On March 13, 2010, almost 900 families raising children with special needs, professionals and exhibitors from throughout the Commonwealth filled the Seaport World Trade Center in Boston. Their backgrounds and experiences were diverse, and included families who spoke Chinese, Portuguese, Spanish and Somali, but their purpose was the same – to attend the annual Visions of Community conference hosted by the Federation for Children with Special Needs. Some families were first time attendees; others attend every year. One conference ‘regular’ remarked, “You guys have hit another homerun!” The entire Federation staff, Board of Directors, and numerous volunteers worked hard to provide a great day of learning and networking.

“A goal of the Visions of Community conference is to provide a place where individuals with a common interest – that of raising children and youth with special needs – can find each other and realize they are not alone.”

Opening Session

At the opening session, the Federation’s Executive Director, Rich Robison, welcomed everyone on behalf of the Federation and conference co-sponsors, which included the Early Intervention Parent Leadership Project, Massachusetts Families Organizing for Change, and the Parent/Professional Advocacy League. Additionally, Dr. Robison acknowledged the generous support of the Seaport World Trade Center, who donated the conference space and the breakfast.

Dr. Robison provided context for the name of the conference, citing a Webster’s dictionary definition of ‘community’ as “A group or class having common interests.”

Continues on page 8
MassPAC in Action: Encouraging Parent Leadership and Parent-District Partnerships throughout the State

By Amanda Green, MassPAC Coordinator

According to Massachusetts state special education regulations, each school district should have a Special Education Parent Advisory Council (PAC) which advises the district on “matters that pertain to the education and safety of students with disabilities” and also participates “in the planning, development, and evaluation of each district’s special education programs.”

The Massachusetts Association of Special Education Parent Advisory Councils (MassPAC) is celebrating its first year as a project at the Federation for Children with Special Needs. MassPAC’s mission is to help PAC leaders work effectively with schools in order to improve the education of students with disabilities. Highlights from the year include:

- Parent leaders from 37 PACs attended trainings in Boston, Foxborough, and Holyoke.
- Nearly 1500 e-mail messages were posted to the MassPAC listserve.
- Two webinars about needs assessment surveys and outreach to diverse populations attracted parent leaders from around the state.
- MassPAC established an Advisory Board with four experienced PAC Chairs and two experienced administrators of special education.
- MassPAC Coordinator Amanda Green and Advisory Board member Candace McCann were invited to present at the Massachusetts Administrators for Special Education conference in March.
- MassPAC partnered with the Massachusetts Department of Elementary and Secondary Education (DESE) on the final editing of the DESE Guidance for Special Education Parent Advisory Councils publication. Read this technical assistance document at www.doe.mass.edu/sped/pac, and share it with your district!

If you are the parent of a child with a disability, consider getting involved with the PAC in your district! You can make a genuine, positive difference for your child. If you are a PAC leader, consider getting involved with MassPAC! We are here to help you. For more information, visit the MassPAC Web site, www.masspac.org, or call MassPAC Coordinator Amanda Green at 617-399-8307.

HERE’S WHAT PEOPLE ARE SAYING ABOUT MASSPAC...

"Being a member of MassPAC has given us a way to develop the focus and impact of our PAC. Thank you!” PAC Chair

“I really look forward to working with you to build a new, trusting relationship with the PAC.” Administrator of Special Education

"Through the training on Saturday I have realized what a critical role the PAC can play in shaping the Special Education program in our district and the importance of my role as the PAC Chair.” PAC Chair.
Finally, the Health Care Reform debate has ended. The President signed the “Patient Protection and Affordable Care Act (P.L. 111-148)” on March 23, 2010. While media coverage of this historic event has highlighted the controversial issues and breadth of reactions to the legislation, the bill does include key policies that will benefit many families of children with special needs. Many of these have escaped broad media attention.

For instance, as the new law is phased in, it will ensure that everyone has access to health insurance. It also prevents health insurers from refusing coverage to children with “pre-existing conditions.” Families of children with special health needs no longer will have to fear financial catastrophe will result from their child’s diagnosis.

The new law includes continued funding for the Family-to-Family Health Information Centers. These centers, located in every state, help families raising children and youth with special health needs access services, health care information, and supports. The Massachusetts Family-to-Family Health Information Center is a project of the Federation.

Two additional important aspects of health reform, which will positively change the quality of life for thousands of individuals with disabilities in the years to come, have virtually escaped public discussion. First, the bill contains the provisions of the CLASS Act, (Community Living Assistance Services and Supports). The purpose is to help adults with “severe functional impairments” obtain the services and supports they need to stay functional and independent, while providing them with choices about community participation, education and employment. For many years, the community of advocates for individuals with disabilities fought to “establish a national, voluntary insurance program for purchasing community living assistance services and supports.” This act now includes provisions that will provide a cash benefit to individuals with ‘functional limitations,’ so they can purchase the non-medical services and supports necessary to maintain community residence. This is a huge step forward for adults with disabilities.

