Visions of Community 2008

Keynote Speaker
Paul Reville

Keynote Speaker
Keith P. Jones

Nearly 800 participants in attendance

“All students achieve, all means all – no excuses, no exceptions.”
- Paul Reville

This year’s Visions of Community conference, held on March 1, 2008, at the World Trade Center in Boston, boasted 700 attendees, 68 exhibitors, 61 requests for on-site childcare, 53 requests for interpreter services, more than 30 breakout sessions, and 5 author book signings. To sum it up, the annual Federation conference was a tremendous success! Many of the attendees commented that not only was the Federation a huge part of their lives, it was apparent that their families were also part of each Federation staff person’s life.

The day began with inspirational keynote presentations by Paul Reville, the Chair of the Massachusetts State Board of Education and Keith Jones, president and CEO of SoulTouchin’ Experiences.

Mr. Reville welcomed the crowd and commented that, despite the snowy weather and challenging travel conditions, he wasn’t surprised to see a full house, because these parents were used to dealing with challenges.

As a parent of two children with disabilities, an educator and policy maker, he wanted to see his daughters receive a challenging education. “If they have a strong education, it can make our children’s lives significantly better,” and, “they can live happy, independent lives.”

As Chair of the State Board of Education, Mr. Reville stated his concern for all children, but especially for children with special needs. His goals include closing achievement gaps, increasing competency on the MCAS and ensuring all Massachusetts students make adequate yearly progress. He’d also like to see schools be more responsive to students’ needs and looks forward to the day when, “All students achieve, all means all – no excuses, no exceptions.”

Keith Jones used a mix of humor and stories from his experiences in special education to share his message that disability knows, “no age, color or gender, and that the disability community is cool because they accept everyone.” He spoke about the importance of making sure people with disabilities receive a quality education so they can, “Get up, get out, engage and contribute,” to their community. Noting that we live, “in a wondrous
Federation Staff in the News

In the last several weeks, two Federation staff members have made the news! The Office of Minority Health at the U.S. Department of Health and Human Services wrote an article about Sara Diaz, Outreach and Training Specialist for Spanish Speaking Families. When Sara moved from Columbia to Massachusetts with her son with Down syndrome, she had a difficult time accessing services and supports. She realized she was not the only Spanish-speaking mother facing these challenges. As a result, she formed a Spanish-language support group for families of children with Down syndrome. Read more at www.omhrc.gov:80/templates/browse.aspx?lvl=2&lvlID=19 (English) or www.omhrc.gov/espanol/templates/content.aspx?ID=6436&lvl=1&lvlID=29 (Espanol).

Rhea Tavares, Outreach & Training Specialist for Portuguese Speaking Families, was featured in the Boston Globe for her work mentoring a young boy. Informing, Educating and Empowering families is the mission of every Federation staff, but Rhea’s work is unique because her mentee lives in Slovenia. Using a webcam, she regularly ‘visits’ with his family, answers questions and demonstrates skills to Tim, who has the same disability as Rhea - ectrodactyly – short arms ending below the elbow, with a single finger in place of the forearm. Rhea, who moved to Boston from Brazil, did not receive any supports in her native country and did not want to ask for services and supports here. On her own, she figured out how to dress, eat, carry schoolbooks, write and more, and now Tim is learning these same skills. Read the article at www.boston.com/lifestyle/articles/2008/04/26/international_bond/.

For more information, contact Sara at sdiaz@fcsn.org or 1-800-331-0688, ext. 328. Rhea is available at rtavares@fcsn.org or 1-800-331-0688, ext. 329.
It was a pleasure to see so many of you on March 1 at Visions of Community, the Federation for Children with Special Needs’ annual conference. As I look out my window and see the budding trees, it’s hard to believe we had eight inches of snow on the day of the conference. In spite of the weather challenges, we had a record turn out.

Thanks for joining us for a fantastic day of networking and learning. My thanks to the many projects at the Federation that helped sponsor the day. These include Family TIES, the Massachusetts Parent Information and Resource Center (PIRC), the Parent Training and Information Center Project (PTIC) and the Massachusetts Family-to-Family Health Information Center (MA F2F HIC). In addition, I am pleased to acknowledge the support of our collaborating partners: the Early Intervention Parent Leadership Project (EIPLP), Mass Families Organizing for Change (MFOFC) and the Parent/Professional Advocacy League (PAL). Other state agency partners supported the conference as well. I think this speaks to one of the goals of the annual Visions of Community Conference - to bring our community together and realize the wealth of available supports, the shared resources and the inspiration! This most certainly works towards fulfilling the Federation’s mission of informing, educating and empowering families and their professional partners.

