On May 21, 2010, the Federation for Children with Special Needs welcomed more than 350 guests at its 11th annual Gala. Federation staff, board members, honorees – past and present, families, professional partners, and other supporters gathered at the Seaport Hotel in Boston to celebrate the work of the Federation. This event also recognizes the accomplishments of special individuals who have worked hard to improve the lives of individuals with disabilities and their families.

The cool jazz of the Tough Love Trio set an elegant tone for the reception and silent auction, which featured 140 items. After dinner, Master of Ceremonies Joyce Kulhawik introduced each event, which included exciting and expressive performances by the Familias Latinas Unidas por el Sindrome de Down Dance Troupe, awards, and a concert by pop/folk artist Seth Glier.

Congratulations to Dan Habib and Betsy McNamara, recipients of this year’s Presidents Award. This husband and wife team used their family’s experiences to bring inclusion to the forefront in their award-winning documentary “Including Samuel.” Betsy shared that making the documentary was, “a journey of leadership and advocacy.” Dan stated, “Inclusion will change the world because it embraces diversity by ability,” and continued, “Some day we will look back at separate classrooms and say, ‘why did we separate kids with disabilities?’”

Dr. Karen Levine received this year’s Martha H. Ziegler Founders Award for her work to improve the well-being of children with challenges. She enjoys, “figuring out what makes a child laugh, what makes him tick, what’s the way in?” and then getting that ‘way in’ integrated into a classroom setting. She recognizes, “the Federation takes it [what she does with individual children] to the next level and also advocates at the state and federal level.”

Continues on page 8
Farewell to Selena Sheaves, Development Coordinator

Families may never have spoken with her on the phone, but for the past 2.5 years, families and staff have benefited from the work Selena Sheaves has done behind the scenes at the Federation. Selena was originally hired as an executive assistant, but her interest in and talent for development led to expanded duties as the Federation’s development coordinator. In an effort to increase public awareness about the Federation, and the donor base, she created house concerts, the Valentine’s Campaign, and expanded the exhibitor hall and exhibitor experience at the Federation’s Annual Visions of Community Conference. In fact, due to the prizes and exhibit hall entertainment, ideas Selena implemented, exhibitor participation at the conference has increased 25%. She also helped coordinate the annual Gala, and has stewarded on-going relationships with the Federation’s financial supporters.

Prior to joining the Federation staff, Selena was a stay-at-home mom. She was aware of the Federation and the work of the organization and thought, “That is the kind of work I can do, the kind of place I can be passionate about.” While at the Federation, Selena participated in the Parent Consultant Training Institute offered by the Parent Training and Information Project. For years, she and her husband had tried to get educational services for their daughter with special needs. After taking the training, she felt empowered and did successfully negotiate the placement, services and supports her daughter needed.

At this time, Selena’s two daughters once again need her at home full-time, and Selena has left the Federation to prioritize the needs of her family. She’s also going to take some time to herself, and looks forward to blogging and gardening. In parting, Selena shared what a wonderful experience it was to work with everyone and that she appreciated the opportunity and experience. We extend our heartfelt thanks for the work she has done, and extend our best wishes for a smooth transition to this next phase of family life.

Social Security and Health Benefits for Young People with Disabilities Who Go to Work

By Melanie Jordan, Institute for Community Inclusion

Did you know that Social Security and MassHealth programs have work incentives that can provide a “safety net” for young people with disabilities who want to give work a try?


To receive print copies, contact Melanie Jordan at 617-287-4327 or melanie.jordan@umb.edu.

This publication is sponsored by Work Without Limits, a Massachusetts Disability Employment Initiative funded by the Centers for Medicare and Medicaid Services (CFDA No. 93.768) and managed through a partnership by UMass Medical School Center for Health Policy and Research, UMass Boston Institute for Community Inclusion, and Massachusetts Executive Office of Health and Human Services. Visit www.workwithoutlimits.org for more information.
From the Executive Director:
Thanking Our Volunteers

In reflecting on the number of volunteers and the amount of volunteer time from which the Federation has benefitted this past year, I am overwhelmed with appreciation! More than 150 volunteers have donated over 5,000 hours of volunteer service to support the Federation and the families we serve.

