 2**
Current Performance Level: With support from her IEP Team and according to her preferences, Jillian has obtained a job at the local YMCA. Transportation has always been provided up to this point. Jillian has never had the opportunity to use the bus system.

**Measurable annual goal:** Monday through Friday, Jillian will use the public transportation system to get to and from her job placement, independently arriving at work on time, for any five consecutive days.

**Benchmarks:**
- By the end of the first quarter, accompanied by an adult, Jillian will walk to the bus stop, ride the bus to work, and get off at the correct work bus stop.
- By the end of the second quarter, Jillian will be able to independently walk to the bus stop, ride the bus to work and get off at the correct work bus stop.
- By the end of the third quarter, Jillian will independently walk to the bus stop, ride the bus to work and get off at the correct work bus stop.

**How many goals should be written?**
The Team decides the number of goals necessary to meet your child’s needs. Keep in mind that it is best to choose only the goals that will make the biggest difference. If there are too many goals, it will be difficult for your student to make effective progress in each goal area.

**How can teachers and other school professionals be sure my student is making progress toward his/her goals?**
Teachers and other school professionals track student progress by recording scores and other data over the school year. By recording data related to the goals and objectives, they can measure your student’s progress or lack of progress.

IDEA 2004 has made some changes to measuring progress and reporting. IEPs are now required to include a description of how your child’s progress toward meeting the annual goals will be measured, and a description of when periodic progress reports will be provided to you, the parent.

When the Team is writing the goals and objectives/benchmarks it is a good idea to ask:

- How will the school track your student’s progress?
- What will be the source of the data? (Check list, quiz, etc.)
- What will be the data collection schedule? (How and when will they record data for each goal?)
- Who will collect the data? (Aide, Teacher, Special Educator, Student, Peer, other)

**How will I be informed about my child’s progress toward meeting the goals?**
Your IEP Team should identify the progress-reporting schedule and include it in your child’s IEP, as IDEA 2004 requires. You should receive progress reports at least as often as parents of children without disabilities receive reports of their children’s progress. Typically, progress reports are sent out at the same time as report cards.

**What should I do if my student is not making effective progress toward her/his IEP goals?**
Schools must make a good faith effort to help your child meet the goals and objectives/benchmarks listed on the IEP. If you think your child is not making effective progress toward meeting his/her goals, it is important to ask for a meeting of the IEP Team to discuss this concern. Team members will review the goals and the services intended to help your child reach those goals. If changes need to be made, an addendum will be written to the IEP.
The MassHealth Standard/CommonHealth Premium Assistance Program

Information from the Massachusetts Family-to-Family Health Care Information & Education Center, a project of Massachusetts Family Voices

The MassHealth Standard/CommonHealth Premium Assistance Program is an added benefit of the MassHealth system. Unfortunately, information about and eligibility for this program is not linked to the Medical Benefit Request (MBR) form, the single application for all the MassHealth programs. Families must fill out a separate application to apply for this benefit. Read about program eligibility and then call the toll-free number below to request an application or to ask follow up questions.

The MassHealth Standard/CommonHealth Premium Assistance Program provides financial assistance to families who have a family member that receives MassHealth Standard or MassHealth CommonHealth and who pay private health insurance premiums.

In order to be eligible for Premium Assistance:
1. You must have at least one family member on MassHealth Standard or MassHealth CommonHealth.
2. You must pay your premiums for private health insurance out-of-pocket (if your employer pays your health care premiums, you are not eligible for this benefit).
3. Your private insurance must offer the Commonwealth of Massachusetts required benefits. These include payment for: early intervention; mental health (this includes inpatient and outpatient, as well as substance abuse treatment); hospice; other inpatient and outpatient services; physician, surgical, laboratory, radiological and maternity services; durable medical equipment; home health care services; ambulance transport; and special formulas for people who need low protein foods.

