The Federation for Children with Special Needs will host its annual Gala on Friday, May 1, 2009, at the Seaport Hotel in Boston. This year’s celebration also marks the 35th anniversary of the Federation. We’ve come a long way since 1974, when Martha Ziegler and others founded what began as a grassroots parent movement, and is now a nationally-recognized, parent-run center that informs, educates and empowers families of all children, including those with special needs in the areas of early childhood, special education and healthcare.

**Gala Honorees Chris and Marianne Cooper**

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The Gala is a time to celebrate our accomplishments and to look forward to what we hope to achieve in the year to come. It is also a time to recognize others for their efforts on behalf of families with children with special needs. Each year, the Federation presents the Martha H. Ziegler Founder’s Award to those who advocate, inspire and promote equal opportunities for all children, including those with special needs. At this year’s event, the Federation will present the Founder’s Award to Academy Award winning film actor Chris Cooper and film and television actress and screenwriter Marianne Leone Cooper for their dedication to assisting families in need to gain access to educational advocacy support and services to improve the quality of children’s education. In addition, the Coopers, along with the New England based Romanian Children’s Relief Fund, have helped raise money for children with disabilities in Romanian orphanages. They also serve on the board of directors of AccesSportAmerica, a nonprofit organization that supports athletic programs for people with disabilities.

**Come Celebrate!**

You can mingle and relax to the smooth jazz sounds of the Tough Love Trio during the reception and silent auction. Afterwards, enjoy the wit and warmth of our Master of Ceremonies, Angela Peri. Angela is an actress, comedian and the founder/owner of Boston Casting. This company has cast actors for the films The Pink Panther, The Proposal, and Real Men Cry, as well as various television shows, such as The Apprentice, Fear Factor and The Sopranos.

**Be inspired!**

The Gala is also a time to celebrate all that you have done to help keep the Federation going for 35 years! You can contribute by:

- **Donating to the silent auction**
- **Becoming a sponsor**
- **Advertising in the event’s program book**
- **Purchasing individual tickets or a table**

We will post additional information, as it becomes available, on our Web site at www.fcsn.org.

If you have questions, or would like to contribute, please contact Selena Sheaves at 617-236-7210, ext. 372 or e-mail ssheaves@fcsn.org.
Losing your home can be devastating. To minimize the disruption to your child’s life, you can continue to have your students attend the same school they attended before your family became homeless, if you want them to, and it is feasible. This right is protected by the federal McKinney-Vento Homeless Education Assistance Act. Decisions about all children should be “student-centered” and “individualized.” Your child’s original school will also provide transportation, if necessary, as well as referrals to medical and dental care and food assistance. If low cost medical or dental services are not available in your community, schools can use McKinney-Vento funding to provide these services directly to your child.

According to the McKinney-Vento act, your child is homeless if he or she lacks “a fixed, regular, and adequate nighttime residence.” This includes those who:

- Live doubled up with friends or family because they cannot afford housing
- Live in motels, hotels, camp grounds, abandoned buildings, bus stations, and parks
- Live in emergency shelters
- Are awaiting foster care placement

If your child receives special education services, the requirement of the federal Individuals with Disabilities Education Act (IDEA) that students be educated in the least restrictive environment does not take away your child’s right to remain in his or her original school district. For example, if you are temporarily living with relatives close to School B but used to live near School A before you became homeless, your child has the right to continue to attend School A until you find a permanent home.

Every school system has a homelessness liaison that can assist you to obtain the services your child needs. Find your liaison by contacting your local school administration office or by calling Peter Cirioni, 781-338-6294, or Sarah Slutterback, 781-338-6330, Massachusetts Coordinators for the Education of Homeless Children and Youth. You can also find a listing of liaisons on the web at http://www.doe.mass.edu/mv/homeless.asp.

For more information:

- Resources on homelessness and special education from the National Center for Homelessness Education: www.serve.org/nche/ibt/sc_spec_ed.php
- MA Department of Elementary & Secondary Education McKinney-Vento Homeless Assistance webpage: www.doe.mass.edu/mv

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On May 1, 2009, we will celebrate the 35th anniversary of the Federation for Children with Special Needs at our annual Gala at the Seaport Hotel in Boston. We hope you will join us for this notable celebration.

For those unfamiliar with our beginnings, in 1972, the Coalition to pass the Massachusetts’ Special Education law wanted to ensure that parents of students with special needs would understand their rights and their children’s rights to educational opportunities under the new law. Martha Ziegler, our founder, and others heeded the call, and the Federation, which began as an ‘around the kitchen table’ idea, is now a nationally recognized, parent-run organization.

We incorporated in 1974, as one of the first parent-run organizations devoted to assisting families of children with special needs in understanding special education laws and navigating the special education system. We inform, educate and empower parents. We also promote parent/professional partnerships so schools, hospitals, public and private agencies, and others will benefit from the shared expertise and experience of parents and professionals working together to provide the services and supports all children need.

Phyllis Sneirson, who retired from the Federation staff after 32 years, once remarked that when the new special education law was passed, she thought parents would only need information and assistance for six months, a year at most. No one ever thought that the advocacy needs of parents on behalf of their children with special needs would become a long time endeavor. But, here we are, and look at some of what we’ve accomplished!

