Are you ready to start thinking about spring? If so, mark your calendars!

It's time for the Federation’s Annual Spring Gala and Silent Auction! “Gala 2012, Celebrating Every Child,” will be held on Friday, May 4th, 2012 from 6pm until 10pm. Please plan on joining us at the beautiful Seaport Hotel, located on Seaport Boulevard in Boston, for a fabulous evening!

The Annual Spring Gala is the Federation’s most important fundraising event of the year. This signature event features a fabulous silent auction, inspiring entertainment, and a host of honorees who will be recognized for their efforts in improving the lives of children with special needs by informing, educating and empowering their families.

We are thrilled to welcome as the emcee of this year’s event, Bianca de la Garza NewsCenter 5’s award-winning anchor and reporter! We are also pleased to honor three wonderful people who have inspired us, and who have furthered the work of the Federation in a variety of ways.

New York Times bestselling author of “The Best Kind of Different,” Shonda Schilling, a parent of a child with Asperger’s, will receive the Martha H. Ziegler

continues on page 9
Staff Updates:

New Arrivals
We are pleased to welcome Patti Hackett-Hunter, M.Ed., as the new Project Director for Mass Family Voices. In this role she will also direct and oversee activities of the Massachusetts Family-to-Family Health Information Center (MAFtoFHCIC). Patti has been an active family advocate for many years and has raised a son with significant disabilities. Her work on the national health care policy level includes serving as the co-director and founder of the Health Resources and Services Administration Maternal and Child Health Bureau Healthy & Ready to Work National Resource Center. Patti brings a variety of expertise in tools to empower families and to increase youth involvement in self-care management. She has a background in teaching regular and special education. Her belief is “What’s health got to do with it? Everything!” Welcome Patti!

The Federation’s Recruitment, Training, & Support Center for Special Education Surrogate Parents (RTSC) is excited to welcome our new Training and Support Specialist, Janie Crecco. Janie has over two decades of experience working with children as a Master’s Level Clinician, most recently on the Children’s Behavioral Health Bureau. She is also a certified Intensive Special Needs Teacher. Janie’s experience is invaluable support to our volunteers across the state. Welcome Janie!

The Parent Training and Information Center at the Federation welcomes Jun Yu Ou (Susan) as our new Outreach Coordinator to the Chinese Community. Susan speaks Cantonese and Mandarin and is able to broaden the outreach in her community. She has a Masters of Management from Cambridge College and an undergraduate degree in Law. Susan brings a unique understanding of Chinese special education students in the Boston area. She has provided one-on-one tutoring to students with multiple disabilities, and has completed the Federation’s Parent Consultant Training. Susan looks forward to helping parents from her community through the special education process in school. Welcome Susan!

Fond Farewells
This past August, Janet Vohs retired after 34 years of tireless effort on behalf of Massachusetts’ students and families. Janet retired as Director of Publications for the Massachusetts Parent Information and Resource Center (MassPIRC) here at the Federation. In that role, she consistently produced high quality publications covering a wide range of important topics written in easily accessible language. Prior to working for MassPIRC, Janet worked on the Parents Engaged in Education Reform (PEER) project, and was longtime editor and author for the Federation’s “Coalition Quarterly” newsletter. Janet’s work has been instrumental in making the Federation what it is today. We extend our deepest gratitude to her for all the work she has done, and wish her a joyful and healthy retirement.

The Federation’s Boston office to inform us. If you wish your name to be withhold, please call or write the Federation’s Boston office to inform us.

The views and opinions herein do not necessarily reflect views or policies of the U.S. Department of Education, or of the Federation for Children with Special Needs. Ads herein do not constitute endorsement by the Federation for products, services, or organizations.

Newssline and its contents are copyrighted by the Federation for Children with Special Needs; some material may carry other copyrights as well (noted where appropriate). Permission is granted to quote from us at length, while giving credit to Newssline, a publication of The Federation for Children with Special Needs (and original author, if appropriate).

Newssline’s mailing list may occasionally be made available to organizations in which we believe our readers may have interest. If you wish your name to be withheld, please call or write the Federation’s Boston office to inform us.

The Federation for Children with Special Needs

Our Mission:
To provide information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

Board of Directors:
James Whalen, President
Michael Weiner, Treasurer
Miriam Wiley, Clerk
Deborah Allen
Emanuel Alves
Sarah Commerford
Dan Heffeman
Anne Howard
Joseph Petner
John Reichenbach
Randi Sargent
Patricia Schram
Director Emeritus: William Henderson

Follow the Federation’s webinar series on Transition, with Terri McLaughlin and Leslie M. Leslie

The next webinar, Making Transition Happen: Goals, Supports & Services will be held on Wednesday, April 25 from 12 -1 PM. Bring your headphones to work and listen during lunch. To register contact leslie@fcsn.org for information on how to sign up for this free webinar.

Also check out the Federation’s website for prior recorded webinars on transition:
September 16, 2011 - Discussing Transition Services at an IEP Meeting
February 8, 2012 - Transition Assessments: Key to Transition Goals
From the Executive Director

How long is 40 years? Long enough to make a real change!

In 1972 . . .

• The average price of a new home was $27,550.
• The first scientific hand-held calculator (HP-35) was introduced (price $395).
• Five White House operatives were arrested for burglarizing the offices of the Democratic National Committee, setting in motion the Watergate Scandal.
• Massachusetts Special Education Law, Chapter 766, was signed by Gov. Sargent. It was the first non-categorical law guaranteeing all children the right to a free appropriate public education (codified at M.G.L c. 766), and served as the model for the first federal special education legislation.
• The Federation for Children with Special Needs was born out of the Coalition to Pass Chapter 766 in order to ensure that parents of children with special needs would be able to exercise their new rights. The Federation incorporated as a non-profit organization in 1974.

Former Massachusetts Director of Special Education, Mary-Beth Fafard described Chapter 766 as among the major legislative changes with the potential to deal effectively with growing concerns about special and general education in the state. She wrote, “In 1972 the educational services provided by the Commonwealth of Massachusetts for students with disabilities could best be described as fragmented, underfunded, highly segregated, unreliable, and driven by professional interest. Three thousand students with mental retardation had been placed in large state institutions where they were receiving minimal educational support. Public schools were unclear about their responsibility to educate students with disabilities and, too often, had insufficient numbers of professionals, programs, and classrooms to provide the necessary services. A shared sense of alarm about these educational conditions united parents, teachers, legislators, and advocates to work together to create Chapter 766.”