Volunteers help us answer the more than 16,000 calls we receive in our PTI (Parent Training and Information) Call Center, and present workshops in many of the more than 350 cities and towns across the state. Others volunteer time to support the 900 participants at the Federation’s Annual Conference, help with our annual Gala, serve on our Board of Directors, and act as Federation ambassadors across the state and nation. College interns assist with various projects and activities. We depend upon each and every volunteer to help meet the demands of our busy, parent-run organization.

It turns out that our volunteers are not alone. In 2009, “Volunteering in America” (see Massachusetts data at www.volunteeringinamerica.gov/MA) reported 1.4 million MA residents, or 25.5% of the state population, volunteered. They provided 137.4 million hours of service, which is about 31 hours per resident. Clearly, we are a part of a wonderful and giving community.

And, volunteering is not only good for the Federation and the families we serve, but it is also good for each volunteer. In April 2007, the Corporation for National & Community Service released “The Health Benefits of Volunteering.” This report, based on an examination of 30 research studies, documents the correlation between volunteering and health. They found that adults who volunteer live longer, have lower incidence of heart disease and depression, have better physical health and are happier than people who do not volunteer their time to help others. Older volunteers (> 60 years) had the greatest health benefits, but the study also found that people who began volunteering when they were younger were more likely to continue to be of service to individuals and organizations as they age, and will enjoy the same health benefits when they are older. Read the full report at www.nationalservice.gov/pdf/07_0506_hbr.pdf.

I want to warmly thank each of our volunteers for their commitment to the Federation’s work and mission. And I’d like to invite anyone who wishes to volunteer to improve their health by volunteering at the Federation.

Thank you all. We couldn’t do it without you.

Sincerely,

Rich Robison
Executive Director

Federation Web Presence: Watch Us, Tweet Us, Friend Us

The Federation for Children with Special Needs strives to inform, educate and empower families by providing workshops and individualized technical assistance to families, our professional partners, and others. And, in order to have information available in formats that meet each family’s needs, learning style, and schedule, the Federation has increased its web presence and use of social media and now posts information in a variety of formats.

Families can watch video of Federation workshops and conferences on our YouTube channel, receive short resource and event updates via Twitter, and friend us on Facebook. We also post Newsline as web page content, rather than just in portable document format (pdf). Readers no longer have to download the file before they can read the newsletter. Each issue is easier to navigate, as the table of contents is available on every page. Readers can link directly to articles of interest, rather than having to scroll through the entire file.

Unfortunately, due to budget concerns, the Federation is making an additional change to Newsline. After this issue, we will mail 3 of the 4 yearly issues. The 4th edition will be available exclusively online. And, in hopes of reducing overall printing and mailing costs, we hope you will help support the Federation, and the environment, by opting to receive Newsline electronically.

Sign Up for E-Newsline: If you want to continue receiving Newsline, free of charge, we need to update your Federation database record and make sure it includes your e-mail address. Please take a few minutes to provide this information at http://fcsn.org/publications_resources/newsline/newsline_subscribe.htm.

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Supporting Student Achievement: Massachusetts System of Tiered Instruction

By Amanda Green, Parent Training and Information Project

Is your child struggling in school? If so, you may want to find out if your district is one that supports student learning through a system of tiered instruction that aligns with the Massachusetts System of Tiered Instruction [‘Tiered Instruction’ in this article]. This new system is one way in which schools can:

• Find out what each individual student needs.
• Track each student’s progress toward meeting Massachusetts learning standards as laid out in the Curriculum Frameworks.
• Teach each student the way s/he learns best.
• Provide increasing or decreasing levels of support – depending on what the student needs.