A second provision will extend the Medicaid “Money Follows the Person” Rebalancing Demonstration program through September 2016 (effective 30 days following enactment), and allocate $10 million per year for five years to continue the Aging and Disability Resource Center initiatives through 2014. This will provide states with new options for offering home and community-based services through their state Medicaid programs instead of having to apply for a federal waiver. Finally, it will establish the Community First Choice Option in Medicaid to provide community-based attendant supports and services to individuals with disabilities who require an institutional level of care. For many years, Senator Kennedy worked to create this option for families and individuals, and it is a dream come true. Individuals with disabilities will be able to remain in their communities with appropriate supports and services!

On the day President Obama signed the “Patient Protection and Affordable Care Act,” we received a message from Connie Garner, who for many years worked with Senator Kennedy as a staff member of the Health, Education, Labor and Pensions (HELPs) Committee. She wrote, “I wanted to wait until today, when the health care bill was signed, to congratulate all of you for the most incredible effort I have ever seen to achieve social supports for those with functional limitations. Remember how this was never going to happen? How this was not the right time? How it wasn’t really health care? .... well you overcame all those obstacles by working together and bringing forward the voice of ‘real people’ to their representatives in Congress. I want to thank you all on behalf of Senator Kennedy’s wish and real desire to see this program enacted.”

The Federation, in turn, extends our sincere thanks to Connie for her leadership and perseverance in helping to achieve this incredible victory. With these new reforms in place, our family members’ futures are much brighter.

Best wishes for good health,

Rich Robison
Executive Director
Nurses work in a variety of settings, with a wide range of duties, but their aim is the same - to ensure improved health outcomes and opportunities in everyday life for children, youth and their families. Here are some examples of the many ways that nurses care for our children:

• **Hospital nurses** oversee all aspects of their patients’ needs and provide day-to-day care during a stay, long or short. **Nurse Managers and Nurse Educators** support the nursing staff.

• **Nurses working in a doctor’s office** provide direct care. They monitor vital signs, administer immunizations, and document health concerns. They also help facilitate communication between families and medical providers and sometimes with health insurers to ensure services are covered and that prior approvals, if needed, are in place.

• **Clinical Nurse Specialists and Nurse Practitioners** have advanced degrees. They work alongside physicians to identify and address your child’s health concerns. They may work in a hospital or in a doctor’s office.

• **Homecare nurses** provide similar services for children with complex medical needs in their homes. With doctor’s orders, these nurses manage a child’s health needs, which may include use of advanced medical technology. This allows children with complex needs to be cared for in their homes, instead of in the hospital or other long-term care facility.

• **School nurses** manage the health and wellness of all students, including those with special healthcare needs. Managing and documenting medical, medication, and technology needs for a student can be overwhelming, and school nurses do it for many children, all at once, every day.

• **Public health nurses** combine their nursing skills with public health principles and focus on improving health on a community-wide basis. Many work in state programs that support children and youth with special healthcare needs.

National Nurses Week was observed May 6 – 12, 2010. This annual observation is an opportunity to express heartfelt appreciation for the high-quality care and dedication that nurses provide to children and youth with special healthcare needs. Where would we be without our nurses? Have you thanked a nurse today?

Visit the American Nurses Association at www.nursingworld.org to learn more about the history of National Nurses Week.

Remember to Thank Important Members of Your Child’s Team

By Mary Castro Summers, Director, Family TIES of Massachusetts

Myrto Flessas and her husband have a son and a daughter and while both children are exceptional, their son has exceptional educational, medical and social/emotional needs. When Myrto needed help understanding the services and supports her son would need to be successful in school, she called the Parent Training and Information (PTI) Project at the Federation. Myrto is also an attorney with a focus area in special education. When she wanted to know more about special education advocacy, she completed the PTI Parent Consultant Training.

Myrto and her family appreciated the excellent, comprehensive supports she received from the Federation, and continued to stay involved. She read Newsline to learn about Federation events and other subjects of interest to families raising children with special needs. As an active member of her local disability community, she is always pleased to hear that other families also received useful information and supports from the Federation.

She even dreamed of being on the Federation’s Board of Directors, and now, that dream has come true. We are pleased to welcome Myrto Flessas as a member of the Federation’s Board of Directors. She is very excited about this opportunity! As an attorney, advocate and parent, she looks forward to helping support the on-going work of the Federation so we can continue to support families. Myrto shared, “You just have to go to one Visions of Community conference to realize and recognize how much the work of the Federation affects so many lives, and empowers so many parents.”

Federation Welcomes Myrto Flessas to the Board of Directors
A Medical Home is a model for delivering primary care. The American Academy of Pediatrics defines a Medical Home as: accessible, comprehensive, family-centered, compassionate, culturally and linguistically appropriate and coordinated.

The Maternal and Child Health Bureau defines “care coordination” as “services that promote the effective and efficient organization and utilization of resources to assure access to necessary comprehensive services for children with special health care needs and their families.” When services are coordinated, there is less duplication, fewer gaps in services and decreased risk of medical errors. For example, when a child with complex health needs sees many medical specialists, each may prescribe medications. If the child’s doctors have a complete, up-to-date medication list, they are less likely to prescribe medications that should not be taken together, or that would counteract a medication another doctor has ordered.

Parents raising children and youth with special healthcare needs (CYSHCN) understand the importance of coordinating their child’s care. In fact, if you ask a roomful of parents of CYSHCN if they have a care coordinator, few raise their hand. When you rephrase the question and ask which parents are their child’s care coordinators, many raise their hand.