- Thirty-five years of advocacy and assistance to thousands of parents a year.
- Received federal funding as the first Parent Training and Information Center (PTI) in the nation in 1975. As a result, at least one PTI or Community Parent Resource Center exists in every state, including some US territories. The authorizing language is part of the Federal special education law, the Individuals with Disabilities Education Act (IDEA).
- Trained hundreds of advocates throughout the Commonwealth who work and volunteer their time to assist others.
- Helped lay the groundwork for the formation of Family Voices, a national, grassroots organization speaking on behalf of children and youth with special healthcare needs. The Federation chartered Massachusetts Family Voices, one of the original state chapters. The Massachusetts Family-to-Family Health Information Center, one of 41 federally funded Centers throughout the country, is a project of the Federation.
- Supported the development of the Parent Information and Resource Centers (PIRC) under No Child Left Behind. Parent’s PLACE, the Massachusetts PIRC, is a project of the Federation.

We recognize our ‘parents helping parents’ model is effective and powerful. And, while we are proud of our accomplishments, our work is not done. In the months and years ahead, we will face difficult challenges. Resources are vanishing, yet the needs of our children will be as great as ever. Recently, our Board of Directors and members of our staff worked together to develop a strategic plan to help sustain us for the next five years. The Federation remains committed to our work and knows that families are the best advocates for their children. The first 35 have gone quickly. Help us make the next 35 years an even greater success.

Let’s all work towards that end.

Best wishes,
FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

Parent-Teacher Conferences: Tips for Success

By Janet Vohs, Director of Publications, Mass PIRC

A parent-teacher conference is a specific time for parents to meet with their child’s teacher or teachers to discuss the child’s progress in school. Unlike open houses, when parents of all the students in a particular class meet at the same time with the classroom teacher, these conferences are between a teacher and the parents of an individual student. These meetings help teachers gain a better understanding of their students’ learning strengths and needs, and help parents learn ways to support their children’s education at home.

Parents of students with disabilities appreciate these opportunities to meet with general education teachers who may not always be available for IEP meetings. Even if your school does not schedule these conferences, you can request to meet with the teacher whenever you have questions about your child’s participation in a particular class.

Before the Conference:

- Let your son or daughter know you will be speaking with his or her teacher. Ask about his or her favorite and least favorite subjects. Consider inviting your middle and high school students to the conference.
- Bring a list of questions to ask. Ask your child to help prepare the list. Since time is limited, ask the most important ones first.
- Think about your hopes and dreams for your child’s future, and be prepared to share that information with the teacher. Note your child’s special talents and strengths, as well as concerns.
- Note your child’s special learning or health needs, and any updates you want to share. If your child is having difficulty in the class, share the approaches that have worked at home, previously at school, or in other settings.
- Review your child’s most recent test scores, report cards, or schoolwork that reflects strengths and challenges. If your child has taken the MCAS, bring a copy of the “Parent/Guardian MCAS Report.” It is a valuable tool for pinpointing areas where special attention is needed.
- Bring a pen and paper to make notes, to write contact information for the teacher and any follow up you both agree to.
- Notify the school in advance if you need a translator. The school must make every effort to provide one for you. A friend or family member may accompany you and translate, but it is important that your child not be the translator.
- Assure the teacher that you are deeply interested in your child’s academic success, that you appreciate the teacher’s work, and that you fully expect to be a partner in your child’s education.
- Ask what the class will be learning over the next grading period.
- Ask for specific ways you can support your son or daughter’s learning at home. Request study sheets and other information that can help you help your child.
- Ask when you can expect regular progress reports.
- If you do not understand something, ask for an explanation. Being a partner means that you understand what each other is thinking and doing.
- If you don’t agree with the teacher, explain your point of view. Discussing differences of opinion can lead to a better way to help your child.
- Ask the teacher where your child needs to improve, and if additional help or tutoring is needed and available.
- Ask how the teacher prefers to be contacted: e-mail, voice mail, notes, in-person, or another way. Some teachers now use Web sites or classroom newsletters to keep parents up-to-date about classroom assignments and other news.
- Let the teacher know the best way to contact you. If printed material will be sent home, ask how often you can expect it so you can look for it.
- Let the teacher know if school materials need to be translated into your home language.

At the Conference

- Start on a positive note, be on time, and smile. Even if you have met the teacher before, introduce yourself and say the name of your child.
- Ask when you can expect regular progress reports.
- If you do not understand something, ask for an explanation. Being a partner means that you understand what each other is thinking and doing.
- If you don’t agree with the teacher, explain your point of view. Discussing differences of opinion can lead to a better way to help your child.
- Ask the teacher where your child needs to improve, and if additional help or tutoring is needed and available.
Check your notes. Start right away to do the things you and the teacher agreed on. Discuss the plans with your child.

Include your child as part of the team. Stress that you are all working together. When progress is being made, acknowledge your child and the teacher.

Middle-school students are starting to take control of their own learning. Support their independence, while still keeping in contact with the teachers. Think ahead to college and life after high school. Ask what courses are crucial for preparing for college. Help your student select as many rigorous courses as possible.

High school students must score at the Proficiency level on the 10th grade MCAS tests in reading and math or score at the Needs Improvement level in those subjects and successfully complete an Educational Proficiency Plan (EPP). Students must also meet or exceed the Needs Improvement score on one high school Science, Technology/Engineering MCAS test in order to receive a diploma. If MCAS scores show that your child needs extra help to pass, ask for tutoring immediately.