In other states, similar systems are sometimes called “Response to Intervention” or “RTI.” RTI is used to identify children who are struggling in school and to ensure that they receive the right instruction or intervention to be successful. To learn more about RTI, which was first defined in federal special education law, visit the National Center on Response to Intervention at www.rti4success.org or the RTI Action Network at www.rtinetwork.org.

Using the Massachusetts System of Tiered Instruction framework, schools hold all students to high standards both academically and behaviorally, track student progress frequently, tailor teaching to individual student needs, and provide increasing levels of support to students who struggle so that all children get what they need to succeed.

How does the Massachusetts System of Tiered Instruction work? The diagram below, created by the Massachusetts Department of Elementary & Secondary Education, shows a pyramid divided into three sections or “tiers,” surrounded by two concentric circles. Along the left side of the pyramid is a two-headed arrow.

In the past, schools would sometimes wait for students to fall behind and then refer them for a special education evaluation. Tiered Instruction is a new approach to ensure that students are supported from the very beginning of the educational process. Some low-performing school districts are now required by state regulation to implement Tiered Instruction.

The Pyramid

The pyramid’s bottom tier, Tier 1, is “Core Instruction.” This refers to the kind of teaching and learning that happens in a general education classroom, either in small or large groups. In a district using Tiered Instruction, students in Tier 1 must be taught using high quality, research-based methods, in a way that meets their individual academic and behavioral needs. Students are tested regularly to measure progress and to determine which students are struggling and may need additional support. Testing at all tiers also gives teachers important information which allows them to adapt lessons and materials to meet each student’s needs. Eighty to ninety percent of students would learn the key concepts through instruction in Tier 1.

Tier 2 is “Supplemental.” This tier is for students who, through ongoing data collection, are identified as needing additional support. Tier 2 gives students the chance to benefit from targeted small group instruction or extra teaching time. Again, students are taught using research-based methods (when these are available) and are tested regularly to measure progress. Five to ten percent of all students would receive instruction in Tier 2. Schools provide interventions in Tier 2 in addition to core instruction.

Students who are not progressing in Tier 2 move to Tier 3, where they receive “Intense” instruction and more frequent testing to measure progress and to help them meet grade-level standards. One to five percent of students would receive instruction in Tier 3.

The Inner Circle

Inside the inner circle, around the pyramid, are six core components of the Tiered System.

1. “Flexible Tiers” (emphasized by the double-headed arrow on the left side of the pyramid) means that students are not taught at only one tier at a time. A student could be taught and tested at Tier 3 for reading, Tier 2 for behavior, and also at Tier 1 in other subjects. Likewise a student could receive Tier 2 services, show improvement, and move back down to Tier 1.

2. “High-Quality Core Curriculum & Instruction” is key. Massachusetts Curriculum Frameworks are the blueprint for what all students are taught (including students who receive special education services).

Continues next page
Supporting Student Achievement: Massachusetts System of Tiered Instruction (continued from previous page)

3. “Research-Based Academic Interventions & Assessment Practices” means that teaching and testing should be based on research, when available. This requirement is essential if students are to make progress.

4. “Research-Based Behavioral Interventions & Supports” refers to the fact that the whole child is important. In Tiered Instruction, students are supported not only academically but also behaviorally.

5. “Universal Screening & Progress Monitoring” means that all students will be tested regularly to determine if they are making progress and to help teachers adapt their teaching methods to suit each student’s learning needs.

6. “Collaborative School/Family Problem-Solving” means that parents are valued partners in the education process. They receive information from the district about Tiered Instruction and about their children’s progress. Parents are invited to participate in making decisions related to their own children’s education, as well as on the Tiered Instruction system.

The Outer Circle

The outer circle shows the five kinds of districtwide supports that need to be in place for Tiered Instruction to be successful.

1. At the top of the circle is “Leadership,” since district and school administrators are responsible for taking the lead in putting Tiered Instruction into action and ensuring its success.

