The Federation for Children with Special Needs will host its 11th Annual Gala and Silent Auction from 6 – 10 pm on Friday, May 21, 2010, at the Boston Seaport Hotel. The Gala is the Federation’s single most important fundraising event. Our goal is to raise $150,000 to help fund the programs and services that the Federation provides to Massachusetts families raising children and youth with special needs and critical health issues. These programs are a valuable source of information and support for families and for the professionals who serve them.

While the Gala is a fundraiser, it is also a time to celebrate our work and to honor others for the work they do on behalf of families raising children with special needs. Boston’s Legendary TV Arts and Entertainment critic Joyce Kulhawik will emcee our dinner and awards ceremony. This year’s Founders Award honors child psychologist Dr. Karen Levine, co-author of “Replays,” for her dedicated and innovative work on behalf of children with complex needs and their families. The President’s Award will be given to filmmaker Dan Habib and his wife, Betsy McNamara for their efforts in bringing inclusion to the forefront through their own personal experiences documented in the film, “Including Samuel.” The Federation will also honor Mrs. Barbara Popper, recipient of the national Maternal and Child Health Director’s Award for her more than 40 years of commitment to promoting the health of women and children.

The evening will feature entertainment by folk/pop artist Seth Glier, jazz from the Tough Love Trio, and the choreography of the Familias Latinas Unidos por el Sindrome de Down dance troupe, a group of young Latino dancers whose members have Down syndrome.

For information about attending, donating an auction item, or other sponsorship opportunity, call Selena Sheaves at 617-236-7210 or e-mail ssheaves@fcsn.org.
Comings and Goings at the Federation . . .

Parent Training and Information Project Bids Farewell to Robin Foley: Parent Leader, Advocate, Colleague and Friend

Robin Foley has been the Director of Special Education Projects at the Federation for eight years. In that time, Robin has built the Federation’s special education projects into a strong and cohesive group, become a visible and effective advocate at both the state and national levels and has perfected a model of collaboration in special education advocacy that has earned her the respect of parents and professionals across the state, and throughout the country. She has worked collaboratively with the Massachusetts Department of Elementary and Secondary Education, and the U.S. Department of Education to ensure state and federal special education laws, policies and procedures around eligibility, parent involvement, appeals and other processes effectively support the educational needs and the rights of students with special needs and their families.

Robin is also the parent of three children, one of whom has special needs. At this time, Robin needs to be closer to home and more available to support the needs of her family. It is with regret, but ultimate respect for her decision to prioritize the needs of her family, that we say good-bye to our colleague, mentor and friend. We also extend our thanks on behalf of the entire Federation staff and the thousands of families Robin has helped. There are not enough words to express our appreciation for her hard work, help and guidance.

Robin’s resignation will be effective on April 1, 2010. If you’d like to be in touch with Robin prior to that, e-mail her at rfoley@fcsn.org.

Visions of Community 2010

A Conference for Families of Children with Special Needs and the Professionals Who Serve Them

March 13, 2010 • Seaport World Trade Center, Boston
“Nothing About Us Without Us!” is a slogan often used by advocates and leaders in the disability community to make it clear that any discussion about rules, program procedures and policies must have meaningful representation from the population being served. “Population representation” is a cornerstone of our democracy. It promotes the voice and participation of the people affected by the decisions made by those in power. The December 2009 issue of the Axis Group I’s Reality Check newsletter (http://axisgroup1.net/) includes an article by Connie Wells, a long time advocate of quality health care for children with special health needs. She writes about the “Authentic Voice: the voice of those originating from the population served by the program; the voice of individuals whose lives will be directly impacted by the outcomes of program planning, development, implementation and evaluation.”

In general, however, our democracy operates on the idea that “majority rules.” Hence, we tend to make decisions based on the opinions of 51% of the people involved in the discussion. This raises some serious problems for those groups who, by virtue of their numbers, will always be in the minority.

Promoting the voice and participation of families, consumers and individuals with disabilities ensures that the intent of a program or service is truly obtained. Many state and federal laws, publically-funded programs, professional and family consumer organizations have built in safeguards to ensure that the involvement and “authentic voice” of the consumer is heard, even though, at times, these procedures may be trivialized or ignored, especially if you’ve ever felt like the “token parent” at a meeting. In these difficult economic times, parents of children with special needs and those at risk need to be heard. The Federation for Children with Special Needs was founded and has thrived for 35 years on this very principle. We are a parent-run organization founded by parents for parents. Our unique mission and guiding principles seek to empower families to maintain their voices in reliable and effective ways. So, get up, get out, and get involved. Share your voice. Be active in at your children’s schools, ask about advisory opportunities at your early intervention programs, primary care practices, hospitals, and within the agencies that provide services to your children and families. The various projects at the Federation can offer you any support you may need to participate.

