Gala 2011 – Celebrating Every Child

The Federation for Children with Special Needs hosted its annual spring fundraiser “Gala 2011, Celebrating Every Child” on Friday, May 13, 2011, at the Seaport Hotel in Boston. Guests enjoyed a lovely reception and had fun bidding on hundreds of silent auction items, followed by dinner, music, and awards. This annual event is more than a fundraiser. It is a time to recognize and honor individuals whose work has made a difference in the lives of families raising children and youth with special needs and to celebrate the work of the Federation’s staff, Board of Directors, and volunteers.

Family and Community Engagement in Every School for Every Child

By Gavin Pond, Services Coordinator, Massachusetts Parent Information Resource Center

In 1974, a group of parents founded the Federation for Children with Special Needs with the belief that every child has something unique and special to contribute to his or her community. Every time a child fails to reach his or her potential, the world we all share becomes a little less rich, and the future a little more grim. Leaving no child behind, however, is easier said than done. Fortunately, work in the special needs community has taught us some valuable lessons about what really works. The first lesson is that all families want the best for their children. Families know their children best, sacrifice for their future, and support them as they live, grow, and learn. When educators forget this fact, they lose their most valuable resource. The second lesson is that families, schools, and communities can do a lot more working together than separately. We believe that schools must engage families and community members as partners in the education of all children. When effective family and community engagement is an integral part of the work that schools do, every child gets the support he or she needs to succeed.

continues on page 4
Back to School – Some Things to Have in Your Knapsack

By Daniel T.S. Heffernan, Esquire

In addition to shopping for the kids’ latest fashions, a new lunch box, and those cool markers, here are a few items for the back-to-school backpack for parents of students with special needs:

**Bullying Prevention:** The new Massachusetts Anti-Bullying Statute, General Laws Chapter 71, Section 37O, requires schools to develop and provide parents with a written plan to address bullying prevention and intervention. The plan must provide bullying prevention and intervention training for teachers and students in each grade. School districts must also inform parents of both the victim and the perpetrator of any instances of bullying. If a child has a special need or disability that affects social skills development or makes that child vulnerable to bullying, the Team is required to include skills and proficiencies needed to avoid and respond to bullying in the IEP. Ask for your school’s written policies on bullying prevention; consider whether your child’s IEP should specifically address issues around bullying; and, be vigilant about any instances of bullying lest they escalate into major problems.

**Thinking About What’s Next Already?** While all parents wonder about their kids’ futures, parents of children with special needs invest a tremendous amount of energy worrying, planning, and investing in their children’s futures. Acknowledging the importance of long-term planning, Massachusetts requires that transition planning begin when a student turns fourteen. It is your right to have meaningful and comprehensive transition planning and services for your child; there are many great ideas and programs emerging in the areas of transition. Attend a workshop on transition (the Federation has excellent ones offered throughout the year). Ask for, or independently obtain, appropriate evaluations, such as vocational assessments, that allow you to craft an appropriate post-school vision for your child and obtain the services necessary to make that vision a reality. Since children are eligible for special education services until they graduate from high school or turn 22, you may want to hold off on accepting a high school diploma if your under 22 child does not have the necessary skills to successfully transition out of school. There has been a boom in transition programs and you should explore private programs or push your school district to provide an appropriate one for your child. Many school districts have hired transition specialists, vocational experts, and the like to focus resources on developing or improving their homegrown transition services motivated, in part, by the desire to avoid having to fund outside placements.

**Not Getting the Services You Were Expecting?** Unfortunately, when school opens, some parents are greeted with the news that their child will not be getting the services called for on the IEP. This frequently occurs when a therapist has quit and not been replaced, or the home service provider, for various reasons, has failed to provide all the agreed upon hours. It is important to keep an accurate record of the amount of services missed. Make every effort to work cooperatively with the school district to make up those missed services. Sometimes it benefits both the school and student to make up hours during vacation time. It is your child’s right to have those services made up. In certain circumstances and with proper advance notice to the school district, you have the right to find another service provider and be compensated for the cost. If the services are reasonable and comparable to what the school district was to provide, school districts have been ordered to compensate parents for those costs.

**Take a Look for Yourself:** It is well established that parents, their experts, and evaluators, have the right to observe any current or proposed program for their child. Access must be timely and sufficient to allow parents or their designee a meaningful opportunity to assess the program. A first hand look is invaluable in determining how a student is actually doing in a program, and for providing suggestions for changes to the student’s program. Observations made early in the school year allow the modifications to be implemented early so the student obtains the maximum benefit.