The maximum benefit per eligible family member is $660/month. However, variables such company size, the cost of your private insurance premiums, your monthly CommonHealth premiums and if you have COBRA all affect the amount of Premium Assistance your family receives.

The Premium Assistance program is computerized. If your checks stop coming, it’s not because your benefit ended or was cancelled. It’s because something literally “did not compute” and you should call the program to have your case reviewed. Some common reasons for interruption of benefits are:

- Families do not keep current with their MassHealth Eligibility Reviews. It’s important to fill out these forms and return them within 45 days or the premium assistance benefit will stop.
- There was a change in the family’s employer-based insurance, because either you changed jobs or your employer changed health insurance carriers. It is important to report private insurance changes to the Premium Assistance Program.

To receive an application for the MassHealth Standard/CommonHealth Premium Assistance Program, or for more information, call the program at 1-800-862-4840 and press 1.

1. If you have a child with a disability that is eligible for CommonHealth, but the CommonHealth premiums are more expensive than your out-of-pocket costs, you should factor in the Premium Assistance benefit before you make a decision.
2. COBRA (The Consolidated Omnibus Budget Reconciliation Act of 1986) provides a way for some employees to temporarily (generally 18 months) purchase health insurance at group rates if they have lost their jobs, or lost insurance benefits due to a decrease in work hours. For more information about COBRA, visit www.dol.gov/ebsa/faqs/faq_consumer_cobra.html.

Operation House Call

The operation was a success, and now it is time to thank our sponsors

Dear Newslines Readers:

Thank you for your tremendous response to the Operation House Call article in the Winter 2006 issue of Newslines. Many families read about the program and called to participate. If you were interested, and haven’t called yet, please do—there’s always room for more! Thanks to the Federation for helping publicize Operation House Call and for supporting our efforts to help future physicians better serve the special needs community.

Unfortunately, I neglected to credit the Arc of Greater Boston for their sponsorship of this wonderful, nationally recognized program. The Arc of Greater Boston (also known as GBARC) began the program as a collaborative effort with the Boston University School of Medicine in 1991 and continues this work today as part of its community education efforts.

For more information about Operation House Call visit http://www.fcsn.org/publications_resources/newslines/nlv26n3.pdf (page 9), call me at 781-861-3770 or e-mail: johnsusanna@rcn.com.

Sincerely,

Susanna Peyton
Coordinator, Operation House Call
Medical Debt:
Is your family suffering financial hardship due to the costs of your child’s health care?

The Access Project, a national health care policy resource center, is investigating the failure of health insurance to protect people from financial problems. Families with a household member with a disability or chronic condition are most at risk of having unaffordable medically-related bills—a 2005 Kaiser study found that 26% of households where at least one member has a chronic condition or disability have an overdue medical bill.

We are currently collecting stories from privately insured Massachusetts families that are struggling to keep up with medical bills due to their children’s special health care needs. We will use this information in a report that will discuss the reasons why even people who have health insurance often find themselves in financial jeopardy due to medically related expenses.

Personal accounts help to bring data alive in reports and news stories about medical debt—they are the best way to attract much-needed attention to this problem.

We are looking for people who:
Currently have medically-related debt
Were privately insured—whether through their employer or insurance they purchased individually—when they first went into debt because of medical expenses

If you are willing to share your story confidentially, please contact Andrew Cohen at The Access Project. Email: acohen@accessproject.org, or phone: 617-654-9911, ext. 231 (he will promptly call you back so you don’t have to pay for the call). For more information about these issues, visit The Access Project website: www.accessproject.org.
Family TIES of Massachusetts, Together In Enhancing Support, is a statewide information and support network for families of children with special needs. It is a project at the Federation for Children with Special Needs, funded by the Massachusetts Department of Public Health, Division for Perinatal, Early Childhood and Special Health Needs. Family TIES has three focuses: families of children with special needs can receive information and referrals, direct parent-to-parent support, and training from Family TIES.