Chapter 766 was hailed as a national model for meeting the educational needs of children and youths with disabilities, and was the basis for the development of the Federal Law known as IDEA (the Individuals with Disabilities Education Act). The basic tenets of the law were praised as progressive, if not revolutionary, in remedying past inadequacies and inequities. Within 20 years, the results of the law’s implementation were impressive. Of all students with special needs, 96.5% received educational services in public schools, only 3.5% attended private day or residential programs, and no students with mental retardation under the age of 21 were placed in state institutions. These conditions were achieved even while fiscal support for education in the Commonwealth was slowly diminishing.

How long is 40 years? It seems a lifetime, but look at how much has been accomplished.

Happy 40th Birthday Chapter 766!

Rich Robison
Executive Director

Make a Difference . . . in a Student’s Life.
Become a Special Education Surrogate Parent.

• Are you a parent of a child with special needs?
• Are you an education professional or student looking for a one of a kind experience?
• Do you have experience with the IEP process?
• Can you commit 10-20 hours a year to make a difference in the life of one of our state’s neediest children?

If you answered yes to any of these questions, you might like to volunteer as a Special Education Surrogate Parent (SESP). SESPs make educational decisions for children in state custody whose parents cannot. They attend Team meetings, sign IEPs, and monitor the child’s progress with the full legal authority of a parent to make special education decisions. To learn more, contact the Recruitment, Training, and Support Center for Special Education Surrogate Parents by calling (617) 236-7210, emailing rtsc@fcsn.org, or check out our website at www.fcsn.org/rtsc.
MassHealth Do’s and Don’ts

By Beth Dworetzky

MassHealth is the name of the Massachusetts Medicaid programs. There are many different MassHealth coverage types. Eligibility for a particular coverage type depends, in part, on:

- Family size and family income in relation to the federal poverty level (FPL)
- Access to other health insurance
- Disability status of a family member, and
- Citizenship status of the applicant.

Individuals can qualify for a wide range of MassHealth covered services based on financial need. In addition, if family income is too high, individual family members can be eligible for MassHealth based on their medical, developmental, and behavioral health needs. MassHealth is a comprehensive health benefit, and can be a great way to help pay for needed health services, even if you have other health insurance. However, it can be difficult to understand eligibility, the application process, and any costs associated with MassHealth for a child with a disability. Below are some DO’s and DON'Ts for navigating the MassHealth system.

DON'T assume your family income is too high for a child with a disability to be eligible for MassHealth – even if you have other health insurance. MassHealth CommonHealth provides a comprehensive set of health services for individuals with disabilities, regardless of income.

DON'T panic if you have applied for MassHealth for a child with a disability and you receive a letter saying your child does not qualify because your family income is too high. All this means is that your gross annual family income is more than 150% FPL (more than $33,528 for a family of four) so you don’t qualify for MassHealth Standard. If you completed a MassHealth Child Disability Supplement and MassHealth Medical Records Release forms for each health provider your child sees, the MassHealth Disability Evaluation Services unit will perform a disability determination for your child so he or she can get MassHealth CommonHealth based on medical need.

You will pay a monthly premium for MassHealth Commonhealth for your child. If the premiums are not less than your monthly out-of-pocket expenses, or do not get your child health services that are not covered by any other insurance you may have, DO call and cancel the policy. DON'T assume you will not have to pay the premiums just because you never use the policy. You are responsible for paying the premiums.

If you have other health insurance, and you pay at least part of the premiums, DO call the MassHealth Standard/CommonHealth Premium Assistance (MSCPA) program to see if you can get some financial assistance towards the other health premiums you pay. Note: The CommonHealth premium structure is two-tiered. When you use Commonwealth as a secondary payer to other health insurance, you pay a “supplemental” premium. However, if your other insurance is eligible for MSCPA, you will pay the full cost of the Commonwealth premium. So, it will seem like your premium increased. The number for the MSCPA program is (800) 862-4840, ext. 7.

DO call the Massachusetts Family-to-Family (F2F) Health Information Center for free, confidential assistance navigating the MassHealth system. Staff can explain your child’s eligibility, the application process, provide an estimate of CommonHealth premium you can expect to pay, and can help you identify the things you need to think about in order to make an informed decision about CommonHealth for a child with a disability. Contact the F2F at (800) 331-0688, ext. 301 or visit www.massfamilyvoices.org.

Personal note: It has been my honor to direct the Massachusetts Family-to-Family Health Information Center. I have enjoyed speaking with, meeting, and helping the thousands of families who have called for assistance, attended workshops, and attended the annual Joining Voices conference. I am proud to have worked alongside the dedicated Federation staff that work tirelessly on behalf of families raising children with special needs and our professional partners. Recently, I have accepted an opportunity to work on a national project dedicated to financing of care for children and youth with special health needs, a subject about which I am passionate. I leave knowing the knowledgeable and compassionate F2F staff will continue to provide excellent assistance. - Humbly yours, Beth Dworetzky

Their Quality of Life is at the Center of Our Family Supports

When you have a loved one with a disability, the Family Support Centers of Seven Hills Family Services make a measurable difference in the quality of life for your entire family by providing the support they need to live full and rewarding lives, including:

- Family Support Specialists
- Information & Referral
- Trainings in English & Spanish
- Comprehensive Education
- Training Library
- Respite Care

For more information, please contact Robin Foley at 508.796.1850 or rfoley@sevenhills.org

Seven Hills Family Services

www.sevenhills.org
What Happens When Discipline at School Leads to Lost Time in the Classroom?

By Michelle Moor, Esquire

It is upsetting for any parent to learn that their child has been involved in a disciplinary incident at school, but for parents of children with special needs school discipline can raise unique concerns. What if a child is being disciplined for behaviors that are not willful, but rather are the result of their disability? Parents may also wonder whether their child is entitled to receive special education services during a disciplinary suspension, or they may feel frustrated when a school district repeatedly disciplines their child but is not willing to provide the services needed to prevent the behaviors from recurring. While school personnel can discipline children with special needs, federal law offers important protections when a child is removed from their program for more than ten school days during the course of the school year.