Keep this knowledge in your backpack. Best wishes for a successful 2011-2012 school year.

Daniel T.S. Heffernan is member of the Federation’s Board of Directors and a partner at Kotin, Crabtree & Strong where he concentrates on special education and civil rights law. Contact him at dheffernan@kcsllegal.com.
As the end of summer approaches, I’ve been thinking about endings and beginnings, the cyclical nature of our activities, and the changes they bring. Parents and their children may feel both anxious and eager about the start of a new school year. Any uneasiness about new teachers, new classmates, and new curriculum is offset by the opportunity to make new friends, learn new things, and get involved in new activities. We are sorry to see the summer end; after all, we’ve waited so long for it to come, but the reliability of a new routine can bring comfort as well.

The Federation is no stranger to the cycle of beginnings and endings. You will read about the ending of the Parent Information and Resource Center (PIRC) programs in this edition of Newsline. The U.S. Department of Education (USDOE) provided federal funding for the PIRCs. They worked to promote broad and systemic engagement of parents and families in their children’s education and school as a way to support improved educational outcomes.

The Mass PIRC was established at the Federation in 1999, and has adapted to numerous changes in the Elementary and Secondary Education Act, most recently known as No Child Left Behind. While many have decried the punitive aspects of this law, the notion that no child, regardless of racial, linguistic, cultural, or barriers of ability should be kept from making educational progress was wholeheartedly embraced in our work. We first called the project Parents PLACE – Parents Learning About their Child’s Education, for we believed that when parents are supported to be life long learners along with their students, the educational process could thrive. We have accomplished much in this decade to ensure that schools and parents can be partners in education. The goal of the Mass PIRC’s Bulletins and Pointers was to ensure that parents and school personnel knew about, and were empowered with, a deep understanding of their shared opportunities and responsibilities for the education of all children.

Earlier this year, the USDOE announced the ending of the funding for all 62 national centers. The abrupt ending of these programs will interrupt essential support and leadership in Family and Community Engagement across the country. That said, the Federation is committed to seeking new ways to ensure strong and vital parent engagement in Massachusetts’s schools. To that end, we are exploring the establishment of a new Family and Community Engagement Team (FACET) at the Federation. This team will be designed to support parents, community leaders, and school personnel to promote high quality family engagement opportunities within the life of the school. Stay tuned. Today we start to create a new ending!

Best wishes to all for a great beginning to the school year,

Rich Robison
Executive Director

News from MassCARE

The MassCARE program at the Massachusetts Department of Public Health has created a new support service for patients infected/affected by HIV/AIDS, and the Federation is pleased to be a part of this important new support. HIV programs at health centers in Springfield, Lawrence, Lowell, Brockton, and Worcester will hire Peer leaders. These Peers will work to reengage patients who may have lost contact with their health center and provide support during medical visits. They will share resources and medical information with all consumers about the virus, overall health and well-being, and ideas for advocating for their families and themselves. Corin Landrum, the HIV Coordinator for Women and Children at the Federation, will meet with and coordinate training for the Peers at each of these five sites, as well as provide advocacy, support and supervision. In addition, she will work closely with other health center staff.

Corin recently attend the VOICES 2011: Mapping Our Way conference in Washington, D.C. This annual event, hosted by the AIDS Alliance for Children, Youth, and Families was an exciting opportunity for Corin. She felt empowered to be with hundreds of other people living with HIV/AIDS, and learned from their strength and wisdom about overcoming and enduring stigma and hardship. While at the conference, she attended workshops about policies and regulations, criminal offenses and HIV as a crime, new studies about HIV positive and HIV negative couples, and more. Corin reported the best part of the conference was meeting with the Massachusetts congressional delegation to discuss the need for Ryan White Act funding, which is the federal legislation that delivers HIV/AIDS care to underserved populations. She explained how cuts in this funding will affect families.

To learn more about the MassCARE program, call Corin at 617-236-7210, ext. 311, or e-mail clandrum@fcsn.org.
Family and Community Engagement in Every School for Every Child

(continued from page 1)

Over the past several decades, educational research has confirmed the connection between family engagement and student success. In A New Wave of Evidence: The Impact of School, Family, and Community Connections on Student Achievement, Anne Henderson and Karen Mapp found that students with engaged families are more likely to succeed. This is true no matter how you measure success. Students get better grades. They behave better. They have a more positive attitude. They are more likely to graduate. They are more likely to go to college. Schools also do better when they engage families and communities as partners. An influential study of Chicago schools identified strong “parent and community ties” as one of five “essential supports” for successful school reform. Without this critical pillar of support, the most well executed improvement efforts are likely to fail.