WELCOME
We are excited to welcome Gloria Klaesges to the Family TIES network as our Western Regional Parent Coordinator. Gloria has two children, a 6-year-old son and a 9-year-old daughter. Her daughter has a rare genetic disorder, Hurlers syndrome, which was treated with a bone marrow transplant from an unrelated donor. Her daughter's medical issues have taught Gloria a lot about coordinating care for medically fragile children, knowledge she willingly shares with other families looking for support. Gloria also realizes families in the Western Region of the state feel isolated and alone, and it can often be challenging to find out about services and supports. She looks forward to making it easier for families to learn about access programs in the region. Please call or e-mail Gloria, introduce yourself and let her know how she can help you and your family. Her phone number is 413-586-7525, ext. 1133 or e-mail gklaesges@fcsn.org.

INFORMATION AND REFERRALS
The Family TIES staff receives telephone calls and e-mails from parents of children with special needs (ages birth to 22) and professionals who work with our families. Requests for information and referrals vary widely and include information about early intervention services, support groups (local and national), healthcare and health insurance options, community recreation and support programs, equipment needs, and transition to adult services. The Regional Coordinators maintain lists, identify new resources, and best of all, help with the challenges of raising children with special needs. The 9th Edition of the Family TIES of Massachusetts Directory of Resources for Families of Children with Special Needs is a compilation of resources. To receive a free copy of the Directory call your Regional Coordinator, or visit our website at: www.massfamilyties.org.

PARENT-TO-PARENT PROGRAM
The mission of the Parent-to-Parent Program is to bring together parents facing similar challenges in raising their children with special needs. We believe that sharing experiences provides strength and support to each other. This volunteer-based program provides opportunities for all parents to share, on both sides of the conversation. Parents contact us in search of a listening ear - another parent who has faced some of the same issues and concerns as they now face. This may be in response to a new diagnosis or a new challenge, a transition in the child's life, or just to recharge their batteries.

Family TIES welcomes experienced parents to assist us in meeting the needs of parents seeking support. We are especially in need of parents of children with complex medical conditions. Family TIES provides a two-hour training for Support Parents. The training curriculum focuses on developing effective, compassionate listening skills. We offer guidance on sharing concerns, information, and support with respect for confidentiality and cultural and individual differences. Trainings are free and offered at various locations throughout the state. To learn more or participate, call our toll-free number, 1-800-905-TIES, or Linea Luck Pearson, the Parent-to-Parent Coordinator.

TRAININGS
Family TIES offers its engaging Let's Get Organized workshop to families of children of all ages with special needs. Call your Regional Coordinator for the workshop schedule, or to arrange this free workshop in your community.

FAMILY TIES REGIONAL COORDINATORS
Greater Boston: Roxanne Hoke-Chandler 617-541-2875
Southeast: Karen Douglass 781-774-6749
Metrowest: Lisa Mayer 781-774-6602
Northeast: Kathie Dell'Arciprete 978-851-7261, Ext. 4018
Central: Barbara Donati 508-792-7880, Ext. 2337
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Parents for Residential Reform: Current Projects

By Andrea Watson

Parent/Professional Training and Information
Parents for Residential Reform (PFRR) provides guidance and support to the parents and guardians of children with special needs in the areas of residential, group home, pediatric nursing home, or hospital care placements, wrap around services, the CHINS (Child in Need of Services) process, and more. We also help people navigate through the maze of state agencies and community supports, including faith-based supports. Individuals who need our help can access it by phone, e-mail, visiting our website or by attending any of our workshops and conferences.

Children Missing From Care Task Force and Recovery of Children
The Massachusetts Department of Social Services (DSS) and PFRR have worked together to help develop a model protocol to respond better to children missing from state care. The Task Force is comprised of DSS workers from area offices, various provider representatives, and representatives from foster care, and the police. PFRR also helps search for young people who are missing from care. Note: 95% of these young people are females who are victims of sexual exploitation; 82% of these young people have experienced trauma or have special needs. We work in partnership with DSS, police departments, the Molly Bish Foundation, and the Family Justice Center at the Boston Police Department to help locate and ensure better outcomes for these at-risk and vulnerable children.

