On November 26, 2007, Rhea Tavares’ birthday, she received a very special gift that would not only change her life, but also the life of a young child half a world away. The ‘gift’ was a letter from the mother of a boy in Slovenia. Earlier in the year, this mom read an article about Rhea in People Magazine. She was motivated to write because her 4-year-old son Tim has the same rare diagnosis as Rhea. They both have underdeveloped arms that stop just before the elbow with a single elongated finger on each. Maja, Tim’s mom, had many questions about how Rhea had become so independent and successful, and asked Rhea to share strategies that would help her help her son become independent.

Rhea and Maja set up webcams so they could have face-to-face discussions and Rhea could demonstrate skills for Tim. After just one web session, Rhea taught Tim to eat using the same utensils as everyone else. He learned quickly and was very proud of himself and his growing independence. The webcam communications were helpful, but Tim and his family wanted to meet Rhea. The Federation for Children with Special Needs, where Rhea works as a Portuguese Outreach Specialist for the Parent Training and Information project and the Massachusetts Parent Information and Resource Center, reached out to the media for donations to help finance her trip. People in Slovenia also donated money so Tim could meet his mentor.

In September, Rhea went to Slovenia. During her nine-day visit with Tim and his family, she continued to teach Tim. She brought gifts: a long-handled sponge, a button hook, a zipper ring, and other accessories she uses to wash and dress independently, and taught Tim how to use them. She also met with Tim’s doctors and teachers and spoke with them about how they could encourage Tim to write with a pencil and use a keyboard. In addition, Rhea demonstrated how she washes and dresses to Maja and showed her the modifications Rhea’s mother made to her clothes so Maja could do the same for Tim.

Inclusive Schools Week
December 1-5, 2008
(for more info see page 5)

Visions of Community 2009
March 14, 2009
(for more info see page 5)
MassCARE Family Support Initiatives

A year ago, Delores Qualls, Project Coordinator for MassCARE Family Support Initiatives at the Federation, was selected to participate in the AIDS Alliance Corps Leadership Program in Baltimore, Maryland. After four intensive training sessions about advocacy, grassroots organization and leadership development, Delores is one of 39 graduates of this influential program. In fact, Delores graduated with honors as her colleagues voted her the “Most Likely to Succeed,” and the “Best Peer.” When asked what contributed to her success, Delores responded, “Always remember that someone is watching you, so always present your best in any given situation.” Congratulations, Delores!

Family Networking Day

The annual MassCARE Family Support Initiative Family Networking Day took place on August 16, 2008, on the charming grounds of the United Church of Christ Conference Center in Framingham. The day began with rain, but once that cleared, the 77 consumers, families and friends who attended this “awesome” event enjoyed a lovely, sunny day filled with fun, food, and friends.

This year’s arts and crafts selections included henna tattoos by tattoo artist Nimmi Sehgal. Everyone was enthusiastic about this new activity. Vikki Segovia, a coordinator from Chelsea, organized construction of a Tree of Life quilt. And, this wasn’t just a girl thing; everyone, women and men, participated in making the quilt from donated materials. In another first, there was a free raffle. The MassCARE Coordinators at each site donated prizes and the Coordinator for Family Support Initiatives, Delores Qualls also solicited donations from local businesses. The prizes were displayed on tables. Each attendee received free raffle tickets, and when their number came up, they could pick the prize they wanted. A family who just moved into their own apartment needed a quilt selected a quilt from the array of prizes. There was something for everyone, including kids, as there were plenty of dolls and toys as well. All in all, it was a day to relax and network. One of the participants remarked the day was “just what the doctor ordered.”

While everyone was welcome to participate in all the activities, there was a separate component for youth so they could play basketball, swim all day, and network with each other.

Each attendee received a welcome packet so they could be more informed about MassCARE services and supports, and perhaps even consider joining the Family Advisory Network (FAN) to help plan future events, including Family Networking Day.

For more information about the FAN or other MassCARE Family Support Initiatives, contact Delores at 617-236-7210 or e-mail dqualls@fcsn.org.

E-Newsline

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FROM THE EXECUTIVE DIRECTOR

My Child Has Special Needs

In a recent conversation, a parent asked with a quizzical voice, “You mean my child has special needs?” To which I replied, “You told me he has an IEP and that he has some behavior issues in school.” “Yes,” she replied, “but I didn’t know that meant ‘special needs.’” I realized in that moment that the term ‘special needs’ doesn’t mean the same thing to each person; that for some it is a stigmatizing label. This exchange occurred during a discussion about schools, funding, MCAS scores and the parents’ receipt of a notice that their children’s school had not met its AYP goal.

AYP or Adequate Yearly Progress is a term defined under the federal No Child Left Behind (NCLB) law. One of the requirements of NCLB is that all students achieve proficient or advanced status on their MCAS test results by 2012. If a school fails to demonstrate adequate progress to meet that goal, it is identified as a school in need of improvement. Moreover, it is not sufficient for a school simply to reach the goal for the average student; the law also requires that schools look at certain groups of students, like students on IEPs, to ensure that all students are progressing.