Of course, all schools interact with families. Every school sends report cards home, holds open houses, and solicits volunteers. So what, exactly, do we mean by “family and community engagement?” A recent paper from the Harvard Family Research Project, Beyond Random Acts: Family, School, and Community Engagement as an Integral Part of Education Reform, offers this description:

**Effective family and community engagement is a shared responsibility of families, schools, and communities for student learning and achievement; it is continuous from birth to young adulthood; and it occurs across multiple settings where children learn.**

Each of these concepts is worth expanding on briefly.

**Sharing responsibility for learning and achievement**

First and foremost, sharing responsibility means working together and not pointing fingers. With this in mind, there are many ways schools can get started. A good first step is to make information about curriculum, instruction, assessments, and policies easily accessible. Schools should also be welcoming. They should encourage families to learn about the school and to participate in learning activities. Once schools share information and establish rapport, family and community leaders should be empowered to participate in meaningful decisions about school policy. Their insight can inform decisions ranging from broad educational goals to specific disciplinary policies or budget priorities. Educators must also reach out to families where they live and work in order to build trust, improve communication, and gain a deeper understanding of the challenges different families face. In everything they do, schools and families must stay focused on improving student outcomes.

**Continuous family and community engagement from birth to young adulthood**

We now know that a child’s first few years have a powerful effect on his or her future. Even after those crucial years are past, children must overcome a variety of social, emotional, and academic challenges to reach adulthood prepared for a successful life. When the strands of family, school, and community are woven together with caring and frequent communication, they form a safety net to catch struggling children and offer support before it’s too late. Families, teachers, peers, guidance counselors, and countless other people affect a child’s life. To do their jobs well, these people must learn from a child’s past and be invested in the child’s future. Family, school, and community partnerships that support children from birth to young adulthood can help make that possible.

**Family and community engagement across multiple settings**

When we think about education, we usually think about classroom instruction. In truth, children only spend a small fraction of their lives sitting at a desk listening to a teacher. Research has shown that children who engage in learning activities outside the classroom often make gains, and children who don’t, usually fall behind. One of the best ways schools can reduce achievement gaps is to fill every child’s life with rich learning opportunities in school and out. There are many ways schools can facilitate learning outside the classroom. They can work with parents to align out-of-school-time learning with class work. They can provide families and students with expanded access to libraries and computers. They can offer supports like after-school homework help. They can also be a crucial link between families and community resources like public libraries, museums, and community centers. It takes more than high quality classroom instruction for all children to reach their potential; a truly outstanding educational system must take advantage of every opportunity to educate its children.

This article only scratches the surface of the ways family and community engagement can help schools prepare our children for success in the 21st century. But, no matter how they do it, families, schools, and communities must share responsibility for the education of every child, from birth to young adulthood, in school and out. continues next page
The Massachusetts Parent Information Resource Center
In 1999, the Federation established Parents’ PLACE (now known as the Massachusetts Parent Information Resource Center, or Mass PIRC) to support family and community engagement in every school for every child. Mass PIRC provides technical assistance to school districts and schools across the state, educates families and professionals, and maintains a fact-filled Web site. In order to break down linguistic barriers to family and community engagement, Mass PIRC has translated its Web site, publications, and workshops into at least three languages. Moreover, in order for each dollar spent to have the maximum possible impact, Mass PIRC has formed partnerships with numerous community-based and faith-based organizations. Regrettably, despite widespread and growing demand for Mass PIRC’s services, budget cuts at the Federal Department of Education will eliminate funding for Mass PIRC and 61 other PIRCs across the nation in September of this year.

In spite of this disappointing news, the Federation is still committed to family and community engagement in every school for every child. We will continue to support schools that have begun working with Mass PIRC to implement Solid Foundation—a research based process for improving family and community engagement. Additionally, the Federation will create a family and community engagement team. At the district level, this team will support strategic planning. At the school level, it will help implement Solid Foundation and offer professional development for school personnel. For individual families, the team will train volunteers to present Mass PIRC’s most popular workshops. We know firsthand the power of families, communities, and schools working together, and we will not rest until it touches the life of every child.

Visit the Mass PIRC Web site at www.pplace.org for a variety of materials about preparing for back-to-school, educational rights, educational standards, resources for English Language Learners, and more.

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For more information, please contact Robin Foley at 508.796.1860 or rfoley@sevenhills.org.

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- Pathways Academy
  A comprehensive, year-round day school for children, teens and young adults with neurodevelopmental disorders.