“Short Term” Removals. If a child with special needs violates the code of conduct, a school district may remove the student from his or her classroom for up to ten school days during the year.

There are two important things for parents to consider when their child has been removed from their classroom on a short-term basis for disciplinary reasons. First, parents can and should request their child’s IEP Team to convene to discuss the incident that led to the need for discipline, and to determine whether changes need to be made to the child’s IEP to avoid another infraction. For example, parents might ask for the school to conduct a functional behavioral assessment or to add social skill, behavioral and/or counseling support to the IEP.

Second, parents should keep track of the amount of time their child has been removed from their classroom for disciplinary reasons during the year. If a school district removes a child from their program for ten school days during the year due to code of conduct violations, then a “change in placement” has occurred triggering the federal protections described below.

Removals Totaling 10 School Days or More. Removal from the classroom, including “in school suspensions,” for ten school days or more can mean either ten consecutive school days, or a series of disciplinary actions that constitute a pattern of removals that total ten school days cumulatively. Either way, once a child has been out of his or her classroom for ten school days or more due to disciplinary reasons, members of the Team must meet to make a “manifestation determination.” The purpose of a manifestation determination meeting is to decide whether the student’s conduct was caused by, or substantially related to, the student’s disability and to consider whether the conduct was the result of the school district’s failure to implement the IEP.

If a child’s violation of the code of conduct is determined to have been substantially related to the child’s disability, then the school district must conduct a functional behavioral assessment and implement a behavioral plan, or if this has been done previously, modify the behavioral plan and IEP. The school district must also allow the child to return the classroom, or if parents agree, to a new placement.

If the violation is determined not to have been related to the child’s disability, or a failure to implement the IEP, then school personnel can discipline the student in the same manner that a typically developing student would be disciplined for the same offense, including expulsion.

However, students with special needs are entitled to continue receiving services from their school district when they are removed from their classroom for ten school days or more regardless of the punishment they receive and even if they are expelled. In other words, a school district must continue to provide adequate services to allow a child to make progress toward their IEP goals any time the child is out of school for more than ten days due to disciplinary reasons.

Serious Offenses. There are three “special circumstances” when school personnel can immediately remove a special needs student from their classroom and place them in an interim alternative education setting for up to 45 school days before conducting a manifestation determination hearing. These three circumstances are when a child: (1) carries or possesses a “weapon” to school; (2) possesses, uses or sells “illegal drugs” during school or at school related function; or (3) causes “serious bodily harm” to another person. The terms weapon, illegal drug and serious bodily harm are each defined by federal law, thus school districts cannot substitute their own definitions of what they think these terms should mean. Under each of these three scenarios, the child’s Team must meet to determine where the 45 day interim alternative educational setting will be. Parents also have the right to appeal any decision related to a manifestation determination hearing or a 45 day placement to the BSEA, and to have their appeal heard in an expedited time frame.

Finally, parents of students who have not been deemed eligible for an IEP should be aware that they can also assert these protections if the school district has knowledge that their child may have a disability.

Michelle Moor is an Associate at Kotin, Crabtree, and Strong, LLP, a general practice law firm in Boston, MA. She concentrates with several colleagues in special education and disability law. Michelle can be reached at kcs@kcslegal.com

Need help staying in your home?
The Home Modification Loan Program provides loans to make access and/or safety modifications to the homes of elders and individuals with disabilities

- Providing loans up to $30,000
- Is not based on credit history
- The interest rates are 0% or 3% depending on your household income
- In most cases, homeowners qualify for the 0% loan

More information: www.mass.gov/mrc/hmlp
617-204-3739
Consejos para navegar el sistema de MassHealth

Por Beth Dworetzky

MassHealth es el nombre de los programas de Medicaid de Massachusetts. MassHealth ofrece muchos tipos de cobertura diferentes. Los requisitos para cada tipo de cobertura dependen en parte de:

- el tamaño y los ingresos de la familia en relación con el nivel federal de pobreza (FPL, por sus siglas en inglés),
- la disponibilidad de otros seguros de salud,
- si en la familia hay alguna persona discapacitada, y
- la situación de ciudadanía del solicitante.

Una persona puede reunir los requisitos para una amplia gama de servicios de MassHealth por su situación económica. Además, si los ingresos de la familia son demasiado altos, cada miembro puede tener derecho a recibir servicios de MassHealth en base a sus necesidades médicas, del desarrollo y de salud conductual. MassHealth es un beneficiado de salud integral que puede ayudarle a pagar los servicios que usted necesita, aunque tenga otro seguro de salud. Pero los requisitos, el proceso de solicitud y los costos relacionados con MassHealth para niños con discapacidades pueden ser difíciles de comprender. A continuación, le ofrecemos algunos consejos para navegar el sistema de MassHealth.

Si tiene un hijo con una discapacidad, no suponga que los ingresos de su familia son demasiado altos para cubrir los requisitos de MassHealth, aun si tiene otro seguro de salud. MassHealth CommonHealth ofrece una amplia gama de servicios de salud a las personas con discapacidades sin importar sus ingresos.

Si ha solicitado MassHealth para un niño con una discapacidad y recibe una carta diciendo que él o ella no reúne los requisitos porque los ingresos de su familia son demasiado altos, no lo preocupe. Eso simplemente quiere decir que los ingresos brutos anuales de su familia exceden el 150% del nivel federal de pobreza (más de $33,528 para una familia de cuatro) y que, por lo tanto, no reúne los requisitos para MassHealth Standard. Si usted ha completado un suplemento por discapacidad infantil de MassHealth (“MassHealth Child Disability Supplement”) y formularios de autorización para que cada profesional de la salud que haya atendido a su niño comparta información de sus historiales médicos con MassHealth (“MassHealth Medical Records Release Form”), la unidad de evaluación de discapacidad de MassHealth (“MassHealth Disability Evaluation Services”) tomará una determinación de discapacidad para que su hija o hijo pueda estar cubierto por MassHealth CommonHealth por razones de necesidad médica.

Usted deberá pagar una prima mensual de MassHealth CommonHealth para su niño. Si las primas exceden los gastos mensuales que usted paga de su propio bolsillo, o no le consiguen a su niño servicios de salud no cubiertos por otros seguros que usted tiene, llame y cancele la póliza. No suponga que usted no tiene que pagar las primas simplemente porque nunca utiliza la póliza. Usted es responsable de pagar las primas.