One of the important benefits of the conference is how it helps link essential services and makes vital connections. Let me illustrate this with a snapshot of my day at the conference. For several years, we have been inviting officials from each of our Massachusetts state agency partners to attend and interact with conference participants. As in past years, this year we also had a very positive response to our invitations, led by Secretary Judy Ann Bigby of the Executive Office of Health and Human Services along with leaders from 12 human services agencies. In addition, we had representation from the Massachusetts Board of Education with Chairperson Paul Reville as one of our keynote speakers along with leaders from the Massachusetts Department of Elementary and Secondary Education (DESE), formerly the Department of Education. At one point, while I was shaking hands with these dignitaries, I suddenly realized the uniqueness of the moment – we had many of the key players that influence and affect our lives as family members in the SAME ROOM, AT THE SAME TIME! With both arms extended and both hands engaged, I was proud to represent the Federation as a literal and figurative bridge between service agencies that provide supports to families with children and youth with special needs. It truly was a moment when the Vision of Community became a reality!

Best wishes to all,

P.S. I’d also like to express my thanks to everyone who attended the Federation Gala on May 2. This event, in addition to being an enjoyable and celebratory evening, is our most important fundraising event, and I appreciate your support.

Call for Nominations

The Federation for Children with Special Needs is seeking nominations for its Board of Directors. We are looking for nominees with expertise in business, finance, marketing and/or development. Board Member responsibilities include but may not be limited to the overall direction of the organization, policy and budget approval, and participation in annual fundraising events as well as at monthly Board Meetings.

Federal regulations require that the majority of our Board Members must have a child, between the ages of birth and 26, with a disability, or have a disability themselves. All interested individuals are welcome to apply.

If you would like to become a Federation Board Member, or want to nominate someone, please contact Selena Sheaves by mail at The Federation for Children with Special Needs, 1135 Tremont Street, Suite 420, Boston MA 02120, by e-mail at ssheaves@fcsn.org, or call 617-399-8372. Nominations are due on June 30, 2008.
Transition planning is essential so that your child can successfully move from the world of school to the worlds of further education, employment, independent living, and community involvement. If you’re the parent or guardian of a student with disabilities who is between the ages of 15 and 22, it’s time to work with your teen and the members of his or her IEP Team to plan for your child’s adult life.

Whatever a student’s abilities may be, it is important to create a plan that encompasses the child’s dreams. Encourage your child to “think big,” and not be merely “realistic.” When all IEP Team members – student, parents, professionals, and service providers – think outside the box, they will find creative solutions to break down barriers that at first might seem impossible to overcome. Many people are surprised by what students with disabilities can accomplish when they are given the chance to try. Although students with disabilities need more support during Transition than their typically developing peers, all students can take college courses, find satisfying work, or both.

Guided by the student’s vision, the IEP Team uses the results of Transition assessments to write measurable IEP goals, which will spell out the Transition services your child will receive. All Transition services should help your child improve his or her academic achievement and develop the skills they need to live an independent adult life. Examples of Transition services include, but are not limited to, learning opportunities such as college classes targeted at specific skill development tied to the student’s vision, employment, community involvement, self advocacy training, travel training, social skills training, job coaching, independent living skills training, or recreation training.

The websites below have lots of information that will help you plan for this important time in your child’s life.

**Individuals with Disabilities Education Act of 2004 (IDEA 2004)**

Explore IDEA 2004 regulations online in the Federal Register at [www.nichcy.org/reauth/IDEA2004regulations.pdf](http://www.nichcy.org/reauth/IDEA2004regulations.pdf). Type the word “Transition” into the FIND box and follow the word throughout the regulations, which start on Register page 46753.


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### General Transition Information
- [http://fcsn.org/pti/topics/transition/index.html](http://fcsn.org/pti/topics/transition/index.html)
- [www.doe.mass.edu/sped/links/transition.html](http://www.doe.mass.edu/sped/links/transition.html)
- [www.nichcy.org/resources/transition101.asp](http://www.nichcy.org/resources/transition101.asp)

### Developing a Vision
- [www.ilr.cornell.edu/edi/pcp](http://www.ilr.cornell.edu/edi/pcp)

### Transition Assessments
- **Assess for Success: A Practitioner’s Handbook on Transition Assessment** by Patricia Sitlington, Debra Neubert, Wynne Begun, Richard C. Lombard, & Pamela Leconte
- [nsttac.org/nsttac/?FileName=tag](http://nsttac.org/nsttac/?FileName=tag)
- [www.tslp.org/docs/QuickbookIEPChecklistFinal091407.pdf](http://www.tslp.org/docs/QuickbookIEPChecklistFinal091407.pdf)

### Self Determination/Self Advocacy
- [www.fvkasa.org/](http://www.fvkasa.org/)
- [www.youthhood.org/index.asp](http://www.youthhood.org/index.asp)