2. “Core Values & School Culture” means that the entire school community – administration, teaching staff, and families – needs to be on board. Everyone needs to understand how Tiered Instruction works and to value its potential to raise achievement for all students.

3. “Family Engagement” means that families are crucial to the success of Tiered Instruction – by partnering with school professionals in decision-making, by participating in the school community, and by encouraging and supporting their children.

4. Ongoing “Professional Development” is essential. Teachers need to keep learning to ensure that they have the skills and knowledge necessary to make Tiered Instruction a success.

5. “Fidelity of Implementation” means that a system is in place to monitor and evaluate the components of the Tiered Instruction model. Districts need to put Tiered Instruction in place in a uniform way in all schools throughout the district. Ideally, every classroom in every school should have the same approach to teaching and testing, in line with Massachusetts Curriculum Frameworks and research-based practices.

If your child is already receiving special education, how will s/he benefit from Tiered Instruction? Tiered Instruction makes classrooms more inclusive. A system that uses research-based teaching methods and regular testing to track progress ensures that teaching methods are tailored to meet the needs of each individual student. In addition, your child might be receiving special education services in one subject (such as math) but still have weaknesses in another area, such as behavior. Tiered Instruction can address those weaknesses. Tiered Instruction also emphasizes the importance of having high standards for every student. All students benefit from an environment in which high expectations are the norm.

Finally, don’t forget that if your child is struggling in school, you have the right to ask for special education testing at any time. Testing results from Tiered Instruction can provide valuable information as part of the special education evaluation. However, special education testing timelines mandated by state and federal law must be followed.

For more information on special education, see A Parent’s Guide to Special Education at www.fcsn.org/parentguide/pgintro.html.

Phone-A-Thon for Kids

There are 32,000 children and teens without health insurance in Massachusetts! Health Care For All has launched the got coverage? Health Coverage For Kids and Teens campaign to identify and enroll uninsured children and teens in health care coverage.

As part of this campaign, Health Care For All, the Massachusetts Family-to-Family Health Information Center and other partner organizations are organizing a one day phone-a-thon. Families will be able to call a toll free number and enroll their children in health coverage over the phone!

The phone-a-thon is Wednesday, September 29, 2010; 9 am to 9 pm. The phone-a-thon number is 1-800-272-4232. Language support is available in English, Spanish and Portuguese.
Conference & Workshop Information for Families Raising Children & Youth with Special Health Needs

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

Joining Voices Conference

The Massachusetts Family-to-Family Health Information Center will host its annual Joining Voices conference on November 3, 2010 at the Hoagland-Pincus Conference Center in Shrewsbury, MA. This free event, for families raising children and youth with special health needs, is a fabulous networking and learning opportunity. Rosalie Edes, Deputy Assistant Secretary, Disability Policies & Programs, Executive Office of Health and Human Services will give the keynote address about the importance of family involvement in helping to shape programs that meet the needs of individuals with disabilities and their families.

In preparing for this year’s conference, the Family-to-Family Health Information Center posted a survey asking families for input about workshop topics. In response to family feedback, workshop topics will address outreach to diverse families, medical home, guardianship and its alternatives, parent-to-parent, transition, and more.

During lunch, participants will have an opportunity to join one or more topic-specific networking sessions about respite, support groups, strategies for encouraging family leadership, care coordination, and maximizing health insurance benefits.

MassHealth Workshop

The Family-to-Family Health Information Center is now scheduling its “Making Cents of Healthcare Financing” workshop for the fall and winter. This workshop, presented free of charge, provides an overview of the MassHealth system, eligibility and the application process, explains coordination of private health insurance benefits with MassHealth, and how to make an informed decision about services.

To schedule a workshop or for conference updates, call Beth at 1-800-331-0688, ext. 210, e-mail massfv@fcsn.org or visit www.massfamilyvoices.org.
**Beneficios de Seguro Social y de salud para los jóvenes con discapacidades que van a trabajar**

Por Melanie Jordan, del Instituto para la Inclusión de la Comunidad (Institute for Community Inclusion)

¿Sabía usted que hay programas del Seguro Social y de MassHealth de incentivo al trabajo que pueden tenderle una “red de seguridad” a los jóvenes con discapacidades interesados en trabajar?