Si usted tiene otro seguro de salud y paga una parte de la prima, llame al programa de asistencia “MassHealth Standard/CommonHealth Premium Assistance (MSCPA)” para averiguar si pueden ofrecerle ayuda financiera para cubrir una parte de dichos pagos. Nota: CommonHealth tiene una estructura de primas de dos niveles. Cuando usted utiliza la cobertura de Commonhealth como fuente de pago secundaria, es decir, después de otro seguro de salud, debe pagar una prima “suplementaria”. Pero, si el otro seguro reúne los requisitos para la ayuda de MSCPA, usted deberá pagar todo el costo de la prima de Commonhealth. Por lo tanto, parecerá que su prima ha aumentado. El número de teléfono del programa MSCPA es (800) 862-4840, ext. 7.

Llame al centro de información del programa de familia a familia (“Massachusetts Family-to-Family Health Information Center”, también conocido como F2F) para recibir ayuda gratuita y confidencial para navegar el sistema de MassHealth. El personal puede explicarle los requisitos para su niño y el proceso de solicitud, el costo estimado de la prima de CommonHealth que a usted le correspondería pagar, y puede ayudarle a identificar las cosas que debe tener en cuenta para tomar una decisión informada con respecto a CommonHealth para un niño con una discapacidad. Póngase en contacto con el Centro de información del programa de familia a familia (F2F) llamando al (800) 331-0688, ext. 301, o visitando la página web www.massfamilyvoices.org.

Nota personal: Ha sido un gran honor para mi dirigir el Centro de información de salud de familia a familia de Massachusetts. He disfrutado hablando, reuniéndome y ayudando a las miles de familias que llamaron buscando ayuda o asistieron a talleres y a la conferencia anual “Joining Voices” (Uniendo nuestras voces). Me enorgullece haber colaborado con el dedicado personal de la Federación, que trabajaba incansablemente en nombre de las familias de niños con necesidades especiales, y con nuestros asociados profesionales. Recientemente, he aceptado la oportunidad de trabajar en un proyecto nacional cuya misión es financiar la atención de niños y jóvenes con necesidades especiales de salud, un tema que me apasiona. Dejo mi presente puesto de trabajo sabiendo que el conocedor y compasivo personal del Centro seguirá brindando un servicio de ayuda excelente a nuestras familias. - Humildemente suya, Beth Dworetzky

Marilyn Gutierrez fue honrada por la Oficina de Programas de Educación Especial (OSEP)

El 12 de diciembre, recibió el reconocimiento de su contribución del glosario en español con el apoyo de OSEP. Marilyn representó a la Federación para Niños con Necesidades Especiales en colaboración con otros tipo de formación para padres IDEA y Centros de Información y Centros Comunitarios de Recursos para Padres, así como las escuelas, distritos, estados, educadores y otros profesionales de habla hispana que sirven a las familias de niños con discapacidades. Glosario www.depARENTcenters.org/glossary/glossary.html
Marilyn Gutierrez honored by the Office of Special Education Programs (OSEP)

On December 12th, Marilyn Gutierrez received recognition of her contribution to the Spanish Glossary supported by OSEP. Marilyn represented the Federation for Children with Special Needs in a collaboration with other IDEA Parent Training and Information Centers and Community Parent Resource Centers, as well as schools, districts, states, educators and other professionals. Spanish-speaking families of children with disabilities are encouraged to use the OSEP Spanish Glossary www.neparentcenters.org/glossary/glossary.html to:

- Eliminate any variances in translations of these terms within their information and training materials;
- Familiarize families with these terms so that they can be effective decision-makers in their children’s lives; and
- Ensure that Spanish-speaking families will have access to information and materials that use consistent terms, when they move from state to state or community to community.

With broad usage, this resource will help families better understand the language of special education and early intervention – a critical component of effectively partnering with professionals and advocating for improved outcomes for their children.

The right of parents to participate in educational decision-making is central to the Individuals with Disabilities Education Act (IDEA). However, many parents are limited in their ability to exercise this right by a lack of understanding of the educational and legal terminology included in IDEA. This is an especially significant challenge for parents of children with disabilities who are not native English Speakers. The Spanish Glossary helps ensure that educational terms related to the implementation of IDEA are translated in a uniform and comprehensible way across states, geographical regions, and communities of Spanish speakers. Thanks Marilyn!

Parent Advisors Take their Experiences to a Higher Level

By Mary Castro Summers, Family TIES of Massachusetts

Marketing research has shown that informed decision-making is key to providing the kinds of services that best meet the needs of consumers. Community, state, and federal agencies and programs that enrich the lives of families and individuals with special needs are no different. They need to be informed too in order to provide the best services for their consumers. Have you considered becoming a Parent Advisor, to share your voice?

Our unique experiences, influenced by the individuality of our child’s needs and the communities that support us, are important to budget-conscious agencies and organizations that need to provide meaningful services to our families. Consider the input you give your child’s medical and educational teams’ about your child’s strengths and needs. Effective parent-professional partnerships lead to operative support plans for your child.

Take your expertise to higher levels to guide the development of services for many more children and families. There are many opportunities to participate as a Parent Advisor, depending on your specific interests, available time, and resources.

- Networks related to your child’s special needs: Learn and share with support groups, online communities, or national organizations to provide education and emotional support, and possibly engage a research community around a specific disability.
- Parent advisory groups: Help to inform local and statewide services, including Early Intervention, school districts, and the medical service providers who care for your child. Do you have a specific interest or area of expertise? If so, join educational advisory councils or ask your pediatrician or hospital about parent advisory groups.
- National networks: One such network is Family Voices, a grassroots organization that seeks to ensure access to family-centered care for all individuals with special healthcare needs and/or disabilities. Its activities bring awareness on a national level, thanks to the involvement of parents just like you.

Family TIES of Massachusetts’ Share Your Voice! Program provides parent advisory support to its funder, the Massachusetts Department of Public Health. Parents may participate in focus groups, surveys, and/or advisory committees. Activities, one-time or continuing, offer parents an opportunity to inform interested groups about the impact on your family of a child’s special needs.