More and more primary care settings and hospital clinics are providing care coordination services for their patients with special healthcare needs. However, parents remain an essential partner in their child’s care, and still need to take an active role to ensure their child’s care is coordinated.

If you are not comfortable in your partnership role in coordinating your child’s care, or just need some management strategies, here are some tips and tools that may help.

- Prepare for each visit with all health providers. For example, bring a list of medications, note any changes in your child’s health, positive or negative, since the last visit, and write down questions you and your child may have.

Continues on page 14

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So Put Your Thoughts in Writing

Many thanks!

A note from Marcia:

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The mission of the Massachusetts Parent Information and Resource Center (Mass PIRC) is to help families be active and effective partners in their children’s education, and to help schools become places where the contributions of all families are welcome. As part of our work, Mass PIRC provides technical assistance to targeted school districts throughout the state about ways to encourage and build parent-school partnerships. Here are some examples of how our work makes a difference for families at home, at school, and in the larger community.

**Promoting Positive Behaviors through “High Fives”**
Mass PIRC works with families and educators at the Francis M. Leahy Elementary School in Lawrence to build family-school partnerships. At a planning meeting, the attendees discussed “High Five,” a school initiative that rewards students’ positive behaviors based on five principles: Respect, Responsibility, Role Model, Readiness, and Relationships. The team wants to adapt the program to help parents use “High Five” at home. Parents will receive guidance on how to be appropriate role models for their children and how to recognize, emphasize and reward their children’s positive behaviors. “High Five” will unite parents and the school in an effort to support students’ positive behavior at home, at school, and in their communities.

**Somali Families Become Part of the School Community**
Somali families contribute a unique cultural and linguistic diversity to the Springfield Public Schools. However, cultural differences made it difficult for them to participate at their children’s schools. Many Somali families did not understand the structure and routines of American schools, and did not realize they had a right to voice their concerns. Many had been living in refugee camps and did not know about receiving and reading mail. In addition, most did not read English. As a result, the families did not respond to school notices. The schools thought the families’ lack of responses was a lack of interest.

To build understanding between families and the school, Mass PIRC consulted with the director of the Somali Center in Springfield. With his guidance, Mass PIRC met separately with the Somali families and then with the schools to hear from both sides. Then Mass PIRC facilitated a meeting with representatives from both groups. As a result, the school community realized they needed to provide more support to all their language groups, and has implemented measures to meet these needs. Now, feeling welcome and a sense of belonging, Somali families are eager participants in their children’s education and contributors to the Springfield school community.
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 Carrie Piaggi, a young woman with Cerebral Palsy. If you are a person with a disability and would like to share your story for publication, please e-mail your contribution to beth@fcsn.org. Submissions should be no longer than 500 words. The Federation reserves the right to edit your contribution.

Finding My Voice

By Carrie Piaggi

I am 16 years old, and I have Cerebral Palsy. Cerebral Palsy is usually caused by brain damage that occurs at or before birth and is marked by muscular impairment, which can cause poor motor coordination. Sometimes, it also involves speech and learning difficulties.

Even though I have difficulty walking, I don’t let it interfere with having fun and enjoying sports. I compete in skiing and equestrian events at Special Olympics. I also enjoy ROPES Course. ROPES stands for Respecting Other People Encouraging Self-Esteem. ROPES is for everyone, not just kids with disabilities. I appreciated that the ROPES instructors, mostly local police officers and teachers, didn’t say, “she has a disability so we aren’t going to accept her.” I could do all of the activities just like anyone else there, and even invented a rope element that is called “Carrie’s Climb.”

On March 13 of this year, a friend and I gave a presentation at the Federation’s Visions of Community conference. Our presentation was based on the movie “Including Samuel.” It’s about a boy named Samuel who has Cerebral Palsy. We showed clips from the film and used personal stories to illustrate and discuss our experiences with Inclusion. I thought it was important for attendees to hear things from my point of view, as a youth with a disability.

I am also an active member of BPA (Business Professionals of America), a career and technical student organization. I competed at this year’s BPA State Leadership Conference. My events were Interview Skills, Fundamental Word Processing Skills, and Basic Office Systems and Procedures. I placed fourth in the Fundamental Word Processing competition and will now go to California to compete in the national BPA competition. I am very excited about this because even before this competition, I wanted to go to college to learn more office skills so I can have a job in office management.

It may sound like everything in my life goes smoothly, but sometimes things go wrong at school. I’ve been going to my IEP meetings since 7th grade, so I could begin to advocate for myself. I know what I need on my IEP, and how to talk with the teachers and other school staff if there’s a problem. Then, we work together to figure out a solution.

Bullying: A Survivor’s Story

By Becky Rizoli, Federation for Children with Special Needs

Like so many others, I was horrified to learn that in January a Massachusetts teen committed suicide because she was the victim of many types of bullying, including cyberbullying. As I stared dumbfounded at the television screen, I thought back to my own middle school years. I have ADD (attention deficit disorder) and an anxiety disorder. And, when I was younger, I had a speech disorder and stuttered sometimes. Any student can be the victim of bullying; however, students with special needs are bullied even more frequently, and I was no exception.