Keep in touch with the teacher to discuss progress and make adjustments as needed.

If you can’t attend a conference as scheduled, ask to reschedule for another place or time.

While staying in touch with your child’s teacher is a good idea all year long, these individual meetings are an opportunity to deepen your relationship and build a strong alliance with the teacher. Today, powerful alliances between families and teachers are more important than ever as students with disabilities continue to forge new pathways for inclusion. Classrooms and teachers may not be used to accommodating a wide range of learning differences. Families may not be accustomed to participating beyond IEP meetings. Parent-teacher conferences are important opportunities to help ensure that all parties experience the benefits of an inclusive education.

Massachusetts PIRC is eager to support families in their efforts to participate in their children’s learning. If this article raises questions or you need further information, please contact us by e-mail at plpace@fcsn.org, or by phone, toll free, at our tri-lingual Info Line at 1-877-471-0980.

MA Family-to-Family Health Information Center

By Beth Dworetzky

Community Health Forum
On December 18, 2008, the Massachusetts Family-to-Family Health Information Center and the Catalyst Center, a national center for improving financing of care for children and youth with special healthcare needs, co-hosted a Community Health Forum for the Obama-Biden Transition Project. These forums, held throughout the country, were an opportunity to discuss healthcare reform and submit ideas that the Transition Healthcare Policy Team could use to revamp the healthcare system, and promote affordable, quality healthcare.

The Transition team provided the list of questions. Our discussion focused on the unique needs of children and youth with special healthcare needs (CYSHCN), and other individuals with disabilities. Attendees agreed that healthcare that works for individuals with special health needs works for all individuals, while the reverse is not always true. For example, prevention services must be more comprehensive for individuals with special health needs and should include counseling and medical equipment. Many children with complex health needs experience bouts of depression when they are older. If counseling was a preventive service, it would help avoid the number of prescriptions for mood disorders and depression. Additionally, if an individual does not have the correct communication device, braces, or wheelchair, he or she can’t be out in the world in a productive way.

The group also identified aspects of the current health system that are problematic. To name a few: there is a disconnect between mental health and physical health services, the employer-based insurance system, under insurance, and the lack of reimbursement for the amount of care coordination needed by children and youth with special healthcare needs.

To share your concerns about healthcare, visit www.change.gov. To read the document submitted by this Community Health Forum, e-mail massfv@fcsn.org.

The Massachusetts Family-to-Family Health Information Center provides information about MassHealth programs to families with children and youth with special healthcare needs. To learn more, call 1-800-331-0688, ext. 210, e-mail: massfv@fcsn.org or visit www.massfamilyvoices.org.

Respite Brochure

The Massachusetts Family-to-Family Health Information Center and the Community Based Systems of Care Workgroup at the Consortium for Children with Special Healthcare Needs have created Getting a Break: A Roadmap to Respite Care for Massachusetts Families of Children with Special Healthcare Needs. This brochure includes a list of respite services available through state agencies, eligibility, a short description of how it works, and contact information. There are also tips, shared by other parents, about finding respite care and making the most of family time to get a needed break from care giving. The brochure is available on-line at www.massfamilyvoices.org/Respite%20Brochure.pdf. If you’d like a hard copy mailed to you, call the MA Family-to-Family Health Information Center at 1-800-331-0688, ext. 210.
Findings from the Advancing Parent/Professional Leadership Development in Education (APPLE) Project

By Barbara Popper

The goal of the APPLE Project, funded by the U. S. Department of Education, was to help build better relationships between parents and schools around issues of special education. The Federation created and presented APPLE Training Institutes for parents and special education personnel. Our research partners at the Institute for Community Inclusion (ICI) at the University of Massachusetts-Boston interviewed participants, and administered surveys. The purpose of the survey was to see if participation in the Institute helped create improved partnerships between school administrations and the Parent Advisory Committees (PACs).

In the first three years of the project, 79 parents participated. A Special Education (SPED) administrator participated as a member of each school district’s team.

Parents filled out research surveys before and after attending the three-day Institute. ICI compared the before and after survey results to analyze the impact of the Institute. They were also able to identify ways that participants used what they learned at the Institute to increase their leadership skills and assume more active leadership roles in their PACs. The most significant findings of the APPLE project include:

1) After the Institute, 93% considered themselves “active” PAC members, whereas only 73% thought they were active PAC members prior to the Institute.

2) Before the Institute, only 39% felt “really part of the PAC;” afterwards 73% felt “really part of the PAC.”

3) After the Institute, 75% considered themselves parent leaders, vs. 53% prior to attending the Institute.

ICI also interviewed the SPED administrators about the impact of the Institute on SPED-PAC relationships. They noted there was improved communication, and that both SPED administrators and PAC parents had a better understanding of each other’s roles and responsibilities. In addition, the PACs were more independent and less reliant on the SPED administrator.

The surveys identified challenges faced by PAC leaders. These included separating out their personal issues from their roles as parent leaders, working with the school district on school politics, ambiguity about the mission of the PAC, and recruitment of new members. We will share additional data when the analysis is completed.