There is another saying, “Walk a mile in my shoes.” Urge others not to second guess the money spent on services and supports for our children with special needs. Children with special needs enrich our lives. We greatly admire our children’s perseverance in light of the unique challenges they face everyday. In difficult economic times, it is tempting to cut services and supports to children with special needs and to children at risk. Some in positions of power may think economic circumstances override the voices of our children and families. It is precisely in times like these that our voices need to be heard. Our voices may seem meek at times, but together we will roar like lions. Let your voices be heard!

Rich Robison
Executive Director

Federation for Children with Special Needs: Annual Appeal

In December, the Federation launched its Annual Appeal. We asked 1000 people to donate $50 each to reach our goal of $50,000 and keep the Federation strong. The Federation gratefully acknowledges the support of the 964 people who heeded our call and donated more than $47,000. A thousand “thank yous” to all!

Federation Web Presence

e-Newsline: The flagship colors of Newsline may be blue and white, but the Federation is going green! In order to cut down on paper waste, and the significant cost of this quarterly publication, the Federation now provides an easy-to-navigate, on-line version of each edition. If you are reading this as hard copy, we invite you to check out the current issue at www.fcsn.org. Same great news, delivered faster and cheaper. Sign up at http://fcsn.org/publications_resources/newsline/newsline_subscribe.htm.

Twitter: Need news you can use in 140 characters or less? Follow the Federation on Twitter at fcsn. It’s free to create an account, and you can read ‘tweets’ by logging in to www.twitter.com or via your mobile phone.
Once considered “just part of growing up,” today bullying is seen for what it is - cruelty that can be devastating for any child. Studies have shown that children who are bullied are more likely to suffer emotional distress, such as anxiety and depression, as well as do poorly in school. Furthermore, bullying is linked to school violence.

In recognition of this growing problem, 41 states now have anti-bullying laws (www.bullypolice.org). Currently many anti-bullying bills are under consideration in the Massachusetts legislature*. These bills call for schoolwide strategies to address bullying and for school districts to formulate prevention and intervention policies and procedures for reporting and investigating bullying.

Because bullying involves an imbalance of physical or psychological power, students with disabilities are especially vulnerable and frequently targeted. For example, in the fall of 2009, responses to a Massachusetts Advocates for Children online survey asked about the extent of bullying against children on the autism spectrum. Nearly ninety percent of parents responded that their children had been bullied. These findings are applicable to most students with disabilities.

The disproportionate targeting of students with disabilities shows that, in addition to schoolwide approaches, many schools include specific strategies for dealing with bullying in the IEPs of students with disabilities. A whole-school approach to creating a safe and respectful climate for all students, combined with specific help for students most at risk, has been shown to effectively reduce bullying behavior.

All children deserve to feel safe in school. The Massachusetts Aggression Reduction Center gives these suggestions (reprinted with permission) for ways parents can support their child who is being bullied:

- Tell your child that this is not his or her fault, and that your child did nothing wrong.

Continues next page
Vulnerable Targets: Students with Disabilities and Bullying
(continued from previous page)

- Gently emphasize that above all, your child should not retaliate or attempt to fight or hit the bully.
- Role-play ignoring the bully or walking away.
- With your child, make a list of adults in school he or she can go to for help, such as counselors or administrators.
- Arrange for him or her to see friends on the weekends, and plan fun activities with the family.

Bullying in schools should be unacceptable to students, teachers, parents and school administrators. Knowing that your child is a victim of bullying can be extremely distressing. The key to stopping bullying is to get the school's cooperation. Since bullying is not an issue faced by just one child, it can help to join forces with other parents through the PTA or other networks to address the issue of bullying. Working with others to communicate the problem to the school will more likely result in an effective school wide response.

*To learn more about anti-bullying bills under consideration, contact the Massachusetts Joint Committee on Education: House Staff at 617-722-2070; Senate Staff at 617-722-1570. Massachusetts Advocates for Children is leading efforts to secure passage of H. 3804 (An Act Addressing Bullying of Children with ASD).

For more information about the Massachusetts Parent Information and Resource Center (PRIC) and how we can support you in your key role as a partner with schools to help ensure your child's success, call 1-877-471-0980 or visit www.pplace.org.