### College Planning
- [www.thinkcollege.net](http://www.thinkcollege.net)
- [www.heath.gwu.edu](http://www.heath.gwu.edu)

### Career Planning
- [www.ncset.org/topics/career/default.asp?topic=1](http://www.ncset.org/topics/career/default.asp?topic=1)

### Independent Living
IDEA 2004 has brought many changes to the educational system, including a requirement for schools to support the efforts of students with special needs to articulate a vision for the future as they prepare to transition from the public school system to adult life. This transition may include continued education, vocational training, and employment, as well as connecting with agencies that provide adult support services. However, parents and young adults are left to navigate one important aspect of adult life on their own – the healthcare transition.

To help facilitate this transition, Family TIES has developed a training for teens with special health needs, chronic illnesses and disabilities. The goal of our “The Ladder of Success” workshop is to explain medical transition and teach teens skills to manage their healthcare needs. As parents, we recognize the magnitude of this task, and realize that transferring this responsibility to our children is an important part of promoting their independence.

If your child sees a pediatrician, one of the first steps in the healthcare transition is to find a primary care physician who is willing to help your teen manage his special health needs, screen for secondary conditions and help with overall health and wellness. Ask your pediatrician, specialty and other healthcare providers to help you identify potential primary care providers. If your health insurer has a preferred provider network, that listing may be a good starting point. Some specialty providers do not transition their patients to adult health care providers, but many do. Talk to your teen’s specialists and if necessary, work together to identify an adult provider who can manage your child's medical condition.

Don’t wait until your child turns 18. These conversations should begin when you start discussing the transition out of school. This gives you time to find a doctor who will focus on the healthcare issues your child will face as an adult.

And, as always, involve your teen in this process. Work together to develop a list of questions to ask potential new doctors, then make an appointment to meet the doctor to see if he or she would be a good match for your young adult.

For more information about the Ladders of Success workshop, or to arrange a workshop in your community, contact Mary Castro Summers at mcsummers@fcsn.org or call 1-800-905-TIES to speak to the Family TIES regional coordinator in your area.

For information about health insurance for young adults with disabilities, read the article about Health Insurance in this issue or contact the Massachusetts Family-to-Family Health Information Center, a project of Mass Family Voices @ Federation at 1-800-331-0688, ext. 210.
“Further education.” These two words, full of promise and high expectations, were added to the mission statement of the Individuals with Disabilities Education Act in 2004. These two critical words embody a hope that is beginning to shape a new kind of future for many students with disabilities. IDEA 2004 sharpened its focus on raising expectations for students with disabilities by taking special efforts to coordinate with the No Child Left Behind Act (NCLB). NCLB promised a quality education to every K-12 student—including students with disabilities—for the very first time. IDEA and NCLB, along with the principle of equal opportunity under the 14th Amendment of our Constitution, combine to ensure that every child, including those with the most severe disabilities, receives an education that will result in positive outcomes, including preparation for further education.

Parents know that students need careful preparation to help them succeed in both college and careers. More than ever before, today’s students will need some type of post-secondary education whether it be on-the-job training, technical training, or college. For parents of students with disabilities, transition to post-secondary life is a pressing concern. Even with the powerful promise of education laws, not all parents have the information they need to help their children make a successful transition to college or higher education. Some parents face language barriers. Families with no tradition of higher education lack personal experiences to pass on. Families with low incomes and those raising children with special needs may assume college is not within their reach. Yet today, many of these same students are finding their way to college or other career education and having successes. This article provides ideas to help parents think about post-secondary education for their child.

Research tells us that family encouragement is a top reason why students aspire to continue their education. Studies have also found that all students do better after high school when there is a strong connection to a caring adult, whether or not that adult is a family member. Your enthusiasm about learning is important—a student’s attitude is one key to academic success.

High expectations and aspirations, while essential, are not enough. Launching a child toward a desirable future also requires helpers along the way. Share your high expectations with teachers and counselors. Your child’s vision, and your high expectations for your child, helps illuminate the path ahead. When everyone knows what you are aiming for, they can help you and your child achieve those goals.

Good teachers are important. NCLB requires that teachers of all core academic subjects, including special education teachers, be “highly qualified” in the subjects they teach. In addition to having state certification and a license to teach, highly qualified teachers must demonstrate competence in the academic subjects they teach. This law says schools must tell you about teacher qualifications if you ask. If a teacher who is not highly qualified is teaching a student, the school must inform the parents even if they do not ask.