Our Parent-to-Parent Program relies on trained volunteer parents, who share their unique parenting experiences with others who want to talk about their emotional and strategic joys and challenges. This rewarding opportunity relies on your family wisdom, and brings satisfaction in realizing the rewards of your caring for your child’s needs. Matches are based on the specific areas of interest of the participating parents.

Family TIES of Massachusetts is a parent-led program that offers information and referral services and trainings through its six Regional Parent Coordinators, as well as emotional support through our Parent-to-Parent Program. We are parents, too, and take into account our own experiences as we listen and support your needs. Not sure who to call: THINK PINK - contact our toll-free line, (800) 905-TIES (8437), or visit our website, www.massfamilyties.org.
Development Corner: Support Our Work, In Your Community

Are you looking for other ways to support the Federation? Here are some ideas that might be of interest to you!

- **Donate new arts and crafts supplies or age appropriate books**: The Federation’s *Visions of Community* Conference is coming up on March 10, 2012. Every year, the Federation provides childcare for approximately 30 children while their parents enjoy a full day of informative workshops and networking opportunities at the conference. Additionally, many Federation staff members run support groups during which childcare is provided. You can help the Federation by donating new books (appropriate for ages 3yrs to 12yrs) as well as arts and crafts supplies (crayons, markers, paper, glue, glitter, etc.). This would be a great community service project for your workplace, neighborhood, or family to participate in!

- **Help the Federation while achieving your daily, personal goals**: The Federation has recently partnered with 1purpose (www.1purpose.com), an organization that helps individuals connect their personal goals with donating to their charity of choice. Whether your goal is to train to run that 5K race you’ve always wanted to run, lose those few extra holiday pounds, or simply get more organized at home or work, through 1purpose, you can accomplish your goals while helping the Federation. Check it out and join Team Federation today!

- **Hold your own fundraiser or “friends event” for the Federation!** Organize a neighborhood car wash, get a group of friends together and invite Federation staff to come and speak, or make the Federation the beneficiary of a local community service event.

- **Spread the word!** Join the conversation with other families through our social media channels! Check out the Federation’s Facebook page, follow us on Twitter, and view our videos on YouTube. Add your thoughts, comments and “perspectives”, on the Federation’s newly launched blog, “Perspectives, What Matters to Us.”

For more information on these and other ways to support and be involved with our mission, contact the Development Office at 617-236-7210, ext. 374 or by email at mjerz@fcsn.org.
Save-the-Date: Gala 2012
Celebrating Every Child (continued from page 1)

Founders Award. Ms. Schilling will be honored for sharing the story of her family’s journey in understanding their son’s diagnosis of Asperger’s Syndrome, and in doing so, helping other parents of children with disabilities know and understand that they are not alone in their struggles.

And finally, the Patricia Blake Advocacy Award will be presented to Joseph Petner, Ph.D., retired principal of the Haggerty School in Cambridge, adjunct faculty member at Lesley University and Wheelock College and mentor for the School Network for Innovative Principals, for his life-long dedication to inclusive schools.

Our President’s Award will be presented to Peter Brennan, former Federation Board member and partner at PricewaterhouseCoopers in Boston, for his seventeen-year commitment to furthering the work of the Federation through his Board service.

Visit www.fcsn.org for event updates on entertainment, silent auction items, and more! If you are interested in helping sponsor the event, donating to the silent auction, purchasing individual tickets or a table, or advertising in the event’s program book please contact Maureen Jerz, Director of Development, at 617-236-7210, ext. 374, or e-mail mjerz@fcsn.org. We hope to see you there!

The Federation is seeking individual and corporate sponsorships for this event, as well as silent auction items! To become a sponsor, or donate to the silent auction please contact Maureen Jerz at 617-236-7210, ext. 374, or by email at mjerz@fcsn.org.
O Que Fazer e O Que Não Fazer em Relação ao MassHealth

Por Beth Dworetzky

MassHealth é o nome dos programas do Medicaid de Massachusetts. Existem vários tipos diferentes de cobertura do MassHealth. Eligibilidade para um tipo particular de cobertura depende, em parte, de:

- Tamanho da família e renda familiar em relação ao nível federal de pobreza (FPL)
- Acesso a outros seguros de saúde
- Estado de deficiência de um membro familiar, e
- Status de imigração do aplicante.

Os indivíduos podem se classificar para uma vasta gama de cobertura dos serviços do MassHealth tendo como base as necessidades de ordem financeira. Além disso, se a renda familiar for muito alta, cada membro da família pode ser elegível para o MassHealth, tendo como base as suas necessidades médicas, de desenvolvimento e de comportamento. O MassHealth é um benefício médico abrangente, e pode ser uma ótima maneira de ajudar no pagamento de serviços médicos necessários, mesmo que você possua outros seguros de saúde. Entretanto, pode ser difícil de entender a elegibilidade, o processo de candidatura, e os custos associados ao MassHealth para uma criança com deficiência. Abaixo encontram-se algumas coisas a FAZER e a NÃO FAZER para navegar-se no sistema do MassHealth.

NÃO assuma que a sua renda familiar seja muito alta para que uma criança com deficiência seja elegível para o MassHealth – mesmo que você possua outros seguros de saúde. O MassHealth CommonHealth fornece um conjunto de serviços de saúde para indivíduos com deficiência, independente da renda.

NÃO entre em pânico se você se candidatou ao MassHealth para uma criança com deficiência e recebeu uma carta dizendo que o seu filho não está qualificado por que a renda de sua família é muito alta. Isto tudo significa que a renda bruta familiar anual é maior do que 150% FPL (mais de $33.528 para uma família de quatro) por isso você não está qualificado para o Padrão do MassHealth. Se você preencheu os formulários de um Suplemento de Deficiência Infantil do MassHealth e de Liberação dos Registros Médicos do MassHealth para cada médico que seu filho visita, a unidade de Serviços de Avaliação de Deficiência do MassHealth apresentará uma determinação de deficiência para que seu filho ou sua filha possa obter o MassHealth CommonHealth, baseando-se na sua necessidade médica.

Você pagará ao MassHealth Commonhealth um prêmio mensal para a sua criança. Se os prêmios não forem menos do que as despesas desembolsadas por você mensalmente, ou não oferecerem ao seu filho os serviços de saúde que não estejam cobertos por qualquer outro seguro de saúde, você terá talvez que CHAMAR e cancelar a apólice de seguro. NÃO assuma que você não terá que pagar os prêmios simplesmente por nunca ter usado a apólice. Você é responsável pelo pagamento dos prêmios.