CHINS Reform
CHINS is a civil process that deals with children who are younger than 17 in hopes of preventing future delinquency. There are four types of CHINS petitions: runaway, stubborn child, truant, and Habitual School Offender. For more information about the CHINS process, visit http://pfrr.org/fs-chins.html.

PFRR has been working with various state agencies, providers, legislators, and other organizations to reform the CHINS process in Massachusetts so it will better serve children and families.

List Serves
PFRR hosts several topic-specific list serves, some nationally, about residential/group home care, juvenile justice, wrap around services, and more.

Visit our website, e-mail or call for more information.
Phone: 617-399-8345
E-mail: pfrr@fcsn.org
Website: http://www.pfrr.org

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**APPLE Institute**

*By Barbara Popper*

The U.S. Department of Education funds the APPLE (Advanced Parent/Professional Leadership in Education) Project at the Federation. The goal of the APPLE Project is to help build better relationships between parents and schools around issues of special education. In addition to providing training to parents and special education personnel, this project has a research component. Our research partners at the Institute for Community Inclusion at the University of Massachusetts-Boston will follow the participants to learn if their involvement with APPLE is helpful in building partnerships between their school administrations and the Parent Advisory Committees (PACs) in their towns.

In March 2006, the APPLE Project held a three-day Leadership Development Institute for five school districts: Maynard, Cambridge, Ashland, Everett, and Framingham. Each district sent a team of parents whose children have IEPs (Individualized Education Programs) and one special education professional; three Special Education Directors attended as part of their district’s team. The APPLE faculty included Rich Robison, Executive Director of the Federation for Children with Special Needs, and co-director of APPLE; Barbara Popper, APPLE co-director; and Marilyn Gutierrez-Wilson of the Federation’s PTI (Parent Training and Information) and APPLE projects. Additional faculty included Roberto Chene of New Mexico whose specialty is conflict resolution; Kathleen Osta, of North Carolina, a specialist in communication strategies, and Cassie Johnston of PAVE, the Washington state PTI. Cassie conducted the True Colors™ Training, a method of helping individuals identify and understand their learning styles.

It was a busy three days. Participants identified barriers to the parent/professional relationship and brainstormed ways to overcome those barriers. They also learned about forming relationships that enhance parent/professional collaboration, setting goals, creating action plans, and about starting new PACs or re-energizing established PACs.

As follow up to the Institute, APPLE project staff has sent finalized Team Action Plans to each of the five districts. A main goal of each plan is to increase parent involvement in their PACs over the next year. During that time, each team will receive continued technical assistance from the Federation, and the Federation will incorporate their ideas into future Institutes.

Currently, APPLE staff is recruiting parents and special education professionals from Mansfield, Grafton, Canton, Gardner, and Billerica attend a Fall Institute. By fall, they hope to identify five more towns as the research continues in 2007. If you are interested in having your town participate, please have your PAC chair or SPED director call Barbara Popper at the Federation at 1-800-331-0688, ext. 322, or e-mail Barbara Popper at bpopper@fcsn.org. She is available to talk with PAC chairs or SPED directors from interested towns.

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**Discussion Group for Parents of Young Children with Disabilities**

Hosted by the Boston Institute for Psychotherapy

The Rice Center for Young Children & Families

1415 Beacon Street • Brookline, MA 02446 • (617) 566-2200

bostoninstitute@bostoninstitute.org

Group leader: Stanley D. Klein, Ph.D.