“A trabajar: Una guía del Seguro Social de beneficios y empleo para jóvenes con incapacidades” (edición 2010) es un folleto para familias ameno y fácil de leer que explica el efecto del empleo remunerado en los beneficios.

El patrocinador de esta publicación es Work Without Limits (Trabajo Sin Límites), una iniciativa de Massachusetts de empleo para personas discapacitadas, financiada por los Centros para servicios de Medicare y Medicaid (CFDA N.º 93.768) y administrada por un proyecto colaborativo entre el Center for Health Policy Research at UMass Medical School (Centro para la Investigación de Políticas de Salud de la Facultad de Medicina de UMass), el Institute for Community Inclusion at UMass Boston (Instituto para la Inclusión de la Comunidad en UMass Boston) y la Massachusetts Executive Office of Health and Human Services (Oficina Ejecutiva de Salud y Servicios Humanos de Massachusetts). Para más información, visite www.workwithoutlimits.org.

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**FAMILY TIES**

**News From Family TIES of Massachusetts**

By Mary Castro Summers, Director, Family TIES of Massachusetts

Family TIES (Together In Enhancing Support) of Massachusetts is a statewide information and support network for families of children with special needs. It is a project at the Federation for Children with Special Needs, with funding from, and in collaboration with, the Massachusetts Department of Public Health, Division for Perinatal Health, Early Childhood and Special Health Needs.

Within the Massachusetts Department of Public Health, there is a Children & Youth with Special Health Needs (CY-SHN) Program. Families with children and youth with special health care needs can learn about this program by calling the Community Support Line at 1-800-882-1435. Staff can explain the eligibility criteria for various programs, as well as provide assessment, short-term intervention and care coordination. Care Coordination staff help parents by modeling how to access services and navigate systems, so parents can learn to effectively advocate for services on behalf of their children. This comprehensive assessment process can identify a wide array of support services about health insurance, financial concerns, medical and in-home nursing services, educational supports, and coordination with other state agencies. They can also help a family identify recreational opportunities and childcare supports.

To learn about community-based programs near where you live, or arrange for a parent-to-parent match so you can speak with a family whose child has a similar diagnosis or that shares a similar life experience, please call Family TIES of Massachusetts at 1-800-905-TIES (8437). Our Regional Parent Coordinators and Parent-to-Parent Coordinator look forward to speaking with you. You can also visit us on-line at www.massfamilyties.org.

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When she entered 4th grade, Tay Evans struggled to read.

Today, she’s a highly regarded marine biologist.

From the day Tay entered The Carroll School, her life began to change. Benefiting from Carroll’s customized education, she became a proficient reader and a confident, lifelong learner. Today, Tay is an aquatic biologist with the Massachusetts Division of Marine Fisheries, using science and her innate creativity to find ways to improve the environment of the oceans.

**THE CARROLL SCHOOL**

Lincoln, MA | 781-259-8342 | www.carrollschool.org
The Federation honored staff member Barbara Popper with the Patricia Blake Advocacy Award for her commitment to promoting the health of women and children, especially those with special health care needs. Barbara related her struggles with hospital visitation when her child was young, and was happy her advocacy efforts resulted in a positive change in policy. However, she acknowledged that not every family has a happy outcome. “Families face situations in hospitals, and at schools that they are not prepared to deal with. The Federation reassures families to trust their instincts and get help,” and Barbara is pleased the Federation is there to provide that information and help to families.

The evening concluded with a beautiful and moving concert by Seth Glier. Seth talked about his 25 year old brother who has autism. When Seth is not on the road, he is his brother’s PCA (personal care attendant). His brother is, “The greatest gift he could ask for,” and is the inspiration for much of his music.