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McLean Hospital is the largest psychiatric facility of Harvard Medical School, an affiliate of Massachusetts General Hospital and a member of Partners HealthCare.
MassPAC: A Seat at the Table

By Leslie M. Leslie, MassPAC Coordinator

The room was silent, the cable television camera light was on and the School Committee chair recognized the SEPAC leader. Finally, after months of work, including analyzing surveys, meetings with school officials, countless emails, and evening phone calls, parents of children with special needs had a seat at the table.

This should be common practice in Massachusetts since the creation of Special Education Parent Advisory Councils (SEPACs). Massachusetts legislation specifically states SEPAC duties include “advising the school committee on matters that pertain to the education and safety of students with disabilities.” Experience has demonstrated though, that both SEPACs and school districts have far to go to achieve this model.

Each SEPAC can define how they meet this advisory standard. For example, the Arlington SEPAC presents the results of an annual parent survey to the School Committee and SEPAC board members comment on timely issues during regular School Committee meetings. The SEPAC also participates in discussions at district subcommittee meetings, specifically those dealing with Policy and Procedures; District Accountability; and Curriculum, Assessment, and Instruction. The SEPAC believes that these subcommittees are excellent vehicles for the SEPAC to understand school decision making, while helping the School Committee understand the special education process and parent experiences to inform them in their deliberations. Building this type of collaborative relationship is vital to the success of any SEPAC.

There needs to be meaningful dialogue. Some SEPACs have voiced concerns that their School Committee failed to act on their findings. A strong and active SEPAC helps to bring legitimacy to the table. Relationships are key: SEPACs should work with principals, superintendents, department heads, curriculum directors, PTAs/PTOs, etc., anyone who may share the SEPAC’s interests. They must explore ways to build coalitions and realize that there may be many avenues to achieve their goals. MassPAC, one project at the Federation that works to educate and empower parents, holds regional training sessions to assist parents in this public advisory role, helping local SEPACs fulfill their statutory duty while becoming a positive force for change.

The Groton-Dunstable SEPAC has done a “bit of relationship building” over the past few years. A superintendent was open to meeting with PAC members, listened to their concerns, and wanted to work with them. Groton-Dunstable SEPAC representatives participated in the Facilities Task Force, two principal searches, and the committee to hire a new Pupil Personnel Services Director. They were invited to speak at all of the district schools’ back-to-school open house nights and to share their experiences as parents of children with special needs at a ‘New Teacher Mentoring’ workshop. Unfortunately, all of this hard work met a roadblock. At the annual business meeting last December only the four current officers showed up, no elections could take place, and the SEPAC has reverted to an inactive status.

To be successful advisors, SEPACs need to do their homework and provide concise information so School Committees will listen. A lot of the success generated by SEPACs is directly related to the amount of energy and time that officers/members have to contribute. Being a SEPAC leader comes with a great deal of personal sacrifice, but earning a seat at the table to advocate for students with special needs is priceless.

To learn more about MassPAC, call Leslie at 617-399-8307, e-mail leslie@fcsn.org, or visit www.fcsn.org

Federation Partners with Special Education Surrogate Parent Program

The Federation for Children with Special Needs and EDCO Collaborative are pleased to announce a new partnership for operating the Special Education Surrogate Parent Program (SESPP). The SESPP recruits, trains, and appoints volunteers to represent children who do not have a parent or guardian to represent their needs in school. It then matches each child with a knowledgeable “surrogate parent” (SESP) for the purpose of special educational decision-making. The Massachusetts Department of Elementary and Secondary Education has asked our two organizations to jointly implement the program. Each agency will be responsible for implementing certain aspects of the SESPP. The Federation will be responsible for volunteer recruitment, training and support of SESPs. The EDCO Collaborative will be responsible for student eligibility determination, SESP appointment, and case management. We look forward to a collaborative effort that will ensure quality volunteer appointments, communication with community partners, and positive educational outcomes for students. The Federation will be seeking parent volunteers to become involved with this program to serve as SESPs. If interested, please contact us at 617-236-7210 or 800-331-0688. Keep an eye out for SESPP updates and articles in future issues of Newsline. We will be sure to keep our readers informed about this exciting new collaboration.
The Federation for Children with Special Needs hosted its annual spring fundraiser “Gala 2011, Celebrating Every Child” on Friday, May 13, 2011, at the Seaport Hotel in Boston. Guests enjoyed a lovely reception and had fun bidding on hundreds of silent auction items, followed by dinner, music, and awards. This annual event is more than a fundraiser. It is a time to recognize and honor individuals whose work has made a difference in the lives of families raising children and youth with special needs and to celebrate the work of the Federation’s staff, Board of Directors, and volunteers.