Under NCLB, students on IEPs also need to make effective progress in the curriculum. This requirement resulted from years of low expectations for students with disabilities that precluded them from having the opportunity to learn the same things as other students. Low expectations were perpetuating a subclass of students that would ultimately lack the skills necessary to pursue their lives’ goals and dreams. These students will learn to read, only when they are taught to read. They will learn to do math, only when taught math skills. Special education is designed to be a service or a set of supports that enables a student to learn better and make better progress. Under NCLB, a school must demonstrate that every group is moving ahead or they will receive a designation.

A school administrator told me, “Labeling schools using the current regulations is quite complex. Most informed observers would probably concur that more Massachusetts schools are doing a better job teaching all students than ever before, while at the same time more schools are classified as failing to meet AYP. There is certainly plenty of room for improvement in most Massachusetts schools. However, by just using the current and perhaps unrealistic regulations for evaluating schools and individual students, we will be dismissing the tremendous progress and achievements of many educators and students.”

Student with ‘special needs’, schools ‘In need of Improvement’ – no one likes these labels. The truth is that labels are neither fair, nor important. What is important is that schools and teachers, families and students find ways to meet high academic expectations and ensure that all of our students are learning effectively.

Let’s all work towards that end.

Best wishes,

Rich Robison

News From Family Ties of Massachusetts

By Mary Castro Summers, Director, Family TIES

Family TIES of Massachusetts is a statewide information and support network for families of children with special needs. It is a project at the Federation for Children with Special Needs, funded by the Massachusetts Department of Public Health, Division for Perinatal Health, Early Childhood and Special Health Needs. We provide information, referrals, parent-to-parent support and training to families of children with special needs.

Federation Conference: The Family TIES staff will be at the Visions of Community conference on March 14. This is always a great opportunity for us to connect with many of the parents who have called, or met us at a workshop, resource fair or other event. Please stop by our exhibit table in the Main Lobby, and pick up the latest edition of the Family TIES Resource Directory.

Resource Directory: The 2009 edition of the Family TIES of Massachusetts Directory of Resources for Families of Children with Special Needs will be available at the Visions of Community conference. If you cannot attend, the new edition will be available on line at www.massfamilyties.org and Regional Coordinators will have copies to distribute.

Parent-To-Parent Program: The mission of the Parent-to-Parent Program is to bring together parents facing similar challenges in raising their children with special needs. This may be in response to a new diagnosis or a new challenge, a transition in the child’s life, or other circumstances. We believe that sharing life experiences lessens the isolation many of us feel, and provides an opportunity to learn from each other as well as learn new ways to support and care for our children and ourselves. Parents seeking this kind of support can contact Family TIES at 1-800-905-TIES (8437), or call Linea Luck Pearson, our Parent-to-Parent Coordinator at 508-792-7880.
Interview with Dr. Lauren Mednick

By Selena Sheaves, Executive Assistant

Lauren Mednick, PhD, a pediatric psychologist at Children’s Hospital Boston graciously shared the following information about behavioral medicine and types of therapies and strategies parents can try at home to help their children cope with anxiety about their medical conditions or upcoming medical procedures.

Q: What is behavioral medicine?

A: Behavioral medicine involves the integration of behavioral and psychosocial knowledge relevant to the medical care of children and adults. I work with children with medical conditions who have trouble accepting or coping with their diagnosis, or who are struggling with anxieties caused by upcoming treatments or surgeries.

Q: What types of therapies might you use to help a child overcome these anxieties and help prepare them for treatment or surgery?

A: I use play therapy, cognitive behavioral therapy, hypnosis, relaxation, biofeedback, distraction, and supportive therapy. I individualize my approach, as each patient reacts differently.

Q: What’s an example of play therapy?

A: If a child is apprehensive about an upcoming catheterization, we integrate an actual catheter during our playtime. We start out slowly with a catheter in the room so the child can see it, and work toward having the child touch or hold the catheter. Eventually, I’ll ask the child to practice using the catheter with a doll. This helps the child become desensitized, familiar and comfortable.

Q: Do you use positive behavioral supports?

A: Yes. Children need measurable goals with a rewards system to motivate them. An example might be a behavior plan with a visual chart for schoolwork or homework, with a specific reward attached to achieving a set goal.

Q: What are your thoughts about the effectiveness of non-traditional therapies and informal “mom interventions” such as aroma therapy, full spectrum lighting, and plants and flowers in the environment?

A: I believe in what works. I believe that alternative therapies can work in conjunction with traditional methods. For instance, if you know cognitive behavioral therapy has proven results in treating anxiety related behaviors, I would recommend using the non-traditional therapies that work for your family in addition to the cognitive behavioral therapy.

Q: How important is it for parents to model calm, appropriate behaviors as an effective teaching tool, and as a way to teach coping skills and help manage difficult behaviors?

A: Children can see or sense when a parent gets agitated, and in turn will become agitated. Likewise, when a parent is calm, the child tends to be less stressed and anxious. Modeling appropriate behaviors is instrumental in teaching our children effective coping skills.

Q: Can a bedtime activity of snuggling close together and reading in a quiet tone have a positive effect on long-term behavior?

A: Yes. Touch is very comforting. Children generally respond well to positive relationships and strong social supports. Love and acceptance give children a sense of self worth and the confidence they need in order to become proactive members of their healthcare team.