My classmates laughed at me and mimicked my stuttering. They knew tests triggered my anxiety and often falsely told me that a teacher had scheduled a test for my next class without my knowing. Girls I had thought were my friends excluded me from their lunch table. Going to school was a nightmare. In those days, school administrators and teachers did not recognize “bullying.” They referred to my experiences as “teasing,” stating is was a normal part of adolescence, and that I should just “stick it out.”

As my classmates matured, their bullying stopped, but the effects lasted. I had low self-esteem, was embarrassed about my differences, and had a hard time making new friends. It took years for me to overcome the damage to my self-esteem. I didn’t even realize that I had been bullied until I started working at the Federation. As I was reading materials for a parent workshop about bullying, I realized that I, too, had been a victim of bullying. I also realized that bullying is not a normal part of growing up. It is a form of abuse and discrimination based on disability, which is illegal. I also realized that the bullying was not my fault.

The Massachusetts Senate and House recently passed S2323: An Act Relative to the Prevention of Bullying. It requires each school district to implement and enforce a bullying prevention plan. It is encouraging to know the Commonwealth is taking action so that future generations of students will not have to fear going to school because of bullies.

Editor’s Note: On May 3, 2010, Governor Patrick signed the anti-bullying law. In addition to this Massachusetts legislation, the federal Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act, protect students with disabilities from “disability harassment.” Visit the U. S. Department of Health and Human Services Web site at www.stopbullyingnow.hrsa.gov/HHS_PSA/pdfs/SBN_Tip_24.pdf for more resources. While schools now recognize bullying for what it is – recurring behavior that is intentionally destructive – the prevalence of cell phones, texting, e-mail, and social networking sites, make it possible for bullies to invade all parts of their victim’s lives. If you are concerned your child is at risk for, or is a victim of cyberbullying, learn what it is and how to prevent it at www.stopcyberbullying.org.
He continued, “A goal of the Visions of Community conference is to provide a place where individuals with a common interest – that of raising children and youth with special needs – can find each other and realize they are not alone, be challenged by putting to use the information and resources they discover, be enriched by the opportunities to network, and be inspired.”

Special guests Kathleen Ludgate, Regional Director of the U.S. Census Bureau, Dr. Jean McGuire, Assistant Secretary of the Office of Disability and Community Services, Department of Developmental Services Commissioner Elin Howe, Ron Benham, a Bureau Director at the Department of Public Health, Paul Reville, Secretary of Education, Department of Elementary and Secondary Education Commissioner Chester, and Lieutenant Governor Timothy Murray, also greeted the audience.

Afterwards, Dr. Robison introduced keynote speaker Dr. Beth Harry, Professor of Special Education at the University of Miami, and parent of a child with complex health needs.

### Keynote Presentation

In acknowledgement of the multicultural audience, Dr. Harry welcomed attendees in many languages. She went on to share her experience as the parent of a daughter with complex medical needs. Melanie was born with cerebral palsy; she passed away when she was 6 years old.

Dr. Harry’s presentation began with an inspirational photo essay about Melanie and continued with selected readings from her book, “Melanie: Bird with a Broken Wing.” In keeping with the ‘you are not alone’ theme of the conference, Dr. Harry acknowledged her fear that she may not be able to cope with challenges of raising a daughter with special needs, but that she found the strength, and grew from strength to strength with the help of doctors, therapists, and her family.

Dr. Harry’s family lived in Trinidad for a time, and she realized that children with complex health needs did not have access to the therapies, services, supports and resources they needed. To provide these services, she started the Imortelle School, named after a tropical tree that grows tall and wild. Cocoa plants do not do well in direct sun, so Trinidad farmers plant cocoa in the shade of the immortelle. Dr. Harry thought this would be an appropriate name for a school, which would provide shelter for children with special needs while they grew.

If you were unable to attend Visions of Community, or did attend but would like to see the presentations and handouts for many of the workshops offered that day, those materials are available on the Federation Web site at http://fcsn.org/index.php.

Watch Dr. Harry’s presentation, and other videos from the conference on the Federation’s YouTube channel at www.youtube.com/fcsnvideos.
Community Partnership Awards

As part of the Visions of Community conference events, the Federation presents Community Partnership Awards to recognize “unsung heroes” – those parents, educators, advocates, health professionals and community leaders - who have made a significant impact in the lives of children with special needs. These awards, originally conceived by Federation Board of Directors member Dr. William Henderson, are the Federation’s way of acknowledging what individuals contribute not only to families, but also to communities. Their efforts enrich the entire community and make it a more accepting place. The Federation was pleased to have Dr. Henderson and Lieutenant Governor Murray participate in this year’s awards presentation.

This year’s Community Partnership Award recipients were:

Outstanding Inclusive Recreation Award
Presented to Lauren and Andy Richardt, Acton, MA for their efforts at creating a Miracle League of Massachusetts baseball program for children, ages 5 – 18, with disabilities, and their able-bodied peers.

Outstanding Educator Award
Presented to Jane Shanahan, W. Edward Balmer Elementary School, Whitinsville, MA for providing a variety of academic enrichment activities to promote a life-long love of learning for all her students.