Executive Director Rich Robison welcomed the more than 360 friends, families, staff, and other supporters of the Federation. Marjorie Clapprood, an iconic personality well-known in the Massachusetts political, healthcare, entertainment and philanthropic communities emceed the event. She set a warm, welcoming tone for the evening, stating that she was grateful for everyone’s attendance and “sponsorship of the Federation.” Marjorie noted that everyone there came, “for the very best of reasons, because the Federation’s programs make a world of difference and speak on behalf of those who have not yet found their voice.” On a personal note, Marjorie shared that she was grateful for the education the Federation gave her, which she has used in her advocacy efforts on behalf of children with special needs, including her grandson.

The Berkshire Hills Music Academy Performance Troupe entertained everyone with a fabulous selection of top 40s hits, Ray Charles classics, and a traditional Peruvian panpipe number. The audience expressed their enjoyment and appreciation with a standing ovation for the wonderful, rockin’ performance!

The Gala featured the debut of the Federation’s new public service announcement (PSA). This short film was produced by Redtree Productions. Boston Casting provided casting services. The piece is narrated by Marianne Leone Cooper and features the music of Susan Werner. Other contributors include John Doucette Film & Video, Video Express and Accomplice Edit. More than 30 local children and their families participated in the making of this PSA! If you have not yet had the pleasure of seeing this amazing, uplifting production, you can view it on the Federation’s Web site at www.fcsn.org.

Jim Whalen, President of the Federation’s Board of Directors, introduced the award presentations. He began with the President’s Award, which recognizes individuals who have made outstanding contributions to furthering the mission of the Federation. Betsy Anderson, co-founder of both the Federation and Family Voices, was this year’s honoree. Betsy, who has been a mentor to so many family leaders, began by thanking her mentors, colleagues, family, and friends. She shared some of her favorite touch points about the Federation and Family Voices. These included the work these two organizations have done to ensure individuals with disabilities and those assisted by medical technology have the health care they need to live at home with their families, attend school, and participate in community life. She acknowledged the presence of Julie and Katie Beckett from Iowa, and noted their monumental efforts, which led to the creation of federal waivers – the Katie Beckett waivers – that allow medically complex kids all over the country to live at home, rather than in hospitals or long term care facilities. Betsy went on to speak about the importance of health and wellness initiatives and the passage of national health reform. Lastly, she acknowledged the power of parent/ professional partnerships, data, and family stories as ways to share numbers and experiences with legislators and create change to make the world a “fair” place for our children. On her retirement this year, the Federation thanks Betsy for her efforts to make the world a better place for families raising children and youth with special needs. We wish her the very best as she transitions to this new phase of life.

Robin Foley received the Patricia Blake Advocacy Award in acknowledgement of the more than 20 years of commitment, caring, and mentorship she has provided to families. Robin thanked the Federation’s Board of Directors, and her Federation family for the honor. She credited her, “career in advocacy to her amazing daughter Lindsay,” and spoke about the importance of advocating for change, stating, “Righting a wrong is a risk worth taking.”

Martha Ziegler, a noted parent leader and the first Executive Director at the Federation, presented the Founders Award to Dr. David K. Urion for his commitment to serving children with special needs and their families, and for furthering the education and professional development of future leaders in the field of neurology. Dr. Urion said it was a “huge, humbling honor” and accepted the award with gratitude. He noted it was his good fortune to have colleagues who allowed him the time to explore work, which is off the beaten path. In closing, he thanked the Federation for being an inspiration, stating, “Every child born is infinitely precious. Benefit everyone, exclude no one.”

Following the awards, singer/songwriter/guitarist Natalia Zukerman, accompanied by Mona Tavakoli on percussion, gave a soulful, bluesy performance, including a live rendition of Susan Werner’s “My Different Son”, the ‘theme song’ for the Federation’s PSA.

At the conclusion of Natalia’s performance, Amy Robison drew the winning raffle ticket for the beautiful hand-made afghan donated by Ellen Hutt (won by Nicole Schraml!). Dr. Robison and Amy then thanked everyone for their support.