Q: Can these types of interventions be effective in the absence of traditional (drug) interventions?

A: Yes. I believe that most psychopharmacologists would like to see therapies in place and give them time to work, prior to prescribing medications. They generally use talk therapy, cognitive behavioral therapy and other methods for teaching coping skills and behavior management before moving on to the use of medications. Of course, in circumstances where a child has become violent, dangerous or is hallucinating, medications are among the first options for treatment. Combination treatments often work best; medication alone is less effective than using medications and therapies together in a comprehensive treatment plan.

Do you wish you knew more about state and federal special education laws that support your student?

The Federation’s Parent Consultant Training Institutes offer Massachusetts parents and professionals the opportunity to learn more about special education laws and processes. We believe that educated parents and professionals are better able to collaborate effectively to develop supports and services that enable students with disabilities to succeed.

Tuition for parents is $325, professionals $425. Limited scholarships are available for parents. Family members may also contact the Massachusetts Developmental Disabilities Council (MDDC) at 617-770-7676 to apply for Consumer Empowerment Funds.

For more information or to download an application please visit our Web site at fcsn.org/pti/advocacy/becomeanadvocate.php or call 1-800-331-0688.
Visions of Community 2009
A Conference for Families of Children with Special Needs and the Professionals Who Serve Them

Visions of Community, the Federation’s conference for families with children with special needs and their professional partners will take place on Saturday, March 14, 2009, at the Seaport World Trade Center in Boston.

The Federation is pleased to host keynote speaker Sarah Vazquez in her first visit to Massachusetts. Sarah, a nationally known motivational speaker, is a young adult with a disability. She will also present a workshop about self-advocacy.

The conference features more than 35 break-out sessions, many presented and/or translated into Spanish, Portuguese, and Cantonese, with topical strands and information covering Early Childhood, Special Education, No Child Left Behind, the Individuals with Disabilities Education Act, Health Care for Children with Special Needs, Transition, Social/Recreation Opportunities and more. In addition to the learning opportunities, this is also a great time to meet the Federation staff, network with other parents, and pick up free resources in our exhibit hall.

The holiday season is upon us. Need a creative gift idea? Consider sending a family member or friend to the Federation conference. Early registration fee is only $70. After February 13, 2009, registration is $85. Registration opens December 15, 2008. For more information about the conference, visit www.fcsn.org.

Inclusive School Week

Inclusive School Week, an annual event hosted by the Inclusive Schools Network at the Education Development Center, Inc., is the first week of December. Mark your calendars for December 1 – 5, 2008, the 8th annual celebration.

This year’s theme is “Together We Learn Better: Inclusive Schools Benefit All Children.” It features efforts by schools, families and communities to promote inclusive education and highlights how inclusion helps improve educational quality and outcomes for all students.

Visit www.inclusiveschools.org to read about inclusive practices, read tips for implementing practices in your school and get resources to help.

The Federation is proud to be a partner organization in these efforts and is the official on-line store for purchasing celebration kits and other merchandise. Visit http://fcsn.org/inclusiveschools/index.html.
Mass PIRC: Helping to Promote Parents as Partners in Their Children’s Education

By Janet Vohs, Director of Publications, Massachusetts Parent Information & Resource Center

It’s hard to believe that prior to 1975, America’s public schools could legally deny an education to children with disabilities. In the more than three decades since landmark federal legislation was passed guaranteeing a right to education to all children with disabilities, the Federation has educated parents about their rights and their children’s rights to a free and appropriate public education. Today, the Federation continues to inform, educate and empower parents not only as their children’s advocates but also in their partnership role in their children’s education.

Mass PIRC

In 1999, eager to help all families benefit from the lessons learned in helping parents of children with special needs, the Federation established Parents’ PLACE, the Massachusetts Parent Information and Resource Center, now known as Mass PIRC. Mass PIRC’s mission is to extend the Federation’s mission of “informing, educating and empowering” to Massachusetts’ families whose children are least likely to receive a quality education, not only because of their disabilities, but also because of their income, where they live, or the language they speak. By providing the information and skills training families need to participate fully in their children’s education, Mass PIRC helps the most vulnerable parents understand their role as valued partners in their children’s education.

No Child Left Behind

The No Child Left Behind Act (NCLB), passed into law in 2002, is our nation’s main law supporting elementary and secondary education. An entire section of NCLB is devoted to defining and describing what parent involvement in education means. It spells out what schools must do to ensure that parents are invited and encouraged to be partners with their children’s educators. Mass PIRC staff understands that a quality education is the most powerful gift we can give to a child to help ensure a path to success. Our mission is to help families be active and effective partners in their children’s education and to help schools become places where the contributions of families are welcomed and encouraged.

Mass PIRC helps promote the NCLB vision of parent involvement in many different ways. In the past year, thanks to Mass PIRC:

- More than 217,300 families and 6,650 professionals received publications, resources, and/or in-person consultations or training at Mass PIRC workshops and events.
- Mass PIRC sent more than 475,000 materials about parental involvement to families, schools, and others throughout the state.
- More than 2,710 community-based and faith-based organizations received information and resources about parental involvement in education.