Resources and Sources


*National Center for Bullying Prevention.* This Web site, at www.pacer.org/bullying, has features for elementary students and for teens, as well as resources for parents and schools.

*Stop Bullying Now!* This U.S. Department of Health & Human Services Web site at www.stopbullyingnow.hrsa.gov helps children understand what bullying is and how harmful it is. It features a resource kit with tips and facts, and includes an extensive database of resources about bullying prevention. The information for adults is available in English and Spanish.


Special health needs may be physical, developmental, behavioral or emotional, and may first become evident in a child of any age. With or without a specific diagnosis, children with special health needs often require health and other related services beyond those needed by other children, due to the complexity and chronic nature of their conditions.

Pre-natal testing can identify some genetic conditions and birth defects before your baby is born. Other conditions are diagnosed at birth, or with additional testing, soon after the baby is born. Sometimes children develop special health needs due to illness, injury or accident. However, many families have nothing more than a “gut feeling” that something is not quite right with their child. Their child’s development and behaviors, like puzzle parts, are pieced together over time before the whole picture emerges and special health needs are determined. As a parent, you know your child best; follow your instincts. If you think your child has special health needs, speak with your pediatrician. This primary health provider is your partner in caring for your child’s health and well-being. It is important to share your concerns and get the doctor’s input. It may take several visits to sort out your child’s symptoms. When you make appointments, ask for extra time for a thorough discussion with the doctor. Write down your questions and concerns before each appointment.

Does your child have special health needs? Consider the following:

- Are you concerned about your child’s eating, weight gain or loss, and sleeping patterns?
- How does your baby respond to light, touch and sound?
- Does your young child learn new skills (walking, talking, playing) about the same time as other children his age?
- Has your child stopped learning new skills or lost skills she had?
- Does your child need treatment for on-going health issues that are unique for a child his age (for example chronic ear infections, asthma, joint pain, or frequent stomachaches)?
- Has there been a distinct change in your teen’s eating and sleeping patterns, hygiene, general attitudes and emotional health?

This is not an exhaustive list. These questions are only a starting point for further discussion with your child’s doctor. You and the doctor will work together to “solve” the puzzle and develop a course of treatment, which may include referrals to doctors that specialize in a particular area of medicine. For example,
The Magic of Metacognition

By Zachary Friedland

When I was in elementary school, I would watch the kids play tag during recess. I never understood why they were happy to run and play while I sat on the sidelines by myself.

During a discussion about classroom management in one of my education classes, I learned about “metacognition,” or the ability to think about one’s own thinking. As I result, I came to the realization that the other students were not ‘happy’ to see me sitting by myself. It’s just that they, and I, had not yet developed the ability to self-reflect, and take responsibility and initiative for developing ways to include me in their play. The other kids didn’t know to ask me why I didn’t join them, and I didn’t know how to be included. As a result of the class discussion, I realized that it’s not that young children don’t care, they just don’t understand. Often, they can’t see anything from another’s point of view unless it is pointed out to them. Depending on the situation, this may apply to people of all ages when you have to explain your physical or mental health needs.

I am in college now, and while I still cannot run and play tag, I am part of a peer group with whom I share common interests and participate in many of the same activities they do, albeit, with some modifications. I am now able to explain my needs, and my professors, fellow students and friends understand. Communication is key when dealing with situations like this; therefore, it is important to be able to let people know when an activity is too demanding or uncomfortable.

Here are some strategies that have worked for me:

• **Know your limits** – Never push yourself to do something you are not comfortable doing just because you feel pressured to or expected to do it. Example: I am a member of a marching band. I have some restrictions in movement, and cannot do all the warm up exercises. I explained this to the band director and other band members. They understand when I sit out a particular exercise.

• **Use your words** - It’s not that people don’t care, they may just not realize you have a health problem if you don’t tell them. Example: My scholarship requires that I take a full course load. I met with Disability Services and set up the accommodations I’d need if I couldn’t carry a full course load. I will be able to keep my scholarship if I need to take fewer courses.