Based on the results of the Institute, the Federation will create materials that school districts can use to identify barriers to PAC-SPED partnerships, create action plans to overcome those barriers, and improve parent-professional partnerships.
How to Succeed in High School When You Have a Disability

By Becky Rizoli

Voices of Self-Advocates: 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 Becky Rizoli, a young woman who has ADD.

If you are a person with disabilities and would like us to consider your personal story for publication, please send your reflection in the mail to: Federation for Children with Special Needs, Attn: Amanda Green, 1135 Tremont Street, Ste. 420, Boston, MA 02120, or e-mail your submission to Amanda at agreen@fcsn.org. Submissions should be no longer than 500 words in length. The Federation reserves the right to edit your contribution.

High school can be difficult. There is pressure to make good grades, fit in socially, pass MCAS, and prepare for life after high school. When you have a disability, high school can be even more of a struggle. I have attention deficit disorder (ADD) and learning disabilities; my high school years were challenging. However, thanks to the support services I received, and my own determination to succeed, I was not only able to graduate on time, but also to make honor roll. Afterwards, I attended college, and earned my bachelor’s degree. Today, I work at the Federation for Children with Special Needs.

Here are some tips that helped me succeed; they can help you be successful too.

· Learn the name of your disability. It was very helpful to me to be able to refer to my disability by the clinical name—Attention Deficit Disorder—instead of just saying that I was “different” or that I had “special needs.” It made me realize that I had a genuine medical condition that many others also have, and that there was a medical reason why I had trouble paying attention. For example, when talking with my instructors, it was more effective to say, “I have ADD, and will need copies of class notes,” rather than, “I have trouble paying attention in class, and will need copies of class notes.” When you state your request using the specific name of your disability, people are more likely to provide needed accommodations.

· Learn how your disability affects you, and the accommodations you need to do well. The more you know about your disability and your learning style, the better prepared you’ll be to advocate for yourself. The Americans with Disabilities Act (ADA), a federal law prohibiting discrimination based on disability, states that public schools and workplaces must provide reasonable accommodations for individuals with disabilities. For more information about the ADA, and how it applies to employment and school, visit www.ada.gov/qandaeng.htm. Note: Once you graduate high school, self-advocacy skills are vital. You will no longer have an IEP that lists services and supports you need, and your parents and teachers won’t be there to advocate on your behalf. Most colleges and universities have disability services and can work with you to make sure you have the accommodations you need to be successful.

· If you are 14 or older, attend your IEP meetings. This is your opportunity to talk about your strengths—the things you like to do, and do well. It is also the time to address your weaknesses so you can be specific about any modifications or other supports you need. It’s also great practice, as you’ll have parents, teachers, friends, coaches and others to help model the advocacy skills you need to develop in order to advocate for yourself.

· Get involved in after-school activities. These look great on your resume, and are an opportunity to meet new friends who share a common interest. Perhaps you would like to try out for a sports team, join the chorus, audition for a school play, write for the school newspaper, or join the photography club. During high school, I participated in the theater program. It helped me overcome my shyness and develop confidence. Overall, it was a wonderful experience. And, the added bonus was a whole new group of friends.

Having a disability does not mean you are stupid and cannot do well. Many successful, accomplished people have disabilities. Stephen Hawking, a world-renoun scientist, has amyotrophic lateral sclerosis, a progressive neurodegenerative illness. Singer-pianist Stevie Wonder is blind. Olympic gold medalist Michael Phelps has Attention Deficit/Hyperactivity Disorder. The actor Leonardo DiCaprio has obsessive-compulsive disorder (OCD), a type of anxiety disorder. Walt Disney, famous for creating animated characters and theme parks, had a learning disability. There was the young girl with a serious stuttering problem. She learned to overcome it and eventually pursued a career in acting. Today, Julia Roberts is one of Hollywood’s most successful actresses. We’re fortunate to have such good role models; if these people can succeed, we can too!
Seven Tips for Partnering with Your Child’s School During the Transition Years

By Amanda Green, Parent Training and Information Project

Before you realize it, your child is a teenager. When he was young, he was eager for you to admire his finger painting, attend school events, and help out with math circle. Now school notices are lost in the backpack, and the answer to “How was your day at school?” is a mutter. Your child is learning to be independent, yes, but does this mean that you have a lesser role to play? No! In fact, during the Transition years of 14 – 22, the partnerships you foster with your child’s school can be key to his success as an adult.

Contrary to what you might think, research clearly shows that parents – not peers – still exert the biggest influence on teenagers. Teens whose parents are involved at school, check homework, and know their children’s friends have more positive post-high school outcomes than teens whose parents do not.

How can you stay involved during the middle and high school years? Here are seven tips:

• Most importantly, get to know your child’s teachers, and make sure they know you and your child. Middle and high school teachers are committed to helping kids – yet they are exceptionally busy people, often with large numbers of students. At the beginning of the year, make a pleasant phone call or send a cheerful e-mail introducing yourself as Sarah’s Mom, expressing your interest in partnering, and asking how you can be most helpful.

• By law, teachers are responsible for implementing your child’s Individualized Education Program (IEP). Ease your child’s transition to the new year by creating a “Sarah-at-a-Glance” one-page document, highlighting your child’s learning strengths and needs, as well as necessary accommodations and modifications. Sitting down with your teen to draw this up together will help to develop her self advocacy skills. Distribute this document to all your child’s teachers and service providers. Your child’s teachers will still need to read the entire IEP, but your one-pager will help the process along.