If you missed this year’s Gala due to a scheduling conflict, please visit our Web site at www.fcsn.org for pictures and video of the event. If you are looking forward to next year’s celebration, pencil the Federation in for May 4, 2012!
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Longfellow Sports Club
Loon Mountain Resort
Lucia Borges Art
Magic Beans
Mahoney’s Garden Center
Maine Narrow Gauge Railroad
Company & Museum
Marriott Boston Copley Place
Massachusetts Bay Lines
Massachusetts Museum of Contemporary Art
Sandra Mazur
Peg McGovern
Millenium Nails
Mint Julep
Mohegan Sun
National Amusements
National Baseball Hall of Fame
New England Aquarium
New England Comics
New England Oriental Rug Gallery
New Repertory Theatre
North End Market Tours
Padaria Brasil Bakery
Party Favors
Party Needs
Peabody Essex Museum
Plimoth Plantation
Providence Children’s Museum
Puppet Showplace Theatre
John and Lynn Reichenbach
Richies
Roche Brothers
Roon Das
S.A. Chrobak Photographic Artists
Sadhana Yoga
Sakonnet Vineyards
Randi and Pete Sargent
Shonda Schilling
Patricia Schram
Seaport Hotel
Shakespeare & Company
Sheraton Boston
Simon’s Shoes
Six Flags Friends
Six Gun City
Sky Zone Boston
SpeakEasy Stage Company
Starbucks Coffee
Sterling Golf Management
Story Land
Taste This Tours
Rhea Tavares
Ten Thousand Villages
The Benchmark Company
The Charles Hotel
The Coolidge Corner Theatre Foundation
The Doug Flutie Jr. Foundation for Autism
The Fireplace Restaurant
The Hall at Patriot Place Presented by Raytheon
The Irving House
The Land of Witches and Pirates
The Liberty Hotel
The Peartree of Brookline
The Picture Place
The Preservation Society of Newport County
The Sports Museum
Totally Wired Sculpture
Turtle Lane Playhouse
Wagner Jewelers
Walter’s Jewelers
Susan Werner
Westport Rivers Vineyard and Winery
Jim Whalen
Wheelock Family Theatre
Wicked Restaurant
Miriam Wiley
Winston Flowers
Yard House
Martha Zeigler
Zoo New England
**Family TIES: Parents Have Homework Too**

By Mary Castro Summers, Program Director, Family TIES of Massachusetts

Do you have mountains of paperwork that relate to your child’s medical and educational needs and community activities? Family TIES of Massachusetts knows it can be hard to manage all this information. Make this the autumn when you get yourself organized! You don’t have to wade through this process alone. We can help with this important task. Having the information you need - at your fingertips - will help you advocate for your child. Remember, you are your child’s most passionate advocate; you are the expert!

Family TIES offers “Let’s Get Organized,” a free workshop for parent groups. Parents have been telling us how relieved they feel when they finally figure out a way to manage important documents, and the piles of paperwork disappear from the house. Is it time you attended a session?

Our Regional Coordinators are happy to meet families at local parent or support groups, Special Education Parent Advisory Council (SEPAc) meetings, or at Early Intervention programs to present this workshop and share ideas and tips for getting your child’s paperwork in order. It sounds like a big job, but with a plan and an orderly system to get started, you too can be well on your way to compiling a binder (provided compliments of Family TIES) for current and important information and documents, with a filing system for everything else.

Contact your Regional Coordinator (number below) to let us know you are ready to get your homework done!

**New Staff**

We are pleased to announce that Maggie Wurm has joined our staff as our Western Regional Coordinator. Maggie is filling the vacancy that occurred when Gloria Klaesges changed roles and became our Statewide Parent-to-Parent Coordinator. We hope that families in western Massachusetts will call Maggie to say hello, and let her know how we can help. Call her at the Western Regional Department of Public Health Office at 413-586-7525.

**Parent-to-Parent Program**

Our Parent-to-Parent Program is very successful and we have seen a significant increase in requests for emotional support from families around the state. Would you like to become a Support Parent and help us to meet this increasing demand? We can never have too many parents who are willing to share their experiences with other parents of children and youth with a wide range of special needs.

Support Parents offer emotional support by phone. You would be asked to make two phone calls to a parent who has contacted us looking for a Parent-to-Parent match – someone they can talk to who understands the challenges they are facing. The process is easy, and it is rewarding to realize how far you’ve come in developing knowledge, expertise, and supportive listening skills.

If you are interested in this opportunity, please call your Regional Coordinator. We will invite you to an upcoming “Listening & Learning” training, the first step toward joining our corps of volunteers who enjoy the opportunity to share their experiences and help other parents to know we are not alone in caring for our children’s special needs.

Contact your Family TIES Regional Coordinator (phone numbers available on our Web site at www.massfamilyvoices.org) or call 1-800-905-TIES (8437). Keep in touch!

Family TIES of Massachusetts is a statewide information and parent-to-parent support project for families of children with special needs and chronic illness. Family TIES is a project of the Federation for Children with Special Needs, with funding from and in collaboration with the Massachusetts Department of Public Health. The program is administered by Parent Coordinators housed in each of the Regional Offices of the Massachusetts Department of Public Health.