Six evenings: 7:00–8:15 pm

Session fee: $45.00 per couple, (insurance accepted)

Individual parent consultations also available

By talking with other parents who are also raising a young child with a disability or special health care need, parents can share the many and mixed feelings related to raising a child with a disability with the goal of dealing more effectively with the challenges of day-to-day life. A range of topics will be discussed including:

- Dealing with difficult emotions
- Communicating with family members and friends
- Managing uncomfortable social situations
- Coping with stress
- Gaining wisdom from other parents
- Changing expectations and priorities
- Nurturing oneself and your marriage
- Finding practical solutions to everyday developmental issues

For more information, contact: Stanley Klein Ph.D. at 617-879-0397

Stanley Klein, Ph.D.

Dr. Stanley Klein is a clinical psychologist and Series Editor of People with Disabilities Press and Director of Disabilities Books, Inc. He is co-editor of four books on the topic of parenting children with disabilities.
Parenting Children with Autism: Safety Issues and Tips

By Karen Douglass, Family TIES Southeast Regional Coordinator

Parents want to do everything possible to keep their children safe. When a child has autism, safety is a complex and often challenging issue. Children on the autism spectrum may have trouble with safety awareness and difficulty communicating, as well as some challenging behaviors that may include a tendency to bolt or wander.

My 5-year old son Keston has autism, and keeping him safe is an ongoing concern. Even now, after much pre-teaching, Keston sometimes just takes off in whatever direction he pleases. I think he would make a great running back because he outmaneuvers me every time. Shouting, "Stop!" or "Keston!" are intermittently successful, but I cannot count on him to listen in a crisis.

When Keston was two, our family lived near the beach. I lived in fear that he would wander down to the water and drown. Even though my husband and I monitored him extremely closely, Keston would manage to wander down to the water. One afternoon we found him wading in neck deep water to reach a dingy that was moored in the bay. Another time, I found him mired in the muck left behind by the ebbing tide. It can be difficult for any child to connect an action to a consequence. For a child with autism, it is even more difficult; they often repeat the same dangerous actions.

Another safety concern I have is that something might happen to me when Keston and I are alone. Keston is nonverbal, so if we were in a car accident, or I fell ill, Keston would not know how to call for help, and how to give emergency responders information. Would they understand that he is a child with a disability and respond to him appropriately in a way that would minimize his fear?

As more parents raise similar concerns about keeping their children with autism safe, more information, advice and safety tools are now available. I have an Autism Awareness magnet on the rear of my car, an Autism Emergency Alert in the rear window and corresponding personal identification information (available from www.leanonus.org), including a photo of my child, tucked into the driver's side visor. If I were in an accident, emergency responders could identify that there is an occupant by the ebbing tide. It can be difficult for any child to connect an action to a consequence. For a child with autism, it is even more difficult; they often repeat the same dangerous actions.

My 5-year old son Keston has autism, and keeping him safe is an ongoing concern...

It can be difficult for any child to connect an action to a consequence. For a child with autism, it is even more difficult; they often repeat the same dangerous actions. With autism and could find out more about him. It is important even if you don't have a child with special needs to have an ICE. (In Case of Emergency) contact keyed into your cell phone so emergency responders can readily identify whom to call on your behalf. [For more information about ICE, refer to page 17 of the Fall 2005 NewsLine at www.fcsn.org/publications_resources/newsline/nlv26n2.pdf.]

Safety at home is as important as safety on the road. On our front door, we have an Emergency Decal that is available from the Autism Society of America (www.autism-society.org). This alerts visitors that an occupant has autism. I would not recommend putting decals on a child's bedroom window because you don't want to identify the child's room for people who have ill intent. We also have a deadbolt on our front door and a simple eyehook on our sliding glass door. This is up high, out of Keston's reach, even if he stands on a chair.

In order to make sure Keston doesn't open the other doors and leave the house unnoticed, we installed a hardwired alarm system. Another option is to purchase an inexpensive door alarm at a local hardware store. These mount onto the door and doorframe. Both systems sound an alarm if the door is opened to alert you that someone is going out or coming in.