What People Say about Mass PIRC

The information helped me “understand MCAS and what I can do to help my child prepare... and what I can do to help my child succeed in school.”

“My son had problems with math, but after the workshop I understood how I could help him succeed.”

“I am a grandmother and I learned how to put myself side by side with my children for their children’s education.”

- The Mass PIRC English, Spanish and Portuguese websites received more than 667,650 visits and 39,590 PIRC documents were downloaded in these three languages.
- More than 14,700 family-friendly resource materials were distributed at 40 community-based events and resource fairs.

Mass PIRC Forges Ahead

In the coming year, Mass PIRC staff will extend outreach to more schools and communities, continue to develop new resources, and explore innovative ways to help families and schools develop empowering partnerships.

Initiatives include:

- Working to help schools across the state adopt proven strategies for engaging families at all levels – from partnering with educators around their own children’s education to volunteering in classrooms, to decision-making on School Councils, to developing school policies.
- Serving as a clearinghouse of information and resources to help families and educators understand how to bridge the gap between educational research and practice.
- Increasing our capacity to reach diverse racial, ethnic, and linguistic groups by forging stronger bonds with faith and community-based groups.
- Supporting cultural diversity by training parents to become trainers and leaders within their own communities.

At Mass PIRC we are proud of what we have accomplished, and look forward to our second decade of helping families and schools work together to meet today’s educational challenges.

To learn more about how Mass PIRC can help you, call 1-877-471-0980, or visit us on-line (English, Spanish, and Portuguese) at www.masspirc.org.

We are eager to hear from you!
Coping with Anxiety

By Selena Sheaves, Executive Assistant and mother of child with an anxiety disorder

Anxiety - feelings of worry and dread - is one way our bodies respond to stress. Everyone experiences anxiety at one time or another. While these feelings are unpleasant, anxiety keeps us safe. It helps us stay alert and maintain focus so we perform better in tense situations. However, some children’s anxieties affect the quality of their daily lives. The tips below may help your child better cope with stressful situations.

1) **Relaxation** – Meditation, breathing exercises or yoga can be good ways to help a child relax. Some children respond well to listening to, or playing, music. Other creative outlets include reading, writing and drawing. All these methods can help your child focus his energies on a particular sense, body movement, thought or idea and allows for physical expression of emotions when words are out of reach.

2) **Exercise** – Get out and walk! Take your child to the park, the playground, roller skating, ice skating, biking, or hiking. Enroll her in a martial arts program, gymnastics, soccer, basketball, or other sport of interest. Encourage your child to exercise for health and enjoyment. Exercise keeps children physically and mentally fit by helping reduce the production of stress-causing chemicals, therefore decreasing symptoms of anxiety and depression. Exercise also contributes to healthier sleep patterns and increased self-confidence.

3) **Listen to your child.** Be open and willing to believe that the issues causing his anxiety are very real to him, even if they seem trivial or non-existent to you. Not everything in life makes sense. When we try to rationalize a child’s anxieties, we send the message that we don’t believe what he is telling us, or respect how he feels. This not only causes more anxiety, but also can erode his trust in our relationship. We must be flexible, reasonable, patient and understanding, and we must take the time and make the effort to not only hear what he is saying, but to really listen.

4) **Preparation and Planning** – When possible let your child know what to expect in certain situations. Whether you’re going to the grocery store or out-of-state, encourage your child to be a part of the planning process. Helping to plan events gives your child a sense of control, and can reduce the anxiety associated with the unknown. Social stories – stories that illustrate upcoming events and situations - are a good way to prepare your child for a field trip, birthday party, or other special event.

Another great way to help children cope with anxiety is to use daily and weekly planners. This can be as simple as a calendar with the child’s schedule posted on the refrigerator, or a more detailed list that states when and where an event will take place, what will happen, and your child’s responsibilities. This is also an effective way to help your child manage her time. The more prepared your child is, the less anxious she will be.

5) **Diet** - Preparing nutritious meals and limiting refined sugars and processed foods can help a child maintain a healthy body and mind. More importantly, by providing a selection of healthy foods, a child can learn to make decisions that contribute to her overall well-being. My daughter remarked, “I feel more aware and better about what I am eating.”

Visit www.fcsn.org for more ideas and resources to help your child cope with anxiety.

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Reembolsos de MassHealth de gastos del bolsillo propio hechos durante el período de determinación de elegibilidad

Por Beth Dworetzky, Centro de Información de Salud de Familia a Familia de Massachusetts

MassHealth es el nombre del programa de Medicaid en Massachusetts. MassHealth patrocina muchos programas diferentes que ofrecen beneficios de salud pública. Para los niños con necesidades especiales de cuidado de salud, los requisitos dependen de muchos factores, por ejemplo, ciudadanía, ingresos anuales de la familia y situación de discapacidad. Si los ingresos anuales de su familia están por debajo del 150% del nivel de pobreza federal (Federal Poverty Level o FPL en inglés), por ejemplo, menos de $31,812 para una familia de cuatro personas, sus niños cumplen los requisitos para MassHealth Standard aunque no tengan una discapacidad y aunque usted tenga acceso a un seguro de salud privado.