Listen to the speeches and watch the dance performances on the Federation’s YouTube channel at http://www.youtube.com/user/fcsnvideos.

The Federation extends heartfelt thanks to our sponsors, contributors, silent auction donors and volunteers whose contributions helped make the evening a success. Mark your calendars for next year’s Gala on May 13, 2011. We hope to see you there!

Visions of Community 2011: Workshop Proposals, Community Partnership Award Nominations & Exhibitor Information coming soon!

The Federation for Children with Special Needs will host its annual Visions of Community conference for families and the professionals who serve them on March 12, 2011. We invite workshop proposals from individuals and organizations throughout the Commonwealth who have information to share about health, mental health, general and special education, social supports, community recreation, human services, policy, and advocacy.

As in past years, we welcome nominations for Community Partnership Awards – those parents, educators, advocates, health professionals and community leaders who have made a significant impact in the lives of children with special needs. We will also host an Exhibitor Hall, a popular and growing feature of each conference.

Workshop proposal forms, exhibitor information, and Community Partnership Award nomination forms will be available for download from the Federation Web site (fcsn.org) in the fall.
Thank You for Your Support

The Federation for Children with Special Needs gratefully acknowledges the generous support of Gala 2010 through donations of the following individuals and organizations:

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When parents and teachers work together, children do better in school. Sharing information—both giving and receiving it—is key to building effective parent-teacher partnerships. Parents have many opportunities to share information about their child with the teachers. If your child receives special education services and supports, parents and teachers will share information as they work together to develop the child’s Individualized Educational Program (IEP). But this is only one opportunity to provide information. Whether or not a student has an IEP, all students have unique needs and there are other ways for parents and teachers to share information that will support each child’s educational progress.

Information to Give

Early in the school year, before concerns arise, introduce yourself to your child’s teachers. First impressions count. Be friendly and confident. The information you are sharing will help the teacher. Consider preparing a one-page description about your child, highlighting strengths as well as concerns. Include examples of the accommodations that have worked in other classes. If you speak English as a second language, let the teacher know you may need help with translations. A teacher or parent liaison who speaks your native language may be able to translate. Or, you might bring a friend or relative with you.

Information to Get

These six questions are a starting point for getting information from your child’s teachers that will help you work in partnership to support your child’s education.

1.) **What is my child expected to learn this year?** Ask for a copy of the class curriculum or syllabus. This is the actual content, assignments and projects. It’s based on the Massachusetts Curriculum Frameworks that guide the education of all students, including students with special needs. Read the Frameworks for the core subject areas at www.doe.mass.edu/frameworks/current.html.

2.) **How will my child’s academic progress be measured?** Beginning in 3rd grade, students take MCAS (Massachusetts Comprehensive Assessment System) tests to see how well they are mastering the material in each core subject. Ask the teacher which MCAS tests your child will take this year. MCAS results can help identify strengths and weaknesses in a subject area. Test grades and report cards show how your child is doing throughout the year. Having ongoing communication with the teacher will help you know about problems in advance, rather than first learning about them on a report card. Ask the teacher to let you know when she is pleased with your child’s performance as well as when there are concerns.

3.) **How do you accommodate differences in learning?** Find out what happens if your child falls behind, seems bored, or is not challenged enough. Ask about opportunities for tutoring or other special help, including clubs or after-school activities that can reinforce your child’s special strengths and interests.

4.) **What would you like to know about my child?** Teachers appreciate knowing about changes at home that may affect the student’s behavior at school. Also, let the teacher know if your child is having difficulties at school or with homework.

5.) **What can I do at home to support my child’s progress in school?** Ask about homework assignments and how much time your child should spend on it. And, ask how you can link what your child is learning in school to activities at home. For example, if your child is learning fractions, perhaps you can cook together and measure ingredients for a recipe. If your child is not doing well in a subject, ask how you can help your child improve and succeed.