Se você possui outro seguro de saúde, e paga pelo menos parte dos prêmios, CHAME o (MSCPA), programa de Assistência ao Prêmio do CommonHealth/Padrão MassHealth para ver se pode receber assistência financeira em relação aos outros prêmios de saúde que você paga. Nota: A estrutura do prêmio do CommonHealth é dupla. Quando você usa o CommonHealth como um pagador secundário de outros seguros de saúde, você paga um prêmio “suplementar”. Entretanto, se o seu outro seguro for elegível ao MSCPA, você pagará os custos totais do prêmio CommonHealth. Então, parecerá que se o seu prêmio tenha aumentado. O número de telefone do programa MSCPA é: (800) 862-4840, ext. 7.

CHAME, através de ligação gratuita, o Centro de Informação de Saúde de Família a Família de Massachusetts (F2F), assistência confidencial de navegação, do sistema MassHealth. Os funcionários podem explicar a elegibilidade de seu filho, o processo de inscrição, providenciar uma estimativa do prêmio CommonHealth que você espera pagar, e podem ajudar que identifique as coisas que necessita refletir para tomar uma decisão baseada em informação sobre o CommonHealth para uma criança com deficiência. Entre em contato com o F2F no (800) 331-0688, ext. 301 ou visite o www.massfamilyvoices.org.

Nota pessoal: Tem sido para mim uma honra dirigir o Centro de Informação de Saúde de Família a Família de Massachusetts. Tenho me afeiçoado ao falar, encontrar e ajudar milhares de famílias que têm chamado para obter assistência, participar de treinamentos, e participar na conferência anual do Juntando as Vozes, Joining Voices. Estou orgulhoso de ter trabalhado juntamente com a dedicada equipe de funcionários da Federação que trabalha incansavelmente a favor das famílias que criam filhos com deficiências especiais e com os nossos parceiros profissionais. Recentelemente, eu aceitei uma oportunidade de trabalhar em um projeto nacional, dedicado ao financiamento de cuidados de crianças e jovens com necessidades especiais de saúde, um assunto do qual tenho enorme paixão. Eu parto sabendo que a equipe do F2F, sabia e cheia de compaixão, continuará a fornecer uma assistência excelente. - Sua mais humilde, Beth Dworetzky.

MassCARE Update

MassCARE is a statewide program for women, families, and adolescents funded by the Massachusetts Department of Public Health. The Coordinator for Women and Families (CWF) is a Federation staff person who provides technical assistance and support for consumers, peers, and staff at five Massachusetts sites. The CWF facilitated a women’s workshop, “Matter of the Heart,” on December 16, 2011 at the UCC conference center in Framingham. Women from three sites (Lawrence, Lowell, and Springfield) came together to learn about cardiac health. The workshop was presented by Healing our Community Collaborative (HOCC) and their Women’s Healthy Eating and Living team. Lively discussion, affirmations, and mutual support completed this day of important learning. Matters of the Heart, Part 2 was presented in Lawrence on February 1. The follow up workshop focused on heart healthy relationships.
“The principal called.” Those three words have struck fear in the hearts of children and adults alike for generations. That fear is the result of the traditional approach to dealing with challenging student behavior. Namely, action is taken when students violate the code of conduct, and their behavior is largely ignored when they follow it. Yet the no-news-is-good-news approach to managing behavior shortchanges many students. In the last few decades, researchers, therapists, and educators have learned to proactively teach students to behave in ways that can improve their academic performance, social success, and emotional well-being. The first step, once a problematic behavior has been identified, is to conduct a Functional Behavioral Assessment (FBA). This article – the first of a two part series – briefly discusses what an FBA is, and when it should be considered by the IEP (Individualized Education Program) Team. The second will explore a variety of behavioral supports, and how to implement them effectively.

An FBA assumes that all behaviors serve a purpose, and happen in a specific context. The purpose, or function, of a given behavior can be to communicate something, to avoid something unwanted, or to get something the student wants. It may be unclear, even to the student, what purpose a behavior serves, but the Team must never assume that a behavior is meaningless, or that its function is invalid. Rather, the Team should come up with a best guess, or hypothesis, about what function a problem behavior serves. The Team should also examine the context of the problem behavior for any clues to its causes and triggers. Using this information, the Team can create a Behavior Intervention Plan (BIP) to positively support the student’s skills and/or motivation to substitute a more appropriate behavior that serves the same function as the problem behavior. If the behavior is the result of a skill that is lacking, the Team can work together to build the skill that can negate the inappropriate behavior.

In 1997, Congress made FBAs and BIPs mandatory, in certain circumstances, for students receiving special educational services. Specifically, FBAs and BIPs are required when a student’s behavior results in 10 or more days of suspension in a single academic year, and that behavior is determined to be a manifestation of that student’s disability. A well-done FBA and BIP can not only minimize or eliminate many problem behaviors, but contribute lasting gains to a student’s academic and social success, not to mention emotional well-being. Too often, however, FBAs are viewed as a last (or second to last) resort rather than as a proactive instructional tool. A struggling student with a good disciplinary record might benefit from positive behavioral supports; they might even help prevent future disciplinary issues. If an FBA does result from disciplinary concerns, it should not only focus on a particular disruptive behavior, but should also include a wider range of behavioral supports to benefit the whole child.

Typically, a student whose behavior is disruptive or aggressive (therefore likely to lead to suspension) will be referred for a FBA, while the student who is withdrawn and non-responsive will not. However, Section 614(d)(3)(B)(i) of the Individuals with Disabilities Education Act (IDEA) states that the IEP Team should “consider positive behavior interventions and supports, and other strategies” to address any behavior that “impedes the child’s learning or that of others.” Courts have repeatedly upheld that “learning” refers to social, emotional, and academic development. That means that any behavior that impedes the social, emotional, or academic development of a student or his/her peers, is grounds to consider an FBA and positive behavioral supports. So, instead of waiting for that dreaded call from the principal, be proactive. Call your child’s counselor, teacher, and/or paraprofessional, and ask if he or she is exhibiting any behaviors that meet the above criteria. If so, check out the resources listed below, convene a team meeting, and begin to empower your child to take greater control of his or her own actions.