Si sus ingresos familiares anuales están por encima del 150% del nivel federal de pobreza y usted necesita suplementar los servicios de cuidado de salud para un hijo con una discapacidad, puede solicitar MassHealth Commonhealth aunque tenga un seguro de salud privado. Para ser elegible para este programa, los ingresos anuales de la familia deben exceder los $31,812 para una familia de cuatro personas y, además, su hijo debe cumplir ciertos criterios clínicos de ‘discapacidad’. Esta determinación de discapacidad puede tardar hasta 60 días.

Una vez que su familia recibe el aviso de que su niño cumple los requisitos para MassHealth Standard o MassHealth Commonhealth, los beneficios son retroactivos hasta 10 días antes de la fecha de recepción de su solicitud de beneficios médicos (Medical Benefit Request o MBR en inglés) por la Unidad de Procesamiento Central de MassHealth (MassHealth Central Processing Unit) en Charlestown.

Si usted ha hecho copagos para citas médicas, terapias, equipo médico durable, medicamentos, etc., durante el período de determinación de elegibilidad, y estos servicios fueron necesarios desde un punto de vista médico y fueron provistos por un proveedor de MassHealth, el proveedor debe reembolsarle sus gastos y facturar estos servicios a MassHealth. El proveedor también debe aceptar el pago de MassHealth como pago total.

La regulación de MassHealth al respecto es la 130 CMR (Código de regulaciones de MassHealth o Code of MassHealth Regulations) 450.203:(B). Si un proveedor recibe pagos de una persona por cualquier servicio pagadero conforme a los términos de MassHealth, sin saber que esa persona era miembro de MassHealth en el momento en que los servicios fueron provistos, el proveedor deberá, al enterarse de que esa persona estaba suscrita a MassHealth, devolverle inmediatamente toda suma solicitada, cobrada, recibida o aceptada por tal servicio.

Si tiene preguntas sobre los criterios clínicos de discapacidad, sobre sus ingresos familiares en relación con el límite de pobreza federal o sobre otros aspectos de MassHealth, o si necesita ayuda para comprender los requisitos de elegibilidad y el proceso de solicitud de MassHealth Standard o MassHealth Commonhealth para un niño con necesidades especiales de cuidado de salud, llame al Centro de Información de Salud de Familia a Familia de Massachusetts (Massachusetts Family-to-Family Health Information Center) al 1-800-331-0688, ext. 210; escriba por correo electrónico a massfv@fcsn.org; o visite la página web www.massfamilyvoices.org.

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MassHealth Reimbursement for Out-of-Pocket Expenses Incurred During the Eligibility Determination Period

By Beth Dworetzky, Massachusetts Family-to-Family Health Information Center

MassHealth is the name of the Massachusetts Medicaid program. There are many different public health benefit programs under the MassHealth ‘umbrella.’ For children with special health care needs, eligibility depends on many factors, including citizenship, annual family income and disability status. If family income is less than 150% Federal Poverty Level (FPL) or < $31,812 for a family of 4, whether or not your child is disabled, and whether or not you have access to private health insurance, your children will be eligible for MassHealth Standard.

If your family income is > 150% FPL, whether or not you have private health insurance, if you need to supplement health care services for a child with a disability, you can apply for MassHealth CommonHealth. To be eligible for this program, your family income must be > $31,812 for a family of 4, and your child must also meet certain clinical ‘disability’ criteria. This disability determination can take up to 60 days.

Once your family is notified your child is eligible for MassHealth Standard or MassHealth CommonHealth, the benefits are retroactive from ten days prior to the date your application – the Medical Benefit Request (MBR) – was received at the MassHealth Central Processing Unit in Charlestown.

If you have paid co-payments for medical appointments, therapies, durable medical equipment, medications, etc, during the eligibility determination period, and these services were provided by a Masshealth provider and were medically necessary, the provider must pay you back and bill MassHealth for the services. The provider must also accept the MassHealth payment as payment in full.

The MassHealth regulation for this is 130 CMR (Code of MassHealth Regulations) 450.203:(B) If the provider receives payment from a member for any service payable under MassHealth without knowing that the member was a MassHealth member at the time the service was provided, the provider must, upon learning that the individual is a MassHealth member, immediately return all sums solicited, charged, received, or accepted with respect to such service.

If you have questions about the clinical disability criteria, your family income in relation to the FPL, other aspects of MassHealth, or need help understanding the eligibility and application for MassHealth Standard or MassHealth CommonHealth for a child with special health care needs, call the Massachusetts Family-to-Family Health Information Center. Phone: 1-800-331-0688, ext. 210, e-mail: massfv@fcsn.org or visit www.massfamilyvoices.org.
Federation Mission Goes International (continued from page 1)

“The power of this connection has broken the isolation of feeling so alone and like the only one with this type of disability.”

The visit was not all work. Rhea, Tim and his family took a boat ride on a lake and went horseback riding. At first, Tim didn’t want to ride, but after Rhea showed him, he tried and he loved it. They also visited Tim’s grandfather at his shooting range where he teaches people to shoot bee-bee guns in preparation for hunting. Tim is too young to shoot now, but Rhea demonstrated the skills he will eventually need in order to participate in this pastime, which his family enjoys. When he’s older, he will be able to hunt with his family, rather than watch from the sidelines.