6.) **What is the best way for us to communicate?** Exchange contact information. Ask for the best way to keep in touch. Some teachers have specific times for making and receiving phone calls. Others may prefer e-mail or written notes sent back and forth with the student.

These questions are only a starting place. You will have additional questions if you need clarification or have a concern about services or supports your child needs. When teachers and parents work as partners, they help ensure each child’s academic success.

Mass PIRC is a Federation project devoted to helping parents of all children participate as equal partners with educators in their children’s education. Call us at 1-877-471-0980 or visit www.masspirc.org. We have a wealth of resources to support you in your partnership role!
Assistive technology (AT) is defined as “any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of a child with a disability.” The Individuals with Disabilities Education Act (IDEA) states determinations for a student’s use of AT must be made on a case-by-case basis to ensure access to a free and appropriate public education (FAPE). If the IEP team – including you - determines that your child needs AT to meet his or her educational goals and ensure FAPE, it must be included in your child’s IEP and be provided by the school district at no cost to your family.

There are thousands of products available for use by students with low vision, hearing impairments, communication limitations, access challenges and difficulty with learning and studying. AT solutions run the gamut from simple, no tech/low tech products that do not require electronic equipment (for example, colored paper and post-it notes) to high tech technology products that are more costly and training intensive (such as text to speech software, augmentative communication devices and mobility equipment). As a parent, you know your child best. Learn about different AT solutions so you can help your child’s IEP team select the AT that will make it possible for your child to meet his or her academic, social and daily living goals.

Ways to Learn about AT Products

- Browse assistive technology web sites to learn about industry standards and manufacturers. Two associations are the Alliance for Technology Access (www.ataccess.org) and the Assistive Technology Industry Association (www.atia.org).
- Use a search engine to search for “assistive technology in the classroom.”
- Request catalogs from companies that distribute school AT products. See a listing at www.massmatch.org/find_at/at_catalogs.php.
- Visit AbleData at www.abledata.com and search the AT database.
- Visit YouTube at www.youtube.com and search “assistive technology in the classroom” to see products in action.
- Ask your child’s teachers and therapists for recommendations.
- Request a school-based AT evaluation from a qualified AT specialist to make sure the AT product will benefit your child. An AT evaluation should consider the learning and work style of the student; the long-range implications, ease of use and maintenance, adaptability, portability, dependability, and technical support.

Be sure to document any staff, student and parent instruction that will be needed to use the AT, as well who will be responsible for maintenance, managing repairs and upgrades. Ask for a trial use of the AT, which often is required prior to purchase.

And finally, consider the funding options. Is the AT an item you want to purchase to retain ownership? Check your health insurance for any durable medical equipment (DME) benefit and spending limits, and to see if there are preferred vendors you must use.

If your child’s IEP team determines that your child needs AT in order to do his/her homework, make sure the IEP states the equipment can be used at home and in other settings outside of school.

Once the equipment has been selected and successfully trialed, all aspects of implementing AT should be described in your child’s IEP and considered at every IEP meeting. Karen Janowski, local Assistive and Educational Technology consultant, suggests three possible discussion outcomes for ensuring the effective implementation of AT at your child’s IEP meeting:

1. AT is considered, is already in place and is working well.
2. AT is considered and the Team will trial new tools or strategies.
3. The team needs additional information and an AT evaluation is indicated.

Being an active participant in choosing your child’s AT will benefit your child, your team and you. By becoming an educated and proactive consumer, you can speed along the acquisition of needed equipment, which can take months, support your child’s classroom team and help your child get the equipment he or she needs to learn and participate independently at school and at home.

For more information about Assistive Technology and IDEA, visit www.wrightslaw.com.

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’s Board of Directors. Learn more about MassMATCH at www.massmatch.org.
What does access to a high quality public education mean for students who cannot attend school because of complex health conditions?