The links below contain several valuable, free, accessible resources on behavioral supports, including an “efficient” FBA form that can be completed by the team in about 15 - 20 minutes.

The Center For Effective Collaboration and Practice: cecp.air.org
Lives in the Balance: www.livesinthebalance.org
OSEP Technical Assistance center on Positive Behavioral Interventions and Supports: www.pbis.org
Efficient FBA: www.pbis.org/common/pbisresources/tools/EfficientFBA_FACTS.pdf

*See “What Happens When Discipline at School Leads to Lost Time in the Classroom?” on page 5 in this issue of Newsline for more details.

Say it with Symbols!
Communicating and Caring with Pictures and Symbols

Save 10% off your purchase at the FCSN Visions of Community Conference! Bring this ad to the Giving Greetings table in the Exhibit Hall or order online at www.GivingGreetings.com

Use coupon code FCSN
The complaint I hear most from leaders of special education parent advisory councils is that their meetings are not well attended by the parents in their district. Where are the parents? While raising a child with special needs brings its share of challenges, a lack of time is not the complete answer. Work issues, shuttling family members to various activities, homework, and cultural differences all affect involvement in yet another group. I also believe that sometimes it is hard for a family to be open about their situation, especially with respect to mental health issues. Unfortunately, what the community is missing is the value of their personal stories.

Sharing your story can help you connect, develop relationships, and find solace in a difficult world. Attendance at a local SEPAC meeting helps you connect to other parents who are navigating the same school system as your children and who may be aware of local community resources to support your family. Just being with people who "get it" is invaluable. By showing up and sharing your story, you validate the struggle that we all have faced. Telling your story can have a ripple effect and empower other families.

Telling your story does not come without risk. You are vulnerable to "exposure" or even criticism. Yet coming out can also bring unforeseen rewards: such as meeting an acquaintance in the supermarket who confided that their family was facing the same challenges and they were glad to have someone "safe" to talk with.

Data and statistics can illuminate some issues, but sharing your personal story at school board meetings or even at state hearings is invaluable. At a recent DESE meeting on the State Performance Plan/Annual Performance Report, the personal stories of parents of children with special needs found a receptive voice. The Council for Exceptional Children recently asked for personal stories to put a human touch on the graphs and charts that typically illustrate the need for increased funding. Finding your voice can shape public discussion and effectuate change.

Most of us are not professional story tellers, but we can learn to revise our story so that others will want to listen. Engaging stories rely on a beginning that hooks the listener, followed by details, leading to a punch line at the end. Learn to craft your story to be an effective tool at Team meetings and maybe even state hearings.

Join us at the Federation’s Visions of Community Conference on March 10th to learn more: Telling your Story – Finding Your Voice workshop during Session 2 (1:30-3:00pm).
It’s a no brainer that we all benefit from having visual reminders of our daily schedules. We call them calendars. Our children with developmental disabilities, and specifically autism, often benefit hugely from having permanent visual reminders of what tasks and activities come next. There is plenty of anecdotal knowledge (just ask your child’s teacher!) and research-based evidence that visual schedules can help children with special needs gain independence and increase on-task behavior in home, school and in community settings. Just knowing what comes next in their day helps all kids transition from one activity to the next with less anxiety.

Using visual schedules and sequences helps our kids master the tasks they need to gain independence in their home routines. A visual schedule will help your child understand what is currently happening, what is coming up next (the sequence of events), and what happens when they are finished with something. Visual schedules made with photographs, symbols, or words can be used to organize and structure daily activities. Generally, picture-based schedules work best for young children and non-readers, and word-based schedules work for your child who reads. The goal is to create a visual system that helps your child learn to do the task independently.

At home, visual schedules can portray an entire day/week or month’s activities, or detail the mini steps of one activity, such as the morning routine. Each routine is learned by doing tasks in sequential order and then if your child is having particular difficulty with one step of the morning schedule, for example brushing teeth, you can divide that step into more detail until he or she masters it. Often, the more stress caused by a situation, the more steps a task should be broken into. Your child may need a visual schedule only temporarily until he or she has learned the steps. Other routines may always need to be available in a visual format. Always build in a reward so your child knows what they are working toward, reinforcing the concept of First, Then.

Visual schedules you can use at home
Use of a weekly/monthly calendar at home can provide the child with important information regarding up-coming events/activities rather than relying on hearing your reminders (and you repeating them over and over). Some examples of home routines that can be broken down into step-by-step sequences with visuals are morning routines, bedtime routines, bathing, brushing teeth, chores, emptying backpacks, getting dressed, feeding the pets, getting ready for school, and going to appointments.

Making Your Own Visual Schedules
I can hear what you’re thinking – sounds like a daunting task in your already busy life. But with a little upfront investment of your time, down the road your child will develop the self-management and skills to do home routines with less supervision.

Visual schedules are easy to make at home. Use whatever visuals your child understands, be it photos, line drawings, symbols, or words. You can make visual schedules inexpensively by using hand drawn or written note cards, or gluing cut-out pictures from magazines. Or simply write them in a list, grid or chore chart for your child who is able to read. You can also use computer clipart, Google images, PowerPoint™ or board making software to help make your schedule. There are lots of pre-made picture and symbols sets you can purchase. Taking your own photographs of the actual location or task is also very powerful for our kids. All you need is a camera, printer, and some tape or Velcro. You can always draw your own pictures as needed to help reduce any anxiety brought on by a change in plans.

Consider how and where your visual schedule will be used by your child. If it’s only within your home, make a schedule that can hang on your wall or refrigerator. Perhaps you need something to use in a specific location. Hang horizontal schedule strips in the bathroom or near the front door. If you need portability, you can put your visuals in any type of binder, photo album, or even specially created portable communication books and wallets.

Some Low Tech/No Tech Solutions:
• Magnetic Calendars
• Pocket wall charts
• Dry erase boards
• Chore charts
• Photo albums

High tech / iDevice Apps:
Yes, there are now many apps for that. There is a growing list of visual supports and schedule apps available for your iPhone or iPad for kids of all ages and abilities. Some even incorporate video for on the spot training and reminders. Some are free, some are low cost, all available from iTunes.
Watching my nephew enter his first year at Northeastern caused me to reflect on some of the challenges and successes of my freshman year at college as a person with a disability. I decided to contact several disability coordinators in order to gather advice for students with disabilities who are starting to think about college. This article is intended to provide helpful hints to students with disabilities engaged in the college search.