Now that Rhea is home, she continues to meet with Tim via webcam. And, as Tim gets older, she can offer an important form of support as an individual who has literally walked in his shoes. Rhea can share the knowledge she has developed through her experiences to help Tim troubleshoot situations and make things just a bit easier for him. In his own way, Tim also supports Rhea. She said meeting Tim, “was a miracle,” as she’d, “spent her whole life trying to find somebody just like her,” and she, “always felt strange and somewhat different.” This meeting has changed her perspective and she no longer feels like a stranger in a strange land. “The power of this connection has broken the isolation of feeling so alone and like the only one with this type of disability.”

Rhea extends her many thanks to the Federation for their support and to all the people who so generously made donations to make her visit with Tim possible.

Rhea and Tim have formed a close bond.
Help Improve Home Health Services for Children with Ventilators and/or Tracheostomies

By Kathleen Fitzgerald Rice, parent of a child with complex medical needs

TrachCare is a parent run support organization for families whose children have tracheostomies and are ventilator dependent. TrachCare, in partnership with other parents, healthcare professionals and state agencies is working to improve home healthcare services for children living at home with ventilator dependency and/or tracheostomies. Our common goal is to create best practices in home healthcare for this unique group of children.

Just a decade ago, caring for these complex children at home was unheard of. However, due to advances in medical care, the number of children living at home has increased dramatically. Now that our children are at home and thriving, TrachCare and others want to assure that they receive safe and quality homecare services.

We need your help to accomplish this goal! We want to hear from other parents like us throughout the state. We need to know how the home healthcare system is working for your ventilator dependent and/or trached child.
• What are the biggest challenges you face with the home healthcare system?

• What parts of the system work?
• What are your suggestions for improving homecare equipment services, nursing care, respite and emotional support?

Please tell us your story and participate in a brief survey to add your voice to our campaign to improve homecare services for children who are trached and/or ventilator dependent. Your information will be confidential. We will use your experiences and ideas to develop advocacy goals and an action plan. Complete the survey at www.zoomerang.com/Survey/?p=WEB228C9AS7Z22, call Kathleen at 617-795-5929, or email k_fitzgerald_rice@hotmail.com. Also look for a survey link on the Mass Family Voices listserv and Federation website at www.fcsn.org. We look forward to hearing from you!

To learn more about TrachCare, visit www.trachcare.org or call 617-527-1990. We host coffee hours, informational meetings and fun family gatherings across the state for families and children.

HMEA’s
The Darnell School
for Educational and Behavioral Services
15 South Street • Hudson, MA 01749
phone: 978.562.6323 • fax: 978.562.5608

The Darnell School, an approved “766 School”, provides intensive educational services to children, ages 9 to 22 years, with an autism spectrum disorder, developmental disability and/or behavioral challenges.

For more information please contact:
Michele Mayer
Vice President for Children’s Services and TRACS
508.298.1170
The Special Education Surrogate Parent Program: Helping children in the custody of the Department of Children and Families

By Beth Farwell, Volunteer Training & Support Coordinator

Would you like to help other people navigate the special education process so they don’t have to go through what you went through? Would you like to use the knowledge and skills you’ve learned as a result of advocating for your own child to help make a difference in another child’s life? The Special Education Surrogate Parent Program provides just such an opportunity!

The Special Education Surrogate Parent Program, funded by the Department of Elementary and Secondary Education, works to support students with special education needs who are in the custody of the Department of Children and Families. As these children have no parent or guardian to represent them, we need the help of skilled volunteers, like you, to become Special Education Surrogate Parents (SESPs). SESP are appointed to students in state custody to fulfill the parent role on the child’s special education Team. We believe every child deserves a chance at academic success. Volunteers with our program advocate on the child’s behalf to ensure he or she is not overlooked and receives the special education services they need to be successful.

We offer free Orientation Trainings so you will feel supported in your role. To learn more about this important opportunity to make a difference in a child’s life, call 508-792-7679, or visit www.sespprogram.org.

Begin a career where putting your heart into your job is more than an expression.

The Special Education programs at Lesley University provide the skills needed to give those students with learning or developmental disabilities the opportunity to reach their full potential as learners.

Initial Licensure programs available in multiple locations across Massachusetts:

- Moderate Disabilities, (PreK–8), M.Ed.
- Moderate Disabilities, (5–12), M.Ed.
- Severe Disabilities, (all levels), M.Ed.

Learn more!
Carol Kiely | New England Regional Director
800.999.1959 ext. 8162 | ckiely@lesley.edu

Pediatric Behavioral Health

Realizing the potential in all students

The Boston College Campus School is a private, publicly funded, special education day school, for students ages 3-21 with severe multiple disabilities, including complex healthcare needs. Founded in 1970, the school is located on the Boston College Campus in Campion Hall and is an integral part of the Lynch School of Education. While the program employs appropriately credentialed and licensed staff, it benefits from involvement of University student interns.

- Staff/Pupil ratio 1:2
- 11 month, 198 day school year
- Current enrollment 45
- Transdisciplinary team approach for service delivery

The Boston College Campus School is licensed by the Massachusetts Department of Education and is a member of the Massachusetts Association of Chapter 766 Approved Private Schools.