I am the parent of a nine year old with congenital muscular dystrophy who is medically fragile. I have a doctorate in education, more than 25 years of public education experience, and I don’t have an answer for my daughter or for others like her. I pose this question with two underlying assumptions. First, I assume that I am not alone. There are likely hundreds of parents in Massachusetts with children who have neuromuscular, mitochondrial, metabolic, or any number of medical conditions that prevent them from being able to attend school. Second, I assume that children with complex health conditions are not provided with the same educational opportunities as their peers.

Technology and educational innovation provide opportunities for students to engage in learning in ways we had not imagined possible a few years ago. Through virtual schooling, webcam and other technologies supported by new educator roles, students for whom physically getting to school is not possible should be able to “go to” school – anytime – anywhere – such as in a hospital room, at home in bed, or at a homeless shelter. We just have to make it happen.

In May, an energetic cross-section of stakeholders from the state education agency, the Federation for Children with Special Needs, state government, education collaboratives, and others met to discuss ideas and generate possible courses of action to support the education of students with complex health needs. We are beginning to collect data, learn about practices in the field, and strategies for virtual educational possibilities.

If you are a parent of a student with a complex health condition, we want to hear from you! Please take a few minutes to complete a short survey at www.surveymonkey.com/s/YS55W6M. On behalf of our kids, let’s help them learn where and when they can!

If you want to get involved in this effort, or would like more information, please call or e-mail the MA Family-to-Family Health Information Center at the Federation at 1-800-331-0688, ext. 210, or e-mail massfv@fcsn.org.
Families raising children with mental health needs face enormous challenges. They struggle to get a clear diagnosis, comb resources online and wait for extended periods to access the treatments and services their children need. In November 2008, the Parent/Professional Advocacy League (PAL) invited parents whose children had emotional, behavioral and mental health needs to participate in a survey. The goal was to better understand the barriers families encounter when accessing needed treatment for their child. The results, which represent data from 471 parents, are detailed in a new report, Overcoming Barriers in the Community.

The most striking finding was the impact of out of pocket expenses on families, as a result of their child’s mental health care. Parents stated there was very little cushion in their budget for health care costs. Thirty-two percent said that their child needed a treatment their insurance didn’t cover while 30% said the co-pay for therapy or medication was difficult to afford.

While respite care has been shown to be a key component in the treatment of children with mental health needs, 19% of parents stated they had never heard of respite care. Of those who had, 75% found it important but difficult to access. Parents also reported that getting a diagnosis was difficult (66%) and that long waits for services was widespread (61%).

Despite all this, parents wrote again and again how much they appreciated support, excellent resources and effective services. They overwhelmingly reported (71%) that the most helpful resource was other parents; the internet was a close second (58%). Forty-one percent described how their child’s services made a difference. Families respond strongly when asked about how their experiences and their knowledge should be used to improve the system that serves them.

Learn more about PAL, the Massachusetts Chapter of the Federation of Families for Children’s Mental Health, and read the report at www.ppall.net.
Brothers and sisters who have a brother or sister with Down syndrome get asked lots of questions. They also have their own questions to ask. The purpose of the book is to provide answers to those questions, and help prepare siblings to not only answer questions they are asked, but also share correct information.

The authors traveled to workshops and conferences across the country where they hosted brother and sister meetings. At each meeting they asked attendees to write their questions then discussed the answers. This book is a compilation of 100 of those questions about Down syndrome, family issues, feelings, dealing with uncomfortable situations, and more.

This book, the result of research, commonsense and experience, while written for siblings, has useful information for all family members, as well as friends, teachers, coaches, and others. If you need an answer fast, the summary points at the conclusion of each chapter provide great guidance, even if you haven’t read the entire chapter or book. And there’s a wealth of local and national resources in the resource chapter.

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

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

**Joining Voices**
Hoagland-Pincus Conference Center
222 Maple Avenue • Shrewsbury, MA
Wednesday, November 3, 2010
A conference for families raising children and youth with special health care needs.
9:00 am – 3:00 pm
For more info visit www.massfamilyvoices.org

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