Our garage door is a particular safety concern. Keston learned how to open the garage by pushing the buttons on the keypad. Last summer, while naked, he escaped, and streaked through the neighborhood. Our solution was to unplug the garage door opener. The safety and security this provides more than compensates for the inconvenience of manually operating the door.

Speaking of neighbors, it is important that we, as parents, do our best to educate neighbors and friends about our children. Understandably, some parents would rather not call attention to their child's disability. However, if the neighbors know about the child's special needs, they are much more likely to act quickly if they see a child outside alone or in other unsafe situations. I also had our town install traffic safety signs at both ends of our street. These signs alert drivers that there is a special needs child in the vicinity. Some drivers ignore these signs and speed through the neighborhood.

However, most drivers take notice and are that much more careful when they approach our block. To find out about the availability of a traffic safety sign for your neighborhood, call your town hall. In my town, I phoned my local councilman to request that the sign be put up and the Department of Public Works installed it.

It is equally important to notify your town's emergency responders about your child. Visit the fire, police and EMT (Emergency Medical Technician) stations...
When I asked my sixth grader how principals could improve middle schools he answered readily, “They need to make it so students who like learning are cool.” Then he cocked his head thoughtfully and added, “But that would be hard.”

Hard or not, the National Association of Secondary School Principals and the Education Alliance at Brown University are giving it a stab with their excellent new book, *Breaking Ranks in the Middle: Strategies for Leading Middle Level Reform*. Written for middle school administrators, this textbook-like publication maps out a route to middle schools in exhaustive detail. It’s not an easy read, but it’s an important read for parents who are interested in the nuts and bolts of running a middle school, and who would like to help educate their own school administrators.

The authors lay out nine cornerstone strategies and thirty recommendations in their attempt to chart the path to middle schools that are “academically excellent, developmentally responsive, and socially equitable.” Among other things, they insist that each student should be well known to at least one adult within the school, that the curriculum must be standardized and structured with the developmental needs of students in mind, that teachers must have proper training and scheduled planning time, and that all stakeholders—students, teachers, families, and community members—should be substantively involved in school decision making.

As the parent of a child with disabilities, I found most interesting the idea that all students should have a “personal plan for progress,” which would chart each student’s strengths, weaknesses, and goals for the future. Students and their teacher-advisors would develop and monitor these plans in order to encourage self-reflection and goal setting, and to prompt students to recognize their own talents. This sounds a lot like an IEP for everyone—without legal strings attached.

Although students with disabilities are not often mentioned, they do put in an appearance in a couple of interesting case studies. It’s clear that the authors are focusing on regular education, but they advocate inclusion. Good practices across the board, they believe, will help ensure the success of all students.

Parenting Children with Autism: Safety Issues and Tips, continued from page 13

Remember that even verbal children with autism can become stressed and not be able to communicate effectively in an emergency. Some parents have success using a medic alert ID tag or bracelet, which are available at most pharmacies. There are also ID tags for a child’s shoe or zipper (visit www.mypreciouskid.com for more information about child safety products). Other families have had success with sewing identifying information into the child’s clothing. For children who are serious wanderers www.projectlifesaver.org offers a rapid response tracking system that is used in conjunction with law enforcement. My son has sensory issues, so he is opposed to any sort of ID tags or labels. We have printed identification cards with Keston’s name and our contact information on business cards and placed them in his backpack and the pockets of all of his jackets.

Another great resource is the Early Search Program sponsored by the Franklin Police Department. This program assists parents of children with special needs or caregivers of people with Alzheimer’s in creating a detailed biographical and geographical binder that could be given to emergency responders if the individual wanders off. It contains detailed information about the

Link to Amazon.com through the Federation website at www.fcsn.org and 6% of your purchase will help support the mission of the Federation.
When this sweet children’s story about a hyperactive turtle named Shelley was originally published in 1989, it was one of the first books about ADHD (attention deficit hyperactivity disorder). The turtle, with its characteristic slow, steady ways, is a wonderful foil for describing the wiggly, impulsive behaviors associated with ADHD. Children will readily be able to identify with how “jumpy and wiggly” Shelley always feels, how hard it is for him to stay in his seat at school, his feelings of being bad because he can’t pay attention, and how he just wants to crawl into his shell.