Well before the college search begins, it is important to remember that any transition services must be inserted in a student’s IEP in order for the high school to provide them. What does “transition” mean exactly to a student with a disability who faces the challenge of going into new surroundings, dealing with new people, and learning to advocate for himself? For me, this meant leaving my friends and academic aides behind, and venturing off to an unfamiliar college campus. There were so many questions that needed to be answered. What services did the school have to provide me? How many classes should I take? How was I going to function on campus? How would I take notes in the classroom?

The first practical piece of advice I have is that, in college, the relationship for gaining access to disability services is a partnership between the student and the school. In other words, students should approach accommodations with an understanding of what is reasonable for the school to provide, and with a willingness to work together to solve problems. It is important to contact disability coordinators at the schools you are applying to as early as you can - the earlier, the better. Mary Powell of Babson College believes that this is the best strategy for success. She finds that the earlier students identify themselves as having a disability, the more she is able to do for them from her office. You will also need to go on the university’s Disability Services website or call its office to figure out what medical documentation you need to submit in order to obtain services. The more you disclose about yourself, the easier it is for the university to determine what services you need.

Once you have been accepted, the next practical tip is to spend time at the university you plan to attend. As I began my freshman year, I quickly realized that life for a student divides into two broad categories: academics and student life. From the academic perspective, get your class schedule early, and map out where your classes are and how long it will take you to get from point A to point B. Ask if you can meet with the professors to introduce yourself beforehand. Don’t be afraid to educate the professor about your situation, particularly in the case where your disability is not readily apparent to the naked eye. Personally, I liked to approach my professors at the end of the first class to discuss my situation. For the student life piece, as far as getting around campus and getting food, etc. I found staff members to be some of my best allies. I will be forever grateful to the cafeteria workers that helped get me my food or the maintenance people who fixed my wheelchair in a pinch. You can’t always run to disability services when you need a hand, even though the door may always be open. Finally, don’t be afraid to ask for help, but also be a self-advocate and remember, any transition, whether with a disability or not, can be a challenge. Hopefully, this article will help as you start your new journey.

Here are two useful websites to help you plan to attend college and succeed once you get there.
www.weconnectnow.wordpress.com
www.thinkcollege.net

Brian McLaughlin graduated from Boston College and Boston College Law School. He started his own solo practice focusing on family law and special needs advocacy in May of 2010. Brian has cerebral palsy and is visually impaired.
A Picture’s Worth: PECS and Other Visual Communication Strategies in Autism, Second Edition

In A Picture’s Worth: PECS and Other Visual Communication Strategies in Autism, Second Edition, Andy Bondy and Lori Frost update a popular handbook on the Picture Exchange Communication System (PECS) and other visual communication strategies for children with autism who have significant communication difficulties. The first four chapters offer concise, jargon-free explanations of how communication works, and how it relates to behavior. These chapters are an excellent reference for any busy parent. They are very brief, with straightforward language and examples to aid understanding, and each chapter ends with a list of excellent resources for continued learning. The fifth chapter, on “Augmentative and Alternative Communication Systems,” covers the practical physical tools to use with children who struggle to form or understand speech. This chapter has been thoroughly revised to include the latest relevant technology (including iPhone and iPad apps) alongside their low-tech alternatives. The remaining chapters offer a step-by-step guide to PECS, including how to decide whether it is right for your child.

This book is an excellent starting point for anyone looking to learn about communicating with a child with autism, and/or considering PECS. The writing is clear and concise, the sections are short, and the headings are bold and easy to find. Each chapter uses examples of real children to illustrate the main points and processes. The section that discusses PECS goes step by step chronologically, and explains important points close to the relevant step. There are also loads of tables, illustrations, and pictures. Weighing in at under 150 pages, it can be read cover to cover in an afternoon, or you can take advantage of its outstanding organization to read it bit by bit in no particular order. Andy Bondy and Lori Frost have accomplished an admirable feat by making up-to-date research and practice easily accessible to the busy parent.

Assistive Technology Corner...
Using Visual Schedules to Teach Independence at Home
(continued from page 13)

- Choiceworks, by BeeVisual (created by local parents Jeff and Michele Walker)
- First Then Visual Schedule and Visual Schedule Planner, by Good Karma Applications
- Functional Planning System and My Video Schedule by Conover Company
- iPrompts, by Handheld Adaptive
- Picture Scheduler By Petr Jankuj
- Pocket Picture Planner by Cognitopia Software
- Video Scheduler by MDR

Learn more:
Boardmaker @ Home Toolkit: www.mayer-johnson.com (requires Boardmaker software)
Do2Learn: www.do2learn.com/picturecards/howtouse/schedule.htm
Visual Strategies for Improving Communication, by Linda Hodgdon
Making Visual Supports Work in the Home and Community by Jennifer L. Saver and Brenda Smith Myles

Randi is the parent of a child living with cerebral palsy who relies on assistive technology for mobility and communication. Randi is also a member of the Federation’s Board of Directors, and the MassMATCH AT Advisory Committee. Learn more about MassMATCH at www.massmatch.org. Randi is the founder of www.SayItWithSymbols.com. For more information, contact Randi at rsargent@sayitwithsymbols.com.
If you have an internet connection and five minutes, you can help us support Massachusetts’ most vulnerable families without spending a cent. For far longer than many of our peers, we have continued to print and mail Newsline in the belief that lack of access to technology should not mean lack of access to valuable information for any family. Yet as the costs of printing and mailing have continued to rise, it has become increasingly difficult to live up to this ideal. We can no longer do it without your help. In order to continue providing this service to those who need it most, we need at least 20% of our print subscribers to agree to receive Newsline via email.

Signing up for e-Newsline is easy!
If you currently receive the printed version of Newsline, scan the QR Code below or visit www.fcsn.org/enewsline, enter your ID# from the mailing label above and your email address. We’ll take care of the rest.

If you are not a current subscriber but would like to join our email list, visit our home page at www.fcsn.org to sign up online.

With deepest gratitude,

Rich Robison
Executive Director