For further information, please contact us:
Phone: 617-552-3480
Email: odonneen@bc.edu
140 Commonwealth Avenue, Campion 197, Chestnut Hill, MA 02467
www.bc.edu/campuschool

We offer a Complete Evaluation Package including Testing, Diagnosis, Management Recommendations and Educational Advocacy

We also offer:
- Learning Disability Evaluations
- Systems Advocacy
- Medication Management
- Cognitive Behavioral Therapy
- Individual and Family Therapy

148 Worcester Street, West Boylston MA 01583
Phone 508-835-1735 www.pbhealth.org fax 508-835-1736
Some children and adolescents have complex medical, behavioral health, educational, social, therapeutic, or other service needs. Finding and obtaining the right services for these children can be a challenge for families and caregivers.

Starting June 30, 2009, Intensive Care Coordination using the Wraparound model will be available across the state to children under the age of 21 enrolled in MassHealth (the Massachusetts Medicaid program), who meet certain clinical criteria. These criteria include identification as a child with Serious Emotional Disturbance, as well as additional medical necessity criteria. MassHealth Behavioral health providers will have more information. Information will also be available at the Children’s Behavioral Health Initiative website at www.mass.gov/masshealth/childbehavioralhealth by June 30, 2009. This new service will be one of several innovative services developed as part of the Children’s Behavioral Health Initiative (CBHI), the effort by all the child-serving agencies of the Commonwealth’s Executive Office of Health and Human Services to develop a coordinated, child-centered and family-focused, strengths-based system of care for children and their families.

Wraparound is not a treatment; it is a structured series of steps for building a community support network for children with complex needs who require behavioral and emotional support. Wraparound puts the family at the center of the planning process, and builds a team around the family’s vision for their child’s future. The team typically includes both formal supports (professionals such as physicians, educators, therapists, and caseworkers) and natural supports (extended family, friends, and people in the community connected to the child and family). Over a period of several months, the team works to make the child’s plan a reality, brainstorming ways to overcome obstacles and to develop resources to help the child succeed. Over time, initial plans usually need some revision; the persistence of the team is a key factor in the development of a plan that really works. It is important to note that the Wraparound process is separate from the Individualized Educational Plan (IEP) at the child’s school, although it is desirable to coordinate the two, and if the child does not have an IEP, Wraparound services do not automatically qualify a child for special education services.

If you’d like to know more about Wraparound services, visit the National Wraparound Initiative website at http://www.rtc.pdx.edu/nwi/. If you have questions about these services, e-mail Dr. Simons at CBHI@state.ma.us.

Easter Seals Demonstration and Loan Regional Center

Increasing access to assistive technology – one person at a time

The Easter Seals Demonstration and Loan Regional Center helps people with disabilities make informed decisions about assistive technology they can use at home, on the job or in school.

- Explore hundreds of devices that can meet a variety of needs. From simple to sophisticated.
- The process is simple! Assistive technology devices are available for demonstration at our Boston center or loaned to individuals for two to four weeks.

Easter Seals Technology & Training Center
89 South Street
Boston, MA 02111
617-226-2634 or 800-244-2756 ext. 634
DLRC@eastersealsma.org
Everything I Didn’t Want To Know About CBT

By Samantha Hutt, Self-Advocate

There were bars on the windows, the floors were cold and most of the time I missed breakfast. This was my second stay at McLean Hospital, and I was getting reacquainted with Cognitive Behavioral Therapy (CBT). My reluctance to absorb all these new ideas was due, in part, to the stigma surrounding checking yourself into a mental hospital. Learn stuff? Attend classes? They must be joking! Despite my initial grief and the grief I gave the mental health professionals, CBT eventually started sinking in.

So what is it anyways? Simply put CBT is a triangle. At each of its three points are ‘Thoughts,’ ‘Feelings’ and ‘Behaviors.’ The lines linking the three points are represented by two-way streets. The idea, as I came to understand it, is that these three things are connected. I am bipolar, and that made a lot of sense to me.

In theory, you can start at any angle. Thoughts can lead to feelings, which create behaviors, or backwards, forwards, upside-down and inside out. It all depends on where you as a person tend to begin. This is fine, but the thing that stuck out in my mind the most during my lessons at McLean was ‘mindfulness.’

It’s not as hard as meditating to find Nirvana at a Buddhist temple in Tibet, but concentrating on one’s thoughts, feelings and behaviors can prove taxing. And, if you have an illness, it’s often not very fun. But once you start trying, the doors it opens are endless.

Take me, 22-year-old Sami, fresh out of McLean. I want to borrow the car and go to McDonald’s for that cheesy beefy good morning I’ve been missing for the past few weeks. Mom says, “No.” A month earlier, I would have reacted like a territorial hyena battling over dinner. But relying on methods learned in CBT, I thought about maybe taking an ice cream break before engaging in heated conversation with my mother. Thus, a clash of the Titans was avoided, and a calmer Sami attempted to reason with her mom about 7.5 minutes later.