Outstanding Administrator Award
Maureen Conroy, Director of Disabilities and Deaf Services, Holyoke Community College, Holyoke, MA - for creating fully inclusive college experiences for students with disabilities.

Outstanding Inclusive Educator Award
Presented to Matt D’Andrea, Principal Old Hammondtown School, Mattapoisett, MA – for creating a school environment where each student, regardless of ability, can learn, grow, and feel like a member of the community.

Outstanding Parent Advocate Award
Presented to Mary Fishman, Sandwich, MA – for her work to ensure children with individual differences are included alongside their peers in school drama clubs, sports leagues, job trainings, and other community activities.

Outstanding Parent Advocate Award
Presented to Cathryn Kaner-Taytslin, Framingham, MA, for her work reenergizing the Framingham Special Education Parent Advisory Council.

Outstanding Community Outreach Award
Presented to Colleen Flanagan, Boston, MA - for her work with young people with disabilities, ages 13 to 25, to develop their abilities and expand the possibilities they see for themselves.

A complete bio of each Community Partnership Award winner is available at www.fcsn.org/conference2010/awardees.php.
Queridos amigos de la Federación para Niños con Necesidades Especiales de Boston Massachusettes

Gracias a la invitación de una querida amiga, Sara Díaz, tuve la oportunidad de alternar con profesionales, profesores y padres en esta conferencia. Quiero decir que soy madre de Giancarlo de 6 años de edad, diagnosticado con Autismo; desde el comienzo no me he dado por vencida y siempre estoy explorando nuevas opciones de desarrollo para el bienestar de mi hijo.

Es tan importante escuchar a padres que han pasado por las mismas experiencias por las que ahora yo estoy comenzando, sus opiniones, sus recetas, sus consejos me han ayudado a sentirme acompañada en este duro caminar. Somos “nosotros los padres” los únicos responsables del crecimiento, desarrollo y de su independencia en el futuro de nuestros niños, vale aclarar que con la ayuda valiosa de profesionales, médicos y profesores es que se avanza y se logran nuestras metas; quiero alentar a los padres de niños con discapacidades a nunca desfallecer y seguir buscando “eso” que a nuestros niños les hace falta.

Quiero felicitar a la Federación por tan grandiosa e importante conferencia con la cual quede impactada con su organización, al personal de apoyo que sin ellos no habría podido haber llevado a mi hijo. Quede con mucha necesidad de haber participado en tantas conferencias a las que no pude entrar “solo pude elegir 3”.

Quiero ser un padre especial, para ayudar a mi hijo y amigos que tienen niños especiales y grandes impedimentos para asistir a conferencias como estas, en mi caso yo obtuve grandiosa información para desarrollarme en el área del Autismo, como nuevos tratamientos con el comportamiento “prevenir, enseñar y responder a planes para una conducta positiva”, También participe en el importante tema del stress en la familia con niños especiales de como sobrevivir y prosperar. ¡Gracias a la Federación por tan importantes temas! Me gustaría que en el futuro la conferencia se dividiera en dos días, para poder absorber toda esta información detenidamente, lo mismo con las exhibiciones.

De manera especial felicito a la Doctora Beth Harry por tan hermosa historia acerca de su hija, me tocó las fibras más sensibles de mi corazón, gracias por tan alentadores consejos, padres como yo vemos que nuestros problemas son pequeños comparados con grandes dificultades por los que algunos padres tienen que pasar, gracias nuevamente a la Federación por invitar a la Doctora Harry.

Gracias a la Federación por animarnos a seguir caminando confiadamente. Que Dios los bendiga y que encuentren en cada evento una inspiración para ayudar a tantas familias que se nutren y desarrollan de ustedes “La Federación para niños con Necesidades Especiales”.

No se olvide de darles las gracias a los miembros importantes del equipo de su niño

Por Mary Castro Summers, Director, Family TIES of Massachusetts

Las enfermeras trabajan en una variedad de ambientes y cumplen una amplia gama de funciones, pero siempre con el mismo objetivo: asegurar mejores resultados de salud y más oportunidades en la vida cotidiana para los niños, los jóvenes y sus familias. Éstos son algunos ejemplos de las muchas maneras en que las enfermeras cuidan a nuestros hijos:

- En los hospitales, las enfermeras atienden las necesidades de sus pacientes y les ofrecen la atención diaria, tanto durante las hospitalizaciones breves como largas. Las enfermeras administradoras y educadoras apoyan al personal de enfermería.

- Las enfermeras que trabajan en consultorios médicos ofrecen cuidados directos. Miden los signos vitales, dan vacunas y documentan las preocupaciones de salud de sus pacientes. También facilitan la comunicación entre las familias y los proveedores de servicios de salud, e incluso con los seguros de salud, para confirmar la cobertura y obtener las autorizaciones previas requeridas.

- Las especialistas en enfermería clínica y las enfermeras especializadas tienen títulos universitarios avanzados. Colaboran con los médicos para identificar y responder a las necesidades de salud de sus pacientes. Trabajan tanto en hospitales como en consultorios médicos.