• According to the law, your child is entitled to receive progress reports as often as children who do not have IEPs. If you want more frequent updates, phone your child’s teacher at regular intervals – perhaps once a week – and ask for a return phone call. Educators are usually good about returning calls, but they are busy people and appreciate reminders. If your child’s school uses a Web site to update parents on student progress and assignments, be sure to check it regularly. Talk to your child about his schoolwork, too. Even though he’s older, he will be more successful if he knows you’re still interested and involved.

• During the Transition years, it’s important for you, your child, and the school to begin partnering together so that your child will develop the skills necessary for a successful adulthood. The Massachusetts Department of Elementary & Secondary Education has created a Transition Planning Form, http://www.doe.mass.edu/sped/28MR/28m9.pdf, which you can print out and bring to your child’s IEP meeting. Before the meeting, use the form as a guide to talk with your child about his vision for the future. What kind of job would he like to have? Where would he like to live? What are his hobbies, talents, interests? What are his needs? What skills will he need to develop to achieve his vision? At the IEP meeting, use this information to guide the Team’s discussion. From age 14 onward, your child must be invited to attend IEP meetings so both you and your child will be able to provide key input into the process. Once the discussion is concluded, goals should be transferred from the Transition Planning Form to the IEP.

• Learn about best practices in Transition by searching the Web, by reading, and by attending workshops. Share information and resources with your child (to help her become an effective self advocate) and with her teachers. Good general books on Transition planning include: Universal Design for Transition: A Roadmap for Planning and Instruction by Thoma, Bartholomew, and Scott and What Every Teacher Should Know About Transition and IDEA 2004 by Kochhar-Bryant, Shaw, and Izzo. Review the Transition Web sites in the Spring 2008 issue of Newsline, available online at http://fcsn.org/publications_resources/newsline/nlv28n4.pdf. Three times a year, the Federation sponsors a two-day Transition planning conference. Learn more at http://fcsn.org/pti/workshops/transition.php, and invite your child’s teachers to attend with you!

• Network with other parents in your local special education parent advisory council (PAC). Learn about your school district’s services for students of Transition age, and volunteer to meet regularly with school officials as a PAC representative to discuss district Transition programming. According to state law, the PAC’s role is to advise the school district “on matters that pertain to the education and safety of students with disabilities.” By partnering with other parents and with your school, you can have a positive impact on both your own child’s education and on the education of all students on IEPs.

Make community connections. Get to know local business owners. Find out how people with disabilities can become involved in your community through recreation programs, volunteering, or jobs. Not only will you build future connections for your own child, you will also help to increase opportunities for other students when you share these resources with your school.

By Barbara Donati and Mary Castro Summers, Family TIES of Massachusetts

Parents of children with special healthcare needs have a lot on their plates. Their children’s care includes the everyday issues of friendships, schoolwork, and what they’d like to be when they grow up. It also includes the complex issues of dealing with, understanding and managing their children’s medical needs, as well as creating opportunities for their children to participate safely and as much as possible in the same activities as their peers. If you wanted support in dealing with these challenges, where would you turn? Your child’s primary care physician and staff can be resourceful allies in helping to manage the medical and community supports your child and family needs.

Medical Home is a concept promoted by the American Academy of Pediatrics (AAP) and the federal Maternal and Child Health Bureau. The Medical Home is not a physical place. Rather, it’s an attitude shared by your child’s medical team, of which you are an integral partner. The key elements include the identification of a primary healthcare provider (or specialist, if that is the team’s decision) who will ensure your child’s care is accessible, continuous, comprehensive, family-centered [Editors note: learn about the new Family-Centered Care Self-Assessment Tools on page 14], coordinated, compassionate, and culturally and linguistically competent.

For parents who have a child with special healthcare needs, which includes chronic illness, a disability or a complex medical condition, the Medical Home is where healthcare and support services intersect. Medical providers and the family work together to coordinate the child’s medical care and needed supports so the child can participate as fully as possible in his or her community.

Why would a medical provider take on this complicated role? Evidence-based research shows that children whose primary health providers oversee acute care, preventive care, and chronic health management are healthier. This is good news for the child, the family, the medical system, and health insurers. This practice improves outcomes and satisfaction for everyone.

How can parents learn more about creating parent-professional partnerships with their child’s primary care provider, ensuring family-centered care, and identifying a Medical Home for their child? Read about the new family-centered care self-assessment tool in this issue, and visit the AAP’s National Center for Medical Homes Initiatives Web site at www.medicalhomeinfo.org. Then, meet with your child’s primary care team to review your child’s medical history, current health status, and ways to promote health and wellness. Share information about your child’s life outside of the healthcare setting - school, community activities, recreation - and develop plans to manage potential healthcare emergencies to lessen their impact. A primary benefit of a Medical Home is the peace of mind that comes from knowing your child’s special healthcare needs will be more fully addressed.