• **Be prepared to offer an alternative** - Don’t be content to sit out just because it’s something you can’t do. Be the first to offer a fun alternative or provide a modification that everyone can enjoy together. Example: my friends like to bowl, but it’s difficult for me. As a compromise, we get at least two lanes, and use bumpers in one, so that not every ball I roll is a gutter ball. And, I never bowl alone. My friends like to bowl with bumpers too.
The MA Sibling Exploratory Committee: Building Supports for Siblings of Children with Special Needs

By Emily Rubin, Director of Sibling Support, Eunice Kennedy Shriver Center, UMass Medical School

Siblings of children with special needs face unique concerns. While these siblings have unusual opportunities for growth, they often encounter daily challenges, which their parents may overlook and their peers may misunderstand. As siblings get older, their issues shift: young siblings are trying to make sense of why and how their families are different, older siblings are stepping into care-giving responsibilities that parents managed previously. Siblings tend to become primary advocates for their brothers and sisters with disabilities, but are often unprepared to assume this role. Without adequate information and support, young siblings can grow up resenting the attention given to their brother or sister with disabilities; others can grow into adults who feel overwhelmed by the social, emotional, physical and health care needs of their brother or sister with disabilities. It is increasingly clear that siblings are a critical part of the inclusion model, yet are an underserved population.

Many siblings don’t self-identify as needing help, but they often struggle with powerful feelings of guilt, worry, over-protectiveness and embarrassment. Siblings need opportunities to express their feelings in safe and nurturing settings. The most effective intervention is for parents or guardians to talk openly with siblings at an early age, acknowledging their complicated family lives in age-appropriate language. Parents and guardians can help siblings figure out what to say to friends and relatives about a brother or sister’s special needs. Individual and/or family therapy with a trained clinician can be extremely beneficial for siblings. Sibling support groups with adult facilitators can also provide a welcoming environment where siblings can talk with other sibs who appreciate what they’re going through. SibShops are one model of recreational support group, where siblings have an opportunity to play games with children who share the common experience of growing up with a brother or sister with special needs.

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Alvos Vulneráveis: Estudantes com Deficiência e a Intimidação Escolar

Por Janet Vohs, Diretora de Publicações, Centro de Informação e Recursos para os Pais

Uma vez considerada “somente parte do crescimento”, hoje em dia a intimidação escolar é vista como ela é – crueldade que pode ser potencialmente devastadora para qualquer criança. Estudos têm demonstrado que as crianças que sofrem de intimidação escolar estão mais propensas a sofrer de angústia emocional, tais como a ansiedade, a depressão, bem como de um fraco desempenho escolar. Além disso, a intimidação escolar está ligada a sérias violências escolares.

Este reconhecimento crescente, vem refletido no fato de que agora, 41 estados têm leis de anti-intimidação escolar, anti-bullying laws (www.bullypolice.org). Atualmente, muitos projetos de lei de anti-intimidação escolar estão sob consideração na legislatura de Massachusetts. Estes projetos de lei pedem amplas estratégias no discurso da intimidação escolar e que os distritos escolares formulam a prevenção e políticas de intervenção e procedimentos para fazer relatórios e investigações sobre a intimidação escolar.

Devido ao fato de que a intimidação escolar envolve um desequilíbrio físico ou poder psicológico, os estudantes com deficiência estão especialmente vulneráveis e sendo frequentemente o seu alvo. Por exemplo, no outono de 2009, respostas a um estudo feito on-line pelo Defensores para Crianças de Massachusetts, Massachusetts Advocates for Children, perguntava-se sobre a extensão da intimidação escolar contra as crianças portadoras do espectro de autismo. Quase 90 por cento dos pais responderam que suas crianças tinham sofrido de intimidação escolar. O resultado destes relatórios podem ser certamente aplicados para a maioria dos estudantes com deficiência.

O alvo desproporcional de estudantes com deficiência mostra que, além da grande abordagem da escola, muitos estudantes com deficiência também necessitam de que estratégias específicas para se lidar com a intimidação escolar sejam escritas em seus IEPs*. Uma abordagem da totalidade da escola para a criação de um ambiente seguro e respeitável para todos os estudantes, combinado com uma ajuda específica para os estudantes de maior risco, já demonstrou que reduz eficazmente o comportamento de intimidação escolar.

Todas as crianças merecem sentirseguras na escola. O Centro de Redução de Agressão de Massachusetts, Massachusetts Aggression Reduction Center, oferece estas sugestões (reimpressão autorizada) de como os pais podem apoiar seu filho/sua filha que está sofrendo de intimidação escolar:

• Diga a seu filho/sua filha de que isto não é culpa dele ou dela, e que ele/ela não fez nada de errado.
• Enfatize que acima de tudo, seu filho/sua filha não deverá retaliar ou tentar brigar ou bater na pessoa que o(a) está intimidando.
• Mude de comportamento assumindo um papel como ignorando o intimidador/a intimidadora ou indo embora.
• Juntamente com seu filho/sua filha, faça uma lista dos adultos na escola que ele ou ela pode procurar para pedir ajuda, tais como os orientadores ou administradores.
• Dê a seu filho/sua filha alguma forma de alívio. Arranje para que ele ou ela veja amigos nos finais de semana, e planeje atividades divertidas com a família.