In 2006, Shelley’s story is just as endearing. To ensure the story remains relevant, Woodbine has published a second edition with some new illustrations and updated information about the diagnostic testing and treatment options for children with ADHD. Shelley’s story helps children and adults recognize and better understand the behaviors that are characteristic of ADHD. It also encourages parents to get their children the help they need to feel better about themselves and be better able to function at home, in school, and with groups of friends.

Woodbine House has donated a copy of this book, and other books from their Special Needs Collection, to the Federation. Call 1-800-331-0688 to see if the book you want is available and to arrange to borrow it. For more information about the Woodbine House Special Needs Collection, and to receive a catalog, call 1-800-843-7323 or visit www.woodbine-house.com.

What’s the difference between ADD and ADHD?

For anyone who is confused about the difference between ADD (attention deficit disorder) and ADHD, the anecdote below, shared by the mother of three boys, provides some perspective and may be helpful when explaining attention problems to a teacher, health care provider, other parents, other kids, or extended family members.

Mom: ADD and ADHD look very different. ADHD is the one where the child moves constantly. It is hard to ignore a jet powered ping-pong ball bouncing around your classroom. ADD, on the other hand, is quite different. Children with ADD are often so laid back they may almost seem lethargic. The thing they both have in common is that a child with ADD and a child with ADHD both have a tough time staying focused. Despite the differences, both ADD and ADHD have the same cause (lack of a neurotransmitter), and have the same treatment.

I have three sons. John has ADHD, Devon has ADD, and Rich is more or less normal. Several years ago, when they were in 4th grade, they were dissecting cow eyes. At one point in the procedure the teacher said, “All eyes up here.” Rich admitted that it occurred to him to pick up his cow eye and toss it toward the teacher. Then he thought, “No, the teacher would kill me.” That is the reaction of a normal, active child. He stopped and thought about it before he acted on the impulse.

With John, the minute the idea hit his mind, the cow eye would have been in the air. That’s ADHD. His mantra is “Ready, Fire, Aim.” The school psychologist says he burns his bridges before he gets to them and then swims the creek.

Devon, my son with ADD, who looks half-asleep all the time, would have missed the whole thing because he wasn’t paying attention and didn’t hear the directions in the first place.
Gala 2006 Acknowledgements

The Federation for Children with Special Needs gratefully acknowledges the generous financial support of the following individuals and organizations. They helped make the Federation's 2006 Gala possible. It is through the collective support of those who gathered on the evening of April 28, 2006 to volunteer their time, energy and financial support that we are able to continue to grow as well as ensure that the Federation's capacities are significantly enhanced to meet the needs of our families.

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The Federation for Children with Special Needs wishes to thank all staff, volunteers and board members for their dedication and commitment to quality education, healthcare, and for their tireless efforts working to protect the rights of all children.

The Federation also wishes to thank the program participants:
Professor Thomas Hehir, the Boston City Singers, Paul La Camera, and all those in attendance at the 2006 Gala.

With Appreciation…
The Federation would like to acknowledge the following individuals and organizations for their support and assistance with the 2006 Gala:

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Ken Perham, Lighting Equipment
Boston Camera, Camera Equipment

Brian Procopio, Assistant Video Editor
Peter Swanson, Video Editor
Putnam Investments
Finish Editorial Soundtrack Studios

These people generously donated their time and talent to create this year’s video presentation. The video provides a compelling picture that speaks to the heart of all that the Federation represents, and features a motivating interview with honoree Thomas Hehir. Each video participant’s story gives some insight into the profound difference the Federation is making in the individual lives of children and families across the Commonwealth. Watch the video on our website at www.fcsn.org.