- Las enfermeras de atención domiciliaria ofrecen servicios similares en el hogar del paciente a los niños con necesidades médicas complejas. Bajo las órdenes de un médico, estas enfermeras atienden las necesidades de salud y a veces utilizan tecnologías médicas avanzadas. De este modo, los niños con necesidades complejas pueden ser atendidos en su propia casa, en lugar de un hospital u otro centro de cuidados a largo plazo.

- Las enfermeras escolares cuidan la salud y el bienestar de todos los alumnos, entre ellos, los que tienen necesidades especiales de atención médica. Atender y documentar las necesidades de salud, medicación y equipo médico de un estudiante puede ser algo abrumador. Sin embargo, las enfermeras escolares hacen esto simultáneamente para un gran número de niños, día tras día.

Continua en la pagina 12
A Learner Becomes a Leader
Mass PIRC has learned that even though parents may understand and speak some English, many lack the confidence to talk with their children’s teachers. To help build parents’ confidence, Mass PIRC offered ESL (English as a Second Language) classes at the Federation. Using Mass PIRC training materials, the classes focused on teaching families about education in the U.S.

Families learned that it is okay to have a voice in their children’s education, and that U.S. schools expect parents to participate. They learned words and terms that would help them participate, such as “accountability,” “curriculum,” “MCAS,” and “assessment.” Most important, they gained confidence as they participated in role-plays and conversations with each other.

One mother wrote, “As an immigrant, I didn’t know where to turn to understand the education system. In this class, I gained confidence and now communicate more effectively with educators. I also became aware of other people in the same situation as me.” Enthusiastic about her newfound sense of empowerment, this mother is taking advanced training at the Federation. She is eager to provide leadership and support to help other parents participate in their children’s education.

District Gains Strength through Diversity
Thanks in part to technical assistance from Mass PIRC, the Worcester Public Schools’ Citywide Parent Planning Advisory Council has greatly increased its membership and is more representative of the district’s diversity. Recently, nearly 200 family and community members from 41 of the city’s 44 schools came together to share their hopes and concerns with district leaders at a citywide Parent/Guardian Roundtable Forum. This unprecedented participation represented a cross-section of the city’s linguistic, racial and socio-economic diversity. For the first time, families, many of whom had never participated before, had a direct line of communication with district leaders.

Families were unanimous in their desire for an “engaging, well-rounded and high-quality education that prepares their children for success in college and career.” One district leader commented that what they learned would directly affect the future of the district, beginning immediately. All participants look forward to continuing the conversation.

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Os enfermeiros trabalham em uma variedade de ambientes, com uma enorme faixa de obrigações, mas o objetivo deles é o mesmo – assegurar melhores resultados de saúde e de oportunidades para a vida diária das crianças, dos jovens e de suas famílias. Aqui estão alguns exemplos das muitas maneiras pelas quais os enfermeiros cuidam de nossos filhos:

- **Os enfermeiros hospitalares supervisionam todos os aspectos das necessidades de seus pacientes e fornecem os cuidados do dia-a-dia, durante uma permanência longa ou curta. Os Enfermeiros Gerentes e Enfermeiros Educadores apoiam o pessoal de enfermagem.**

- **Os enfermeiros que trabalham em um consultório médico fornecem um cuidado direto. Eles monitorizam os sinais vitais, administram imunizações, e documentam as preocupações relacionadas com a saúde. Também ajudam a facilitar a comunicação entre as famílias e os provedores de cuidados médicos e às vezes, junto às seguradoras de saúde para assegurar que os serviços sejam cobertos, e que sejam feitas aprovações prévias, se necessário.**

- **Os Enfermeiras Clínicas Especialistas e os Enfermeiras Clínicas possuem graus de estudo mais avançados. Eles trabalham em conjunto com os médicos para identificar e tratar das preocupações de saúde de seu filho. Eles podem trabalhar em um hospital ou em um consultório médico.**

- **Os enfermeiros para cuidados em casa oferecem serviços similares em suas casas, para as crianças com necessidades médicas complexas. Com a recomendação do médico, estes enfermeiros gerenciam as necessidades médicas da criança, que pode incluir o uso de tecnologia médica avançada. Isto permite que crianças com necessidades complexas sejam cuidadas em suas casas, em vez de cuidadas no hospital ou em algum outro estabelecimento para cuidados de longa duração.**

A Semana Nacional de Enfermagem foi celebrada de 6 – 12 de maio de 2010. Esta celebração anual nos dá a oportunidade de expressar nosso sentido agradecimento à dedicação e atenção de alta qualidade que as enfermeiras oferecem a os niños y jóvenes con necesidades especiales de cuidado de salud. ¿Qué sería de nosotros sin las enfermeras? ¿Le ha dado las gracias a una enfermera hoy?
Educators and assistive technology pros are abuzz about ways to use Apple’s iPod Touch and iPhone to support special education students in the classroom. With the release of Apple’s new larger iPad, the potential for these supports has now expanded to help children and adults who have difficulty using small screens. Here’s what you need to know to help your kids learn with these types of assistive technology (AT).