Recursos en la próxima pagina
Alvos Vulneráveis: Estudantes com Deficiência e a Intimidação Escolar
(Continuação na próxima página)

A intimidação na escola deveria ser totalmente inaceitável para os estudantes, professores, pais e administradores escolares. Descobrir que seu filho/sua filha é uma vítima de intimidação escolar é extremamente angustiante. A chave para se conseguir terminar com a intimidação escolar é obtendo-se a cooperação da escola. Como a intimidação escolar não está provavelmente limitada a uma só criança, a união de forças com outros pais através do PTA ou outras redes de trabalho para se resolver o problema é também recomendado. Trabalhar com outros para comunicar à escola sobre o problema é o mais adequado, deste modo, consequentemente e uma resposta amplamente eficaz da escola.

*Para aprender mais sobre os projetos de lei relativos a anti-intimidação escolar que se encontram sob consideração, por favor entre em contato com o Comissão Mista sobre Educação de Massachusetts, Massachusetts Joint Committee on Education: Equipe de Funcionários da Câmara no (617) 722-2070; Equipe de Funcionários do Senado no (617) 722-1570. O Defensores das Crianças de Massachusetts, Massachusetts Advocates for Children (MAC) está liderando esforços para assegurar a aprovação do H. 3804 (Um Ato Tratando da Intimidação Escolar de Crianças com ASD, Act Addressing Bullying of Children with ASD).

Para obter mais informação sobre o Centro de Informação e Recursos para os Pais de Massachusetts (PIRC) e em como nós podemos apoiá-lo(la) em seu papel chave como um parceiro(a) das escolas na ajuda ao sucesso da educação de seu filho/sua filha, telefone para 1-877-471-0980 ou visite www.pplace.org.

Recursos e Fontes


Centro Nacional para a Prevenção da Intimidação Escolar, National Center for Bullying Prevention. Este website, no www.pacer.org/bullying, tem apresentações para os estudantes elementares e adolescentes, bem como recursos para os pais e escolas.

Pare a Intimidação Escolar Agora! Stop Bullying Now! Este website do Departamento Americano de Saúde & Serviços Humanos, U.S. Department of Health & Human Services, tem com alvo ajudar as crianças a que endemando o que é a intimidação escolar e o dano que ela causa. Também apresenta um conjunto de recursos, resource kit, com dicas e fatos, e inclui um extenso banco de dados de recursos sobre a prevenção da intimidação escolar. A informação para adultos está disponível em inglês e espanhol. Visite o www.stopbullyingnow.hrsa.gov.


La intimidación, antes considerada como una “parte del crecimiento”, hoy se ve por lo que es, una crueldad potencialmente devastadora para cualquier niño. Los estudios han demostrado que las víctimas de intimidación tienen más probabilidad de tener problemas emocionales como ansiedad y depresión y rendimiento escolar pobre. Además, la intimidación está relacionada con problemas de violencia escolar seria.

Esta conciencia creciente de la gravedad del problema se refleja en que 41 estados tienen ahora leyes contra la intimidación (www.bullypolice.org). Actualmente la legislatura de Massachusetts está considerando muchos proyectos de ley contra la intimidación. Esta nueva legislación busca establecer estrategias para responder a la intimidación a nivel de toda la escuela y que los distritos formulen políticas de prevención e intervención y procedimientos para informar e investigar casos de intimidación.

Como la intimidación implica un desequilibrio de poder físico o psicológico, los estudiantes con discapacidades son especialmente vulnerables y a menudo víctimas. Por ejemplo, en el otoño de 2009, una encuesta en línea de Massachusetts Advocates for Children averiguó el nivel de la intimidación contra niños en el espectro de autismo. Casi el 90 por ciento de los padres respondió que sus niños habían sido víctimas de intimidación. Estos resultados son ciertamente aplicables a la mayoría de los estudiantes con discapacidades.

Este porcentaje desproporcionado muestra que, además de enfoques escolares integrales, muchos estudiantes con discapacidades también necesitan que se escriban estrategias específicas para responder a la intimidación en su plan educativo individualizado (IEP) *. Se ha demostrado que un enfoque escolar integral para crear un ambiente seguro y respetuoso para todos, en combinación con ayuda específica para los estudiantes con más riesgo, reduce eficazmente la conducta intimidatoria.