Freedom Flight I: A Poster and Poem by Jessica Vohs
Available for $12, includes shipping/handling. Discount on orders of 20 or more.
The poster is a reproduction of a beautiful watercolor, and can be seen in color on www.jessicavohs.com. 18 x 24 inches, reprinted on a heavy poster stock paper with glossy coating.

Freedom Flight I by Jessica E. Vohs
Butterflies flying free together, each beautiful in its own way.
This is the spirit of human beings. These spirits are not disabled.
We can do and achieve things beyond our wildest dreams.

All we need to be flying free is understanding and a supportive environment that helps our dreams come true.

Let’s open our minds and hearts and fly free together in a most beautiful dance of true life.
Local and regional restaurants and businesses willingly offered their time, services, products, merchandise and food to support the Federation’s 7th annual Gala fundraiser.

This year we were pleased to welcome Paul LaCamera, President and General Manager of WBUR, as the Gala’s distinguished emcee. A children’s chorus from the Boston City Singers performed an artistic and joyful repertoire of songs to compliment the elegant dinner and awards ceremony that followed.

The Martha H. Ziegler Founder’s Award is given to individuals who have had a tremendous impact in improving the quality of life for children and students with special needs. The Federation presented the 2006 Ziegler Award to Professor Thomas Hehir, Director of the School Leadership Program at Harvard University’s Graduate School of Education, to honor his lifelong dedication to improving educational opportunities for children with special needs. An expert in the area of education policies and programs for children with disabilities, Dr. Hehir headed the Office of Special Education Programs at the U.S. Department of Education for six years, and had primary responsibility for implementing the Individuals with Disabilities Education Act.

Proceeds from the Gala provide the critically needed funds to support the work of the Federation. Over the past year, staff, volunteers, and board members worked together to ensure the financial success of this annual event. It is a collective effort and we are pleased to announce that we exceeded our fundraising goal of $150,000.

Our Presenting Sponsors were The Holt Companies, JP Morgan Chase, Jon Jacobson Family Trust and Morgan Stanley. Other contributing participants included Friends of the Federation, Table Sponsors, and Individual Contributors. The Federation wishes to commend all the donors, volunteers, program participants, and supporters who made this the best Gala yet. We are honored by your commitment to the Federation’s mission and thank you for your support.
Golden Access Passport to U.S. National Parks and Forests: Don’t Leave Home Without It

If your family travel plans include a stop at any of the 388 U.S. National Parks and National Forests, and you have a child or other family member with a disability, don’t leave home without first checking into the Golden Access Passport at www.us-parks.com/golden_access_passport.html.

This passport is for U.S. citizens who are blind or permanently disabled and provides free access to U.S. National Parks, forests, monuments, historic sites, recreation areas and wildlife refuges that charge an entrance fee. If the park charges a per vehicle entrance fee, everyone in the vehicle is admitted free of charge. The pass also entitles the holder to a 50% discount on other park fees, such as parking, camping, swimming, boating and tours. This does not include concessions, but each park sets their own rules for pass use, so it never hurts to ask.

You can only apply for the pass in person at a National Park that charges an entrance fee. To find a National Park that charges an entrance fee near where you live or near where you plan to visit, go to www.nps.gov/parks.html and do a geographic search. Each park has its own criteria for the type(s) of proof they need to document your child’s (or an individual’s) disability, so call that park in advance and ask what they require.

If you have any questions, or need a quick tutorial about how to navigate the National Parks Service website at www.nps.gov, call the National Parks Customer Service and Support line at 1-888-467-2757. This line is operational from 6 am–2 pm PST. Extremely knowledgeable and helpful individuals staff this line and can answer your questions, provide further information, or help you use the website.

Parents for Residential Reform & the Federation for Children with Special Needs Invites you to our 8th Annual

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SAVE THE DATES!

Mark your calendars for these upcoming annual events sponsored by The Federation:

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