Family TIES of Massachusetts is a statewide parent-to-parent information and support network for families of children with disabilities, special healthcare needs, or chronic illnesses. For more information, call 1-800-905-TIES (8437) or visit www.massfamilyties.org.
Perder la casa puede ser algo devastador. Para minimizar las dificultades que esto puede causar en la vida de su niño, usted puede solicitar que él o ella siga llendo a la misma escuela a la que asistía antes de que su familia se quedara sin hogar, si así lo desea y si es posible. Este derecho está protegido por la Ley Federal McKinney-Vento de Asistencia Educativa a Personas Sin Hogar (McKinney-Vento Homeless Education Assistance Act). Las decisiones con respecto a cada niño deben “individualizarse” y “centrarse en el estudiante”. Si fuera necesario, la escuela original de su niño también ofrecerá transporte y recomendaciones para servicios de atención médica, dental y de ayuda con la alimentación. Si en su comunidad no hubiera servicios médicos o dentales a bajo costo, las escuelas pueden usar fondos de McKinney-Vento para brindarle estos servicios directamente a su niño.

Según la Ley de McKinney-Vento, se considera que un niño está sin hogar si no tiene “una residencia nocturna fija, regular y adecuada”. Esto incluye a aquellos niños que:

- Comparten un cuarto con amigos o familiares porque su familia no tiene suficiente dinero para pagar su propia vivienda
- Viven en moteles, hoteles, campamentos, edificios abandonados, estaciones de autobús o parques
- Viven en refugios de emergencia
- Aguardan colocación con una familia de crianza (cuidado tutelar)

Si su niño recibe servicios de educación especial, el requisito de la Ley Federal de Educación para Personas con Discapacidades (Individuals with Disabilities Education Act o IDEA) de que los estudiantes reciban educación en el ambiente menos restrictivo, no elimina el derecho de su niño a permanecer en su distrito escolar original. Por ejemplo, si usted vive temporalmente con parientes cerca de la Escuela B pero antes de quedarse sin hogar vivía cerca de la Escuela A, su niño tiene derecho a seguir asistiendo a la Escuela A hasta que usted encuentre un hogar permanente.

Todos los sistemas escolares tienen una persona de enlace para personas sin hogar que puede ayudarle a obtener los servicios que su niño necesita. Póngase en contacto con esta persona de enlace llamando a la oficina administrativa de su escuela o a Peter Cirioni (781-338-6294) o Sarah Slatterback (781-338-6330), coordinadores en Massachusetts del Programa de educación de niños y jóvenes sin hogar (Education of Homeless Children and Youth). También podrá encontrar una lista de personas de enlace en esta página de Internet: http://www.doe.mass.edu/mv/homeless.asp.

Para más información:
- Recursos para personas sin hogar y de educación especial del National Center for Homelessness Education: www.serve.org/nche/ibt/sc_spec_ed.php
- Página de Internet del Departamento de Educación Primaria y Secundaria de Massachusetts (Massachusetts Department of Elementary and Secondary Education) sobre la Ley Federal McKinney-Vento de Asistencia Educativa para Personas Sin Hogar: www.doe.mass.edu/mv

¿Está por perder su casa? Conozca los derechos de educación de su niño

Por Amanda Green, Proyecto de Información y Capacitación de Padres

Support the Federation for Children with Special Needs

The Federation for Children with Special Needs relies on donations to continue providing workshops, trainings and support to families with children with special needs throughout the state of Massachusetts. Due to budget cuts at schools and state agencies, which are resulting in a decrease in services, families need us more than ever for help understanding healthcare financing options, special education, and effective advocacy. Without your support, the Federation would not be able to provide crucial services to families in need. We are grateful for the donations we have received but we, like many, have been affected by the economy and are well below our goal. You can make a difference!

Please help the Federation continue to inform, educate and empower families of children with special education and special health care needs!

To make a donation, please send your check, payable to the Federation for Children with Special Needs, to 1135 Tremont Street, Suite 420, Boston MA 02120. Additionally, you can call Selena Sheaves at 617-236-7210, ext. 372 or make a secure donation online at http://fcsn.org/giving_events/annual_appeal.php.

From all of us at the Federation and the families we serve, thank you for your support!
The CHINS program was developed to help youth with problem behaviors, such as running away from home, refusing to obey his or her parents or guardian, truancy and chronic violation of school rules. While these behaviors are not illegal, they are “not in the youth’s own best interest.” The CHINS program seeks to change the youth’s negative behaviors in the hope of preventing future, more serious delinquency. The CHINS process utilizes the juvenile court’s authority to order the youth to adhere to behavioral guidelines, such as a curfew or consistent school attendance. The court may also order services such as psychiatric, behavioral, or therapeutic counseling, or individual and/or family therapy. Other services may include educational supports, mentoring programs, medical services, camp or other recreational programs, volunteer opportunities or employment. Services are most often provided in or near the youth’s community.

A CHINS may be filed by the parent/legal guardian or police for child below age 17 who runs away from home (CHINS Runaway) or refuses to obey household rules (CHINS Stubborn). Police or school authorities can file a CHINS on a child, age 6 through 16 (the age at which youth in Massachusetts can legally choose to stop attending school) who do not attend school (CHINS Truant) or repeatedly violate school regulations (CHINS Habitual School Offender).