Todos los niños merecen sentirse seguros en la escuela. El Centro para la Reducción de la Agresión de Massachusetts ofrece estas sugerencias (reimpresas con permiso) a los padres para apoyar a un hijo que ha sido víctima de intimidación:

- Explíquele a su niño que él o ella no tuvo la culpa y que no hizo nada malo.
- Ante todo, destaque deliberadamente a su niño que no debe tratar de vengarse, pelear o golpear al niño intimidador.
- Practique con su niño cómo ignorar o alejarse del intimidador.
- Haga con su niño una lista de adultos en la escuela a quienes él o ella puede acudir para pedir ayuda, como consejeros o administradores.
- Dele a su niño un poco de alivio. Arregle visitas con amigos los fines de semana y planeé actividades divertidas con la familia.
Work Without Limits
Contributed by the Work Without Limits Partnership

Have you started thinking about what your son or daughter will do after high school? Does your student want to go to work right out of high school? If so, the Work Without Limits program offers resources to help your family think about, plan for, and do the “homework” that will help your son or daughter enter the workforce and explore a career in an area of interest. These resources include:

• Guidance about how to work with your child’s school towards employment goals
• Information about Massachusetts state agencies, and other organizations that might be involved
• Facts about Social Security benefits

Work Without Limits: Putting Abilities to Work in Massachusetts, (WWL) a partnership of the Massachusetts Executive Office of Health and Human Services, UMass Medical School and the Institute for Community Inclusion at UMass Boston, funded by the Centers for Medicare and Medicaid Services, is a Massachusetts disability employment initiative. WWL works to maximize work opportunities for youth and adults with disabilities, addresses the needs of employers and strengthens the Massachusetts workforce.

What does this mean for families? WWL is pleased to announce the Work Without Limits Web site at www.workwithoutlimits.org. Click on “Individuals and Families” to find information about employment, timelines for beginning the job search while your student is still in school, conducting job searches, benefits, employment strategies, transportation considerations, and links to other resources. WWL will continue to update and improve the site over the next few months. In the meantime, WWL staff will be presenting a workshop at the upcoming Visions of Community conference on March 13. This will be an opportunity to meet the staff, learn more about the initiative and its focus on enhancing employment opportunities in Massachusetts for youth and adults with disabilities.

Víctimas vulnerables: Los estudiantes con discapacidades y la intimidación
(Continuación de la pagina previa)

Recursos y fuentes


Stop Bullying Now! Este sitio web del Departamento de Salud y Servicios Humanos busca ayudar a los niños a comprender qué es la intimidación y el daño que causa. También presenta un juego de herramientas con datos y consejos y una amplia base de datos con recursos para prevenir la intimidación. La información para adultos está disponible en inglés y español. Visite www.stopbullyingnow.hrsa.gov.


a cardiologist will provide consultation about suspected heart defects; for problems with the stomach, colon and intestines, your child may need a gastroenterologist.

If your child does have special health care needs, it will be important to keep records about your child’s health condition and medical services. The American Academy of Pediatrics has created a Build Your Own Care Notebook section on its National Center for Medical Home Implementation Web site at www.medicalhomeinfo.org/tools/care_notebook.html. You can pick and choose from a variety of forms, many in English and Spanish, that were designed to help families organize information, keep track of doctors, health plans, medications, school and health services, and other supports your child and family might need. Even if a care notebook is not how you organize and track information about your child, the materials may provide helpful ideas about the types of information to include in an organizational tool that better fits your style.

What does it mean to have a child with special health needs? You are still the parent of a wonderful and unique child, but your parenting experience may include more than teaching your child to share, play ball, and handle the disappointment of not making a sports team. You may also have to help your child cope with medical tests, hospitalizations, unique feeding routines, and other demands that are different from most families’ parenting experiences.

You are not alone. Your medical team will explain treatment options and help you make decisions. In addition, other families may provide an important source of support and can help you find useful information and resources. For this type of support and information, connect with Family TIES of Massachusetts. Learn more by calling 1-800-905-TIES, or visit www.massfamilyties.org.

For information about working in partnership with your health providers, and information about healthcare financing, call the Massachusetts Family-to-Family Health Information Center at 1-800-331-0688, ext. 210, e-mail massfv@fcsm.org or visit www.massfamilyvoices.org.
Assistive Technology Corner...