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**Need help staying in your home?**

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- Providing loans up to $30,000
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More information: [www.mass.gov/mrc/hmpl](http://www.mass.gov/mrc/hmpl)

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New Funding
On May 17, 2011, the U.S. Department of Health and Human Services, Health Resources and Services Administration announced the new and continuing awards for the Family-to-Family Health Information Centers. The funding for these awards is through the Affordable Care Act. The Federation for Children with Special Needs is pleased to share that its Mass Family Voices project is one of the 51 awardees. We are thrilled to be able to continue to operate the Massachusetts Family-to-Family Health Information Center (MA F2F), which provides free, confidential assistance to families raising children and youth with special health needs around issues of health care financing, medical home, early and periodic screening, navigating community resources, transition, and family/professional partnership.

Save the Date: Joining Voices Conference
The MA F2F is pleased to be able to host its annual Joining Voices conference for families raising children and youth with special needs. This year’s event is:

Tuesday, November 15, 2011
Hoagland-Pincus Conference Center
Shrewsbury, MA

We are using the ideas that everyone shared in the pre-conference planning survey to plan this year’s event, and will offer workshops about social skills and friendships, taking care of the caregiver, technology, transition, and more. Visit www.massfamilyvoices.org for updates. Registration materials will be available the first week in September. If you have questions now, speak with Beth or Bonnie at the number below.

The MA F2F is a Virtual Gateway
Do you want to apply for MassHealth without the hassle of filling out the application? The MA F2F is a Virtual Gateway. Staff has access to the Massachusetts Executive Office of Health and Human Services Internet portal used to enter MassHealth applications on-line. If you want to apply for MassHealth on-line, or need to check your child’s account, help is just a signed Permission to Share (PSI) form away. Speak to Bonnie Thompson or Beth Dworetzky at the MA F2F for more information about how we can assist you.

Call the MA F2F at 800-331-0688, ext. 301, or e-mail Bonnie at bthompson@fcsn.org, e-mail Beth at beth@fcsn.org, or “visit” us at www.massfamilyvoices.org.

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Does your child have “party manners”? Do his teachers, health providers, and others in the community see a well-behaved child, but at home your child acts out and you deal with a different, difficult set of behaviors? Do you find yourself wishing you could show your professional partners your child’s “other side” so you can get help and advice, work together to develop a behavior plan, and be consistent in the strategies you use to manage your child? With a little help from the right technology, you can.

If you have a phone that takes video, a video camera, a flip video, or other video recorder, you can video your child during good times and bad. Record difficult behaviors to share with health providers, teachers, and other members of your child’s team, as well as record and share activities your child does well to demonstrate his strengths.

So, how do you know what device is best? Think about the answers to the following questions:

- What do you want to use the device for?
- How much do you want to spend?
- Does size matter?
- Do you care if the device has a USB port, a memory card, or needs a cable to hook into your computer or television? Talk to sales representatives at stores that sell video devices and read product reviews. Visit CNET reviews at www.cnet.com for reviews of digital cameras by manufacturer, price, size, and more.

Another benefit of purchasing a video device is that you can record your child’s therapy sessions or participation in community activities. Then, you can share the video with family members, friends, childcare providers, teachers, and others to show them any accommodations or modifications your child needs to be successful. This is a way for others to see the techniques used in a therapy session so everyone will be consistent in how they assist your child. You can also upload video of your child to YouTube (www.youtube.com) or Facebook (www.facebook.com) so family and friends who don’t see your child often can watch him in action.

Flip video cameras with USB connections are “plug and play.” You can plug the camera into your laptop or computer and the video will play. If the video has positive and negative behaviors, you can edit out the negative parts and show it to your child on the computer or television so they can see themselves on TV. This is a way to provide positive behavior support, as most kids love to see themselves on TV. All you need is an HDMI cable (you can pick one up at Target or Best Buy, etc.) to connect your laptop to your TV.

There’s an App for That
If you are confused by apps (applications), you are not alone. Not all apps work on all devices. You need to do your homework when it comes to apps. Read the reviews before you download an app to see if others like it, don’t like it, or if there are glitches. Many stores sell apps. Apple has an on-line store at www.itunes.com. And, there’s the Android App Market at https://market.android.com/. Make sure you know what you are downloading before you download it and that you trust the source. Technology is great, but it’s only useful if it meets your need for information, entertainment, education, and will run on your device.