It is important to note a CHINS is likely to be ineffective for a youth who has serious mental health needs, which may hinder judgment or influence actions. Special health care needs which limit or restrict cognitive skills can also hinder a youth’s ability to successfully comply with a CHINS. Additionally, a CHINS is less likely to be effective when the youth’s negative behaviors are the result of environmental factors which are beyond the youth’s control or ability to avoid. These include school or neighborhood bullies, high crime environments, deficits in basic essentials or living conditions, or abuse or neglect in other forms.

When a youth makes the choice to comply with the court’s directives, and has the ability to effectively follow through on that choice, he or she is a candidate for a successful CHINS intervention. The quality of the relationships between the youth and the involved adults are also important elements in the process. CHINS requires the youth to comply with the court’s orders, which are monitored and enforced by his/her probation officer and parents or guardians. Depending upon the reason for the CHINS, there may be other monitoring adults such as local police officers and school officials.

A successful CHINS can reverse a negative behavior path and motivate a youth to make positive choices and engage in appropriate behaviors. Some reflective youth are able to recognize why the CHINS was filed and appreciate the adults involved in the process. Likewise, adults involved in the process may become more attuned to the youth’s needs and develop increased ability to interact and communicate effectively with the youth. A successful CHINS outcome can have a lasting positive impact on the entire family. On the other hand, a youth who is unable or unwilling to comply with the CHINS requirements is much less likely to have a successful outcome or improved relationships.

Before filing a CHINS, a parent or guardian should carefully weigh the pros and cons of the program and draw from their own parental experience to estimate the likelihood of a successful outcome for their child. Some youth may react very negatively to a CHINS and flatly reject the court’s requirements. For others, the CHINS filing could trigger a violent outburst and/or inflame family relations. Parents should proceed with caution even if a CHINS has been recommended by the child’s school, a police officer, doctor or hospital staff, or other trusted professional.

To learn more about the CHINS program and how to file, contact a juvenile police officer in your community or your county juvenile court (www.mass.gov/courts/courtsandjudges/courts/juvenilecourt/index.html).

This article is excerpted from a Child In Need of Services Fact Sheet for Parents and Advocates. Call 617-236-7210 for a copy or download it from the website at www.fcsn.org.
Perder a Sua Casa? Saiba os Direitos Sobre a Educação de Seu Filho(a)

Por Amanda Green, Projeto de Treinamento e Informação dos Pais

Perder a sua casa pode ser devastador. Para minimizar o transtorno para a vida de seu filho(a), você pode continuar a ter os estudantes frequentando a mesma escola que eles frequentavam antes da sua família ficar desabrigada, se você quiser que eles continuem a frequentar e é viável. Este direito está protegido pela Lei Federal de Assistência Educacional para os Desabrigados McKinney-Vento. As decisões sobre todas as crianças deverão ser “centralizadas no estudante” e “individualizadas.” A escola de origem de seu filho(a) também providenciará por transporte, caso necessário, bem como referências para tratamento médico e dentário e assistência para a alimentação. Se os custos dos serviços médicos e dentários não estiverem disponíveis em sua comunidade, as escolas poderão usar os fundos da lei McKinney-Vento para providenciar estes serviços diretamente ao seu filho(a).

De acordo com a lei McKinney-Vento, seu filho(a) estará desabrigado se ele ou ela não tiver “uma residência fixa, regular e adequada para o período noturno”. Isto inclui aqueles que:

- Vivem partilhando acomodações com amigos ou família porque não podem pagar por uma casa
- Vivem em motéis, acampamentos, edifícios abandonados, terminais de ônibus e parques
- Vivem em abrigos de emergência
- Estão esperando ser colocados em estabelecimentos para cuidados temporários de crianças

Se seu filho(a) recebe serviços de educação especial, o requisito da Lei Federal de Educação para Indivíduos com Deficiência (IDEA) que é o de que os estudantes sejam educados em ambiente menos restritivo, não tira o direito de seu filho(a) de permanecer em seu distrito de origem. Por exemplo, se você estiver morando temporariamente com parentes perto da Escola B mas costumava viver perto da Escola A antes de que você ficar desabrigado, seu filho(a) terá o direito de continuar a frequentar a Escola A até que você encontre uma residência permanente.

Cada sistema escolar tem um intermediário de contato para os desabrigados, Homeless liaison, que poderá auxiliá-lo(la) para que possa obter os serviços dos quais o seu filho(a) continua na página 14.
The New Year is an opportunity to re-evaluate priorities and renew commitments to our communities and ourselves. This year, let’s work together to make children’s oral health a top priority in the Commonwealth. The Watch Your Mouth campaign works statewide to increase public awareness about the importance of oral health as part of overall health and wellness. This February, let’s celebrate Children’s Dental Health Month together!

Dental disease is a silent epidemic that profoundly impairs children’s educational progress and basic daily activities, such as eating and speaking. In fact, children miss approximately 51 million school hours every year due to oral health related absences. Fortunately, dental disease is almost entirely preventable, but only when preventive care and access to health insurance and dental providers is available. This winter, let’s raise the bar by ensuring that every child has an equal start in life. Through the Watch Your Mouth Campaign, medical professionals, educators, parents and others are banding together to identify solutions for ensuring preventative oral health care for all children, and working to enact them.