Applications (or apps) are software programs for use on the iPod Touch (no phone/data service required) and iPhone (AT&T phone/data service required). In addition to using these devices to listen to music, there are thousands of apps. Many are free; some are low cost; others cost hundreds of dollars. All apps use touch screen technology, which makes them easy to use, intuitive, and appealing to kids of all ages and abilities. Apps are only available on-line at http://itunes.apple.com/us/genre/mobile-software-applications/id36?mt=8. In the Education category, you can choose from a vast selection of apps and games, designed to teach early math skills, reading, writing, songs, art, foreign languages, sign language and more.

Eric Sailers and Samuel Sennot, two speech pathologists, have identified apps that are particularly beneficial for special education students, and support learning in the areas of augmentative communication, organization, reading, writing, math, music, art, educational games, and accessibility aids. Apps for note taking, videos, flash cards and e-book readers with text-to-speech make learning on the go easier than ever. Apps developed especially for students with autism provide visual schedules and reminders/prompts, communication systems, reward systems, behavior tracking and timers. There are apps that address the needs of individuals with vision and hearing impairments that include Braille and ASL. Review the growing list at http://www.scribd.com/doc/24470331/iPhone-and-iPod-touch-Apps-for-Special-Education.

**Reasons to Love iPods:**

- **Portability** – Their small size makes it easy for ambulatory kids to carry them around so they have the schedules, visual prompts, and communication aids with them. They are also great for keeping kids entertained in the car and waiting rooms!
- **Easy to Use** - Finger touch driven, on screen keyboards, no mouse required.
- **Lower Cost** - The Apple devices cost between $200-$800, significantly less than dedicated augmentative communication devices. Many apps are free or cost less than $5.00. Note: If the device you want is less than $500, your family may qualify for the Assistive Technology Mini-loan program. Learn more at http://www.massatloan.org/aboutmaatminiloan.htm.
- **Visually Appealing** – High quality images with lots of visuals.
- **Ability to Import Your Photos** (the iPhone includes a camera; the iTouch and iPad do not).
- **Coolness Factor** – Looks like the iPhone all kids use, making it a great tool for closing the learning gap between students with special needs and those without.

**Other Things to Consider:**

- **Accessibility** - The small screen size and icons may make it inaccessible for students with fine motor issues. The new iPad, with its larger screen and icons, may resolve this issue, for some. Visit the Assistive Technology for Apple and MAC Users forum at www.ATMac.org for information about accessibility of Apple products for individuals with disabilities.
- **Sound Quality** – After all, iPods were designed to play personal music. You need separate speakers to make the sound audible in the classroom. The iPad is supposed to have louder sound, without requiring additional accessories.
- **Lack of Camera** – The iTouch and iPad do not have a camera feature, but you can import your own photos.
- **Who Pays?** - Insurance does not cover computer-based devices in most cases and schools may not be willing to purchase them. But, check with your school’s AT specialists; they may have trial devices to loan out. Data service can add $30 or more a month to your phone bill.
- **Are They Allowed in School?** - Check with your teacher or special educator about their policy for using phones or hand-held devices in the classroom.
- **Fragility** - These devices are small and somewhat delicate. They are not designed to be dropped or thrown, which may be deal breaker for some students. Repair costs are substantial.
- **Theft or Loss** - Will your child be able to keep track of it at school?

Specialized apps make the iPhone and iTouch a rich educational resource for children with special educational needs. They are cool, fun, and it gives them some independence. But, don’t let your kids near yours if you ever want to use your phone again!

Randi is the parent of a child with cerebral palsy who relies on assistive technology for mobility, communication and daily living. Randi is also a member of the MassMATCH AT Advisory Committee, and the Federation Board of Directors.
• Make sure the primary care provider has a list of your child’s medical specialists and receives summaries of each specialty visit, including recent tests, procedures and the results. You should have copies of these too. Share information about any community services, such as early intervention, or special education services your child receives. When everyone has the same information, your visit can focus on well-child care and development, rather than spending the time updating the doctor.

• After the visit, call for test results and ask for copies of written reports. Don’t assume a test was negative, or the results were within normal range just because you didn’t hear from the doctor or staff. Health providers are busy and, at times, test results get misinterpreted or filed incorrectly. It’s important to follow up, especially if a recent test was to rule out a suspected problem.

• Ask about other community-based services and supports that may be helpful to your family. If the primary care office does not have this information, make sure to connect with the Family TIES of Massachusetts network. They can tell you about early intervention, their parent-to-parent matching program, support groups, and other services and supports in your area. Learn more at www.massfamilyties.org or call 1-800-905-TIES.

• If you need information about health care financing options, contact the Massachusetts Family-to-Family Health Information Center at 1-800-331-0688, ext. 210, e-mail massfv@fcsn.org or visit www.massfamilyvoices.org.

For more ideas about what families can do to help coordinate care for CYSHCN, visit the Managing and Coordinating Care section of the Medical Home Portal at www.medicalhomeportal.org/living-with-child/caring-for-children-with-chronic-conditions/managing-and-coordinating-care.

Remember, when you work in partnership with your children’s health providers, early intervention staff, school personnel, and others, you model the skills your children and youth will need to take responsibility for their own health, to the best of their abilities, and to work together with health providers and others to make decisions about health services, community supports, and more.

Have a care coordination strategy that works for your children and family? Call or e-mail the MA Family-to-Family Health Information Center at 1-800-331-0688, ext. 210 or e-mail massfv@fcsn.org and we’ll post a list to our listserv and Web site.