Ideas for Funding the Assistive Technology Your Child Needs

By Randi Sargent

A new study published in the American Journal of Occupational Therapy found that assistive technology (AT), when employed by a team of therapists and educators, has significant impact on helping children with disabilities achieve their educational goals*. Assistive technology is a broad term that includes a wide range of devices that make it easier for individuals with disabilities to perform certain tasks. Examples include wheelchairs, orthotics, communication devices, computers, software, adapted utensils, dressing aids, large print materials, and even Velcro. In general, AT that is medically necessary is called Durable Medical Equipment (DME). Some AT is very expensive and many families will require financial assistance to purchase it. Here are eight ideas for funding the AT your child needs to succeed in school, community, and family life.

1) Some private health insurance plans have a DME benefit. If you have private health insurance, read your service benefit plan or call your insurance company and ask about DME coverage. Every plan is different, so this benefit will vary by company and type of policy. Be sure to ask about the types of DME they cover, any maximum amount the insurer will pay, the co-payment you must pay, if you need a physician’s prescription and prior authorization, and if they have preferred suppliers or vendors from whom you must get the item. The physician will also have to document the medical necessity of the item.

2) Most of the MassHealth (Massachusetts Medicaid) programs include payment for DME. If your child qualifies for one of the MassHealth programs, and you also have private health insurance, MassHealth will help pay the difference between what your private plan covers, and your share of the cost. If MassHealth is your child’s only insurance, DME is covered if the item is deemed to be medically necessary. Again, you need a physician’s prescription, prior authorization, documentation for the medical necessity of the item, and will have to purchase the item from a MassHealth vendor. [Editor’s Note: if you need information about MassHealth, the Massachusetts Family-to-Family Health Information Center at www.mass.gov/cicrf provides a list of eligible expenses at www.mass.gov/cicrf.]

3) Your school system - If your child requires AT to access the curriculum and meet his or her academic goals, then your school district is required to provide it. Be sure this need is documented on the child’s IEP. The equipment is the property of the school, not yours, so certain restrictions about when and where it is used may apply.

4) Grants from civic organizations or disability specific organizations - Civic organizations, such as the Knights of Columbus, provide grants to children with cognitive and physical disabilities who are younger than 20 years old. Contact your local Knights of Columbus at www.massachusettsstatekofc.org, or other organizations in your town, for information about making a Charity Fund request. Some disability specific organizations, such as the Muscular Dystrophy Association (www.mda.org), also fund DME. [Editor’s Note: Family TIES of Massachusetts has information about many disability-specific organizations and can help you find local contacts. Call Family TIES at 1-800-905-TIES or visit the Family TIES Resource Directory at www.massfamilyties.org.]

5) Low interest loans - Easter Seals manages the Massachusetts AT Loan Program and the Mini-Loan Program to help fund large and small AT. Easter Seals also has AT Regional Centers in Boston and Pittsfield where you can see demonstrations and borrow trial equipment prior to purchasing. Learn more about the Easter Seals AT loan programs at www.eastersealsma.com.

6) If your home requires modifications for accessibility or safety, the Massachusetts Rehabilitation Commission offers the Home Modification Loan Program, which provides no and low interest loans. Learn more at www.mass.gov/mrc/hmpl.

7) Catastrophic Illness in Children Relief Fund (CICRF) - CICRF is a reimbursement program that offers financial assistance to families that have spent more than 10% of their annual income, for family income less than $100,000/year, on expenses related to their child’s diagnosis, but for which there is no other payer. If family income is more than $100,000/year, your unpaid expenses must include an additional 15% of the amount over $100,000. Download the application and read the list of eligible expenses at www.mass.gov/cicrf.

8) Some children’s hospitals have special funds to help families meet needs that insurance does not cover. Ask the nurse practitioner or social worker in your clinic for information.

MassMATCH, the Massachusetts’s Initiative to Maximize Assistive Technology in Consumer’s Hands (www.massmatch.org) provides technical assistance about AT, loan and swap programs, and more. They can also provide demos of products so your child can try it before you buy it. Whatever you purchase to help your child, save your receipts! Many assistive technology items, therapeutic activities, and the health insurance premiums, as medical expenses, may be tax-deductible!

*Effect of Assistive Technology in a Public School Setting, Anne H. Watson, PhD, OT/L, Max Ito, OTR/L, Roger O. Smith, PhD, OT, FAOTA, Lori T. Anderson, EdD, OTR/L, FAOTA, American Journal of Occupational Therapy, January/ February 2010.