I eventually got my cheeseburger through compromise and the simple fact that both of us hyenas were hungry. So mindfulness is a good skill to have. Overall, if you can sort through all the flowery language, CBT is really helpful. Like most things though, you only get out what you put in. I’ve learned that no matter what medications you are on, there are no such things as magic cures. When it comes to mental illness, you still have to want to help yourself.

Watch Your Mouth and Speak Up for Children’s Oral Health

By Czarina Biton, Health Care For All

Massachusetts is known for its history of firsts: we had the nation’s first public school system, the first constitution and the first public health department. However, when it comes to the issue of children’s oral health, the Commonwealth is far from first, but we can do something about it. When communities work together to make children’s oral health a statewide priority, kids gain access to much-needed services.

Dental Decay, the most common chronic childhood disease, is caused by a bacterial infection in the mouth. It is five times more common than asthma and affects children across the nation, including children with special health care needs. In 2001, the National Survey of Children with Special Health Care Needs reported that the most common unmet need was dental care. When any child experiences pain from oral health problems, his ability to eat, think and learn is affected. Moreover, dental disease, if left untreated, can lead to life-long health problems, from heart disease to diabetes to pre-term birth. The good news is that the majority of dental decay is preventable when children have access to protective measures such as regular dental screenings, and fluoride treatments.

Through the Watch Your Mouth campaign, Massachusetts communities work together to prevent dental decay. By working together, we can ensure that kids have access to preventive treatments such as early childhood screenings and dental sealants. Making these services available in schools by partnering with dental professionals and school health centers are effective ways to reach all children. So, let’s watch our mouths, and use them to ask our legislators to ensure that the widespread problem of childhood dental disease is a thing of the past!

Newsline is interested in bringing you the reflections of self-advocates who provide rich insights into their lives as persons with disabilities. In this issue, we hear from Samantha Hutt, a young woman who has bipolar disorder. To learn more about the Cognitive Behavioral Therapy Sami mentions in her article, visit the National Alliance on Mental Illness website at www.nami.org/Template.cfm?Section=About_Treatments_and_Supports&template=ContentManagement/ContentDisplay.cfm&ContentID=7952, or the Mass General Hospital Department of Psychiatry website at www.massgeneral.org/地下struct/cbt/whatiscbt.asp.

For more information contact Czarina Biton at Biton@hcfama.org or call 617-275-2838. You can also learn more at www.WatchYourMouth.org.
This easy-to-read and user-friendly book provides clear strategies that parents, professionals and other grown ups can use to deal with and ultimately prevent childhood meltdowns. In addition, Dr. Baker offers ideas adults can use to change their own behaviors so they will be better able to help children manage and change their actions and conduct. The four-step model helps adults:

1) Manage their own emotions and adjust their expectations
2) Learn strategies to calm a meltdown at the moment it occurs
3) Understand why a meltdown occurs
4) Create plans to prevent future meltdowns

The goal of these steps is to help adults improve their relationships with children, prevent meltdowns, and avoid getting into power struggles.

The Feelings Book. The Care and Keeping of Your Emotions.
By Dr. Lynda Madison. Illustrated by Norm Bendell.
American Girl, 2002
Reviewed by Miriam Scrivener, Family TIES of Massachusetts

Puberty and adolescence are tough times for every child, girl or boy. However, if your child is a girl and has emotional, behavioral or developmental challenges, these times are even harder. This book, recommended for ages 8 and up, has explanations about feelings, and advice that all girls of any age, typically and not typically developing, can use.

Girls can learn to identify feelings by learning to read their bodies. The book explains that the brain and the body are like best friends. Thus, being nervous can make a person’s knees bounce up and down; being stressed can make someone weak and shaky or feel like “having butterflies in the stomach,” and so on. What can be done when feelings get out of control? This book provides exercises and activities that will help your daughter relax and stay focused.

More importantly, this book focuses on learning to assess how girls really feel and how to sort out feelings by emphasizing the need to communicate with someone who cares and can help. Anxiety, disrespectfulness, jealousy, anger, loneliness, sadness, grief and safety are some of the feelings discussed in the book. By using the MOOD-O-METER, adolescent girls can learn to gauge their state of mind and body, learn strategies to cope with feelings, relax, and identify positive feelings. Parents can also use this book to help their daughters learn to manage their feelings.

No More Meltdowns: Positive Strategies for Managing and Preventing Out of Control Behaviors
By Jed Baker Ph.D.
Future Horizons, Inc., 2008
Reviewed by Marilyn Gutierrez, Parent Training and Information Project

This easy-to-read and user-friendly book provides clear strategies that parents, professionals and other grown ups can use to deal with and ultimately prevent childhood meltdowns. In addition, Dr. Baker offers ideas adults can use to change their own behaviors so they will be better able to help children manage and change their actions and conduct. The four-step model helps adults:

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Mark your calendars for these upcoming Events

Inclusive Schools Week
8th Annual Celebration • National
December 1-5, 2008
Please visit www.inclusiveschools.org for details and merchandise.

Visions of Community Conference
Seaport World Trade Center • Boston, MA
March 14, 2009

Federation Gala
Annual Celebration • Boston, MA
May 1, 2009

For more information on these or any other Federation events, please call us at 617-236-7210 or email fcsninfo@fcsn.org

INFORMING, EDUCATING, EMPOWERING FAMILIES