Clarke Schools for Hearing and Speech

New Name
Formerly Clarke School for the Deaf/Center for Oral Education, we recently changed our name to Clarke Schools for Hearing and Speech. This change reflects our distinct mission of teaching children who are deaf and hard of hearing how to listen and talk; and it also highlights our multiple locations—which continue to grow!

New Look
We have also changed our logo to a vibrant mark celebrating the growth and success of Clarke children. Each day, we watch and listen to them as they blossom—gaining confidence and acquiring the ability to reach their full potential.

Same Mission
While Clarke has a new name and a new look, our mission remains unchanged: Providing children who are deaf and hard of hearing with the listening, learning and spoken language skills they need to succeed.

clarke schools.org Boston • Jacksonville • New York • Northampton • Philadelphia
**Book Review**

**Reviewed by Beth Dworetzky**

**Kids Like Me...Learn Colors & Kids Like Me...Learn ABCs**

Written by Laura Ronay, Photos by Jon Wayne Kishimoto (Woodbine House Special Needs Collection. 2009)

These two charming board books, illustrated with photos of children with Down syndrome, provide a fun, colorful way for any child, including a child with a developmental disability, to learn colors and the alphabet. “Learn Colors,” in English en Español, uses photos and geometric shapes to teach colors. Each page of “Learn ABCs” has the letter, in upper and lower case, a photo of a child, a drawing of word that begins with the letter, and the word written across the bottom of the page. Each page also shows the hand position for the letter in American Sign Language.

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

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**Massachusetts 2010 Lifespan Respite Summit**  By Amy Nazaire

On March 25, 2010, the Massachusetts Department of Developmental Services (DDS) and the Massachusetts Executive Office of Elder Affairs (EOEA) hosted a daylong “Massachusetts 2010 Lifespan Respite Summit” at the Best Western Royal Plaza Hotel and Conference Center in Marlborough. A grant from the ARCH National Respite Network and Resource Center, with additional support from the Federal Administration on Aging and the National Family Caregiver Alliance funded the summit. The Massachusetts Developmental Disabilities Council, the Greater New England Chapter of the National Multiple Sclerosis Society, Associated Home Care Inc., and Greater Lynn Senior Services provided additional sponsorship for the event.

The purpose of the Summit was to bring stakeholders together from across the state to identify the needs of Massachusetts families for respite, identify barriers and solutions to statewide respite, develop a mission statement and goals for a Massachusetts Respite Coalition, and establish Massachusetts’ readiness to apply for federal Lifespan Respite Care funding in the coming fiscal year. Jill Kagan, the Project Director of the ARCH National Respite Network and Resource Center in Washington, D.C., gave the keynote presentation.

Ms. Kagan provided an overview of the federal Lifespan Respite Care Act of 2006, which established respite as a national priority. She also spoke about the states that have already established Lifespan Respite programs. Massachusetts is not one of these states, and Jill pointed out that at any given time during 2007, more than 1 million family caregivers in Massachusetts provided care to seniors and individuals with special needs. The estimated value of their care giving was more than $8 billion annually. Lifespan Respite, defined as “coordinated systems of accessible, community-based respite services for all family caregivers, regardless of age or special need,” would be a way to support these unpaid family caregivers.

The 100 people who attended the Summit included families, government agencies, nonprofits, and other organizations that support seniors, adults with both intellectual and psychiatric disabilities, individuals with adult-onset disabilities, and children with complex medical and/or developmental needs, including autism spectrum disorders.

The Summit was also an opportunity to bring together some of the individuals who have been trailblazers in the area of Lifespan Respite, and to begin to build on the foundation they have established. Foremost among these is Carrie Howland, an energetic and eloquent mom who has worked hard to establish a Massachusetts Respite Coalition. The group also benefitted from the contributions and expertise of Dr. Emily Davidson, Director of the Down Syndrome Program at Children’s Hospital Boston. Dr. Davidson has been at the forefront of developing innovative respite options for children with developmental disabilities and their families.

Follow up activities for the Massachusetts Respite Coalition include: establishing a meeting schedule, researching the economic benefits of respite care, cataloguing existing respite resources and developing comprehensive information for families. These activities will help strengthen Massachusetts’ position to apply for federal funding to build upon these activities.

To learn more about the National Respite Coalition visit www.chtop.org/ARCH/ARCH-National-Respite-Coalition.html. For more information about the Massachusetts Respite Coalition, contact Amy Nazaire, Director of Family Support and Children’s Services for the Northeast Region of DDS at 978-774-5000 ext. 386 or via email at amy.nazaire@state.ma.us.
SAVE-THE-DATE

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

PLAN EARLY...

Parent Consultant Training
Rehabilitative Resources, Inc • Sturbridge, MA
Monday through Friday, June 21 through June 25
9:00 am – 4:00 pm
Applications will be accepted from May 3 through June 11

Visions of Community 2011
Seaport World Trade Center • Boston, MA
March 12, 2011
A Conference for Families of Children with Special Needs
and the Professionals Who Serve Them
7:30 am - 5:00 pm

INFORMING, EDUCATING, EMPOWERING FAMILIES