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.
Sibling support services, which range from therapeutic discussion groups to practical information on guardianship, are expanding to meet the needs of siblings across the lifespan. Adult siblings actively involved in the lives of their brothers and sisters with disabilities often participate in professional workshops on future planning, as they navigate complex systems of healthcare, housing, employment and state benefits.

An early and solid foundation of support for young siblings helps them develop into well-adjusted adults who can acquire the skills and knowledge to – should they so choose – advocate effectively alongside their adult brothers and sisters with disabilities. Recently, a group of sibling service providers, mental health professionals, parents and adult siblings within Massachusetts joined forces to create the Massachusetts Sibling Exploratory Committee (MA-SEC). We are committed to developing a statewide network of sibling providers as well as a comprehensive array of services for siblings of people with all types of disabilities. We welcome those who are interested in sibling issues to join us in our efforts.

Emily Rubin, the 2009 Gopen Fellow, focused on siblings of children with behavioral challenges. She wrote a parent guide called “Supporting Siblings of Explosive Children,” which can be downloaded at www.communityinclusion.org/sibsupport. For more information about the Massachusetts Sibling Exploratory Committee or sibling services, call Emily at 781-642-0272 or e-mail emily.rubin@umassmed.edu.

Resources


The Arc of Massachusetts - Some local chapters of the Arc of Massachusetts offer programming for siblings across the lifespan. Visit www.arcmass.org to contact your local ARC.

Think Kids: Rethinking Challenging Kids - Think Kids is an innovative program at Massachusetts General Hospital that provides support groups for siblings of children with behavioral challenges. Learn more at www.thinkkids.org/parents/next.aspx.


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Book Reviews
Reviewed by Beth Dworetzky

Thicker than Water: Essays by Adult Siblings of People with Disabilities
Edited by Don Meyer (First Edition. Woodbine House, 2009, 234 pp.)

Sibshops and listservs are great ways for brothers and sisters to connect and share their experiences about growing up with a sibling with special needs. However, if you want to explore another avenue of support, or need an additional support medium, then Thicker than Water may be ‘just what the doctor prescribed.’ Don Meyer, director of the Sibling Support Project, has edited this collection of essays by 39 adult siblings of people with disabilities, illness and other special needs.

Adult siblings share heartwarming, revealing glimpses into their lives that will make you laugh and cry. If you have a brother or sister with special needs, and do not feel supported, you will realize you are not alone in the multitude of often-conflicting emotions brothers and sisters experience, even as adults, when they have a sibling with special needs. And, if you do not have a brother or sister of with special needs, this book will give you new insight into the issues your friends face, and the emotions they experience, while trying to find a balance between responsibilities to their sibling and their own families.

Helping Children with Down Syndrome Communicate Better: Speech and Language Skills for Ages 6 – 14
By Libby Kumin, PhD., CCC-SLP (Woodbine House, 2008, 393 pp)

There is a difference between communication, speech and language. Everyone develops these skills at different rates, and even individuals without disabilities are not always good at all three skills. The challenge for teaching communication skills to children with Down syndrome is figuring out the best way for each child to communicate, and then helping him or her develop the other needed skills. Some children will use speech; some will use sign language, picture systems or other communication devices.

When problems arise for our children, it helps to learn about the issue before meeting with a specialist or therapist. When we know the types of evaluations to expect, and treatment options, we can make a more informed decision about how to choose a therapist, and work towards a solution. This book helps families understand the options for helping their child with Down syndrome develop communication, speech and language, and includes great ideas for incorporating language development into your family routine. There is also information about assistive technology, sample treatment plans, IEP goals, and more.

Teaching Math to People with Down Syndrome and Other Hands-On Learners. Book 2: Advanced Survival Skills
By DeAnna Horstmeier, Ph.D (Woodbine House, 2008, 481 pp)

The author, parent of a young adult son with Down syndrome, wanted to make sure he had the skills to live independently. As math is an essential skill, she developed hands-on ways to teach her son math, where he could touch and manipulate materials, not just look at equations. She created games so her son, and all students, could have fun, practice skills, and transfer the concepts to long-term memory. She also broke down each skill into manageable steps so students could finish each activity and not be frustrated.

This book, written for parents, brothers, sisters, teachers, friends, and anyone interested in helping a hands-on learner learn math, is not just for children with Down syndrome. Children with autism spectrum disorders or learning disabilities will also benefit. Each lesson uses common household materials. There are games and activities to support each lesson. The appendices include information about calculators, other teaching materials, and recipes that help the students learn fractions. The resources include helpful math Web sites and organizations.

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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