Tablets
Tablet devices, like the Apple iPad2, Motorola Xoom, Blackberry Playbook, or Samsung Galaxy, with their Universal Design (systems that are designed for use by as many people as possible without modification) are helpful to many individuals with disabilities. Again, you really need to do your homework before purchasing a tablet, and www.cnet.com is a great place to read reviews and learn about the features of a particular tablet. Think about how you will use your tablet and check that the apps you want will run on your device. Additional questions to consider include:

- Is the tablet WiFi enabled?
- Do you need to pay for an additional data plan?
- Does the tablet tether to your 3G hotspot on your phone?
- Does it have an USB port? Do you need an USB port? Does it have a memory card?
- Can you connect a keyboard to it?

And, the list goes on and on, depending on how you plan to use your tablet.

Darla is the Director of the Early Intervention Parent Leadership Project (EIPLP) that helps families whose children participate in early intervention programs to develop lifelong leadership and advocacy skills. She loves technology and continually explores ways to use it to make information and support more readily available to families. Learn more about EIPLP at www.eiplp.org and contact Darla at darla.gundler@state.ma.us.

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**Becoming a Self-Advocate**

*By Cat Gogel*

Self-advocacy is not something that comes from out of the blue. In my opinion, there are two main reasons that individuals become self-advocates. The first is through something that personally affects us. The second is by learning from the people who have supported us along the way. In my life, dyslexia has been my struggle and my parents were the ones who helped and supported me.

When I was diagnosed with dyslexia at age 11, my parents had no idea what to do with this new label society had given me. This invisible disability had no affect on my physical appearance or how I spoke. However, it smeared the pages of my written work and blurred the texts I was asked to read. The school didn’t know what to do with my “label” either, and turned a blind eye to my needs. I was left on the sidelines in a game whose rules I did not understand.

I had no idea what I was supposed to do in school. Fortunately, my parents took up the reins. They sought out every possible form of help they could, and spoke to my teachers and the school principal. They worked out accommodations, but were also clear they were not setting up easy escapes for me. They still expected me to do my best and persevere. They helped lay out the ‘blueprint,’ but I would have to ‘build’ my own success.

My parents took on difficult situations with positive attitudes and a strong belief in my potential, for they could see it better than anyone else did. They always kept a smile, they never raised their voices, they made sure I met requirements using my strengths, and above all, they were honest. My parents shared what they learned and heard with me; they explained how meetings went and how they dealt with sticky situations.

Their honesty is what led me to discover the power of positive advocacy and how beneficial it can be when dealing with tough problems. Their honesty is what helped me gain confidence in my own voice, and it gave me the assurance that I could stand on my own.

My desire to advocate for myself stems from the difficulties I faced and continue to face. It stems from frustration and from the knowledge that I am more than dyslexic. It stems from my strong drive to see change, and to accomplish more for myself. All this drive however, would have been nothing but weeds without the help of my parents. They are the reason I have grown and become who I am today; they are the source of my confidence and the essential ingredients in my self-advocacy recipe. My parents realized early on that complaining leads to closed doors. It takes knowledge, reflection, and dialogue to make change. I keep these principles with me every day; they are the cornerstone of my advocacy.

Cat attends Boston College, where she is pursuing a double major in Human Development and Communication. When she graduates, she plans to put her education into action by working to raise awareness about disability issues. For the last year, Cat has been an intern for the MassPAC project at the Federation.

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**Off We Go! Series**


*Off We Go to the Dentist, Off We Go for a Haircut,* and *Off We Go to the Grocery Store* are the first three books in the charming *Off We Go!* series for children with special needs. Each page has a simple sentence that describes one step in each outing. The engaging illustrations by David Ryley clearly show the action described in the text. For example, in *Off We Go for a Haircut,* one page shows a child getting a hair wash; the next page shows the hairdresser toweling the child’s hair dry. These books help prepare children for each experience. The author, who has a child with an intellectual disability, includes ideas for using each book.

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Woodbine House has donated a copy of these books to the Federation. Call 617-236-7210, ext. 317 to make arrangements to borrow a book. See the Woodbine House catalogue at www.woodbinehouse.com.
SAVE-THE-DATE

Visit fcsn.org for more details about these and other events...

**Joining Voices**
*A conference for families raising children & youth with special healthcare needs*
Hoagland-Pincus Conference Center • Shrewsbury, MA
Tuesday, November 15, 2011
Learn more at www.massfamilyvoices.org

**Visions of Community**
Seaport World Trade Center • Boston, MA
Saturday, March 10, 2012

**Gala 2012**
Seaport Hotel • Boston, MA
Friday, May 4, 2012