Massachusetts, known for its long history of innovation in public health and education, falls far behind other states in the nation when it comes to the simple issue of children’s oral health. Communities need to work together to ensure children have access to preventive treatments such as early childhood screenings and dental sealants. Having these services available in schools by developing partnerships with dental professionals or school-based health centers are important ways to reach all children. Schools today require immunizations, hearing and vision screenings. By including dental examinations as part of this health requirement, we would be making a commitment to children’s oral health.

February is Children’s Dental Health Month and there is much to celebrate! You can speak up for children’s oral health by distributing Watch Your Mouth educational materials in your community or helping your community understand the importance of oral health by writing a letter to the editor or OpEd (opinion editorial) for your local newspaper. Learn more at www.watchyourmouth.org/massachusetts.php, and contact Czarina Biton at biton@hcfama.org or 617-275-2838 to find what you can do during Children’s Dental Health month.

Let’s work together, 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!

Project Adventure: Inclusive Recreation for Children with Special Health Needs

By Amy Yang, Project Adventure, Children’s Hospital Boston

Project Adventure is a community based project run by Children’s Hospital Boston. This project promotes inclusive recreational experiences for children and youth with special healthcare needs and disabilities at the Central, Brighton, Chinatown and Roxbury branches of the YMCA. Staff matches adult volunteers with children with special healthcare needs or disabilities, between the ages of 6 and 15, at these Boston area YMCAs so they can participate in an activity of the child’s choice. The adult volunteer’s role is to provide any mental and physical assistance the child needs to take part in the activity. The adult volunteers are mostly college students who are interested in careers in the fields of health or education. Project Adventure is looking for both interested families (with children ages 6-15) and adult volunteers (18 and older) to participate in this inclusive recreational opportunity.

The time commitment is two hours a week for six months. While families are expected to remain on site at the Y while their child participates, they will receive a free family membership so they can enjoy an activity of their choosing, or engage in family activities with their other children.

For more information about having your child participate, or becoming a volunteer, contact Amy at 857-218-4320, or e-mail amy.yang@childrens.harvard.edu.

February is Children’s Dental Health Month

By Czarina Biton, Health Care For All

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Family-Centered Care: Self-Assessment Tool

Family-centered care is one component of the Medical Home. It addresses the partnership between the family and health provider that is essential to ensuring quality healthcare for a child, while at the same time supporting the family's needs for information, as well as connections to services and supports. The Maternal and Child Health Bureau (MCHB) states: Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family-centered care is the standard of practice that results in high quality services.

Family Voices, with funding from the MCHB, has developed a Family-Centered Care Self-Assessment tool. These materials were designed to assist both families' and primary health care settings' awareness about the implementation of family-centered care. The provider version of the tool provides an organized way for primary care staff to identify what they do well, and create a plan to address areas that need improvement. The goal of the family version of the tool is to help families understand their role as a partner in their child's health care, and their role in helping to develop practices and policies in the healthcare setting. Copies of the tools, and the user's guide, are available at www.massfamilyvoices.org.
Book Review

Late, Lost and Unprepared: A Parents’ Guide to Helping Children with Executive Functioning
By Joyce Cooper-Kahn and Laurie Dietzel
Woodbine House Special Needs Collection. 2008, 220 pp
Reviewed by Beth Dworetzky, Massachusetts Family-to-Family Health Information Center

“The executive functions are a set of processes that all have to do with managing oneself and one’s resources in order to achieve a goal. It is an umbrella term for the neurologically-based skills involving mental control and self-regulation.” These skills include the ability to: control emotions, initiate, plan and organize activities, transition from one task to another, and independently solve problems.

The authors, both clinical psychologists, wrote this book for parents, teachers, and other professionals who work with children. They provide a comprehensive discussion about executive functioning and how it affects an individual's learning, social interactions, and ability to cope. At the same time, they stress that executive function weaknesses, or dysfunction, do not provide a complete picture of a person. Executive dysfunction does not influence how smart, engaging, imaginative, nice, etc a person is. Moreover, it does not define an individual’s talents or abilities in other areas. Most important, this book provides concrete strategies, and examples that illustrate how to implement these strategies to help children develop the skills they need to compensate for any executive weaknesses and to be successful, both academically and socially.

Just as there are developmental milestones for physical development, for example, when a child learns to walk or talk, there are milestones for the development of executive functions. There is a lot of variability in the rate at which children development executive function control. Children who need more time to develop these controls, or who have executive weaknesses tend to experience a lot of frustration, which puts them at risk for developing low self-esteem. The parent’s role is to acknowledge their child’s strengths, help them understand their weaknesses, and then figure out the supports they need to solve problems and manage themselves in various situations.

If you suspect your child has executive weaknesses, there is guidance about the types of professionals who test for executive dysfunction. Assessments help rule out other problems and can pinpoint the area or areas of executive function where a child needs support. Parents can share this information with teachers and other professionals and develop partnerships to support the child at school and at home.

Woodbine House has donated a copy of the book to the Federation, which you can borrow by calling 617-236-7210. Learn more about the Special Needs Collection at www.woodbinehouse.com.

Parent Consultant Training Institutes

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.


Summer 2009: Monday through Friday, June 22 – June 26, 2009, 9 am – 4 pm. Central MA location to be announced.

For more information, and to download the application, visit http://fcsn.org/pti/advocacy/becomeanadvocate.php.
Federation for Children with Special Needs

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