The school counselor is another important resource with special knowledge of resources to help you and your child plan for the future. The guidance counselor can let you know about college preparatory programs that may be available. In Massachusetts, many middle and high schools have formed partnerships with institutions of higher education across the state to help students prepare for college. Many of these programs are free to students. Some even offer stipends to offset the cost of participating in them. All five campuses of the University of Massachusetts sponsor such programs, some specific to students with disabilities and those who are economically disadvantaged or who are English-language learners.

Today, across the country, many more students with significant disabilities are taking college classes. Massachusetts students with severe disabilities are benefiting from a new partnership between two-year and four-year colleges and public school districts. This unique program, called the “Inclusive Concurrent Enrollment Partnership Program for Students with Disabilities” allows high school students with severe disabilities, ages 18–22, to participate in college classes alongside their peers while still on an IEP.

Historically, special education and regular education have evolved as two separate systems, often with two separate concepts of what desirable outcomes should be. Today’s laws explicitly state that the purpose of the educational system is to ensure that all students have access to the same high expectations and high quality education that will prepare them for post-secondary experiences, employment, and independent lives. Thanks to these visionary laws, and to the efforts of families, advocates, and students with disabilities, new possibilities are emerging and new paths are being forged.
Health Insurance Options for Young Adults with Disabilities

Supplemental Security Income, or SSI, is a federal program administered by the Social Security Administration. It provides a monthly cash benefit, which Massachusetts supplements. And, in Massachusetts, a person who is eligible for SSI receives MassHealth Standard, comprehensive public health insurance for individuals with disabilities. SSI eligibility depends on two factors. The applicant must meet certain disability criteria and have very limited income and assets. For children younger than 18 years old, even if they meet the disability criteria (www.socialsecurity.gov/disability/professionals/bluebook/ChildhoodListings.htm), family income counts towards their eligibility. If family income is too high, the child may be eligible for MassHealth Standard (without the monthly cash benefit), or MassHealth CommonHealth insurance.

Once the child turns 18, family income does not count toward the individual’s eligibility. If the ‘child’ has limited income and assets, and meets the adult disability criteria (www.socialsecurity.gov/disability/professionals/bluebook/AdultListings.htm), he or she will be eligible for SSI, and MassHealth Standard health coverage. Learn more about SSI eligibility at www.socialsecurity.gov/pubs/11011.html.

In April 2006, Massachusetts passed health care reform legislation called Chapter 58: An Act Providing Access to Affordable, Quality, Accountable Health Care. This state law mandates all Massachusetts residents, over age 18, must have health insurance. In addition, Chapter 58 extends dependent care available through private health insurance to age 26 or until 2 years after the family no longer claims the child on their tax return – whichever comes first. This is one option for providing continued health insurance for your young adult.

If your adult ‘child’ is mentally or physically incapable of earning his or her own living, the family’s private health insurance may offer Adult Disabled Dependent Coverage. You need to contact your insurance company to find out: 1) if this is an option, 2) what documentation they require from your child’s physicians, and 3) if there is an extra premium.

Additional Resources
The Healthy and Ready to Work National Resource Center at www.hrtw.org has excellent health care resources and provides an overview of systems and services, youth involvement, tools and solutions, and much more.


Visit Health Care Transitions at http://hctransitions.ichp.ufl.edu/resources.html for great training materials (English and Spanish) to use with your child to help him or her learn to manage their own special health care needs.

For additional information, or to learn more about services and supports offered through the MA Family-to-Family Health Information Center, call 1-800-331-0688, ext. 210, e-mail massfv@fcsn.org or visit www.massfamilyvoices.org.

E-Newslinese

In the last few years, Newsline subscriptions have increased from 12,000 to more than 28,000! The Federation strives to get critical information out to families, but we struggle with the printing and mailing costs of our quarterly newsletter. Now you can receive Newsline electronically, cut down on mailbox clutter, save some trees and support the Federation, all with a few keystrokes. Sign up for e-Newsline at http://fcsn.org/publications_resources/newsline/newsline_subscrib.htm. Get the same great information, delivered via e-mail, faster and cheaper than regular mail.
Helping Your Teen Find a Summer Job

By Amanda C. Green, Information Specialist, Parent Training and Information Project

Summer is coming. It’s time to think about a job for your teenager with disabilities. During the Transition years, from ages 15–22, a summer job can be an important way for your child to make community connections, find out what kinds of work she likes to do, learn and practice work habits, and discover the skills she will need in the future. This is also a good opportunity to help foster your child’s growing independence by helping her learn to advocate for herself. As an adult, she will need to understand her own strengths and weaknesses and be able to explain the supports she needs to be successful. Working together to find a summer job for your child helps advance these goals.

Find out if the school has conducted any work-related Transition assessments (such as an Interest Inventory or Functional Vocational Evaluation). Use the results to help you and your child compile a list of her strengths and weaknesses. Encourage your child to ask her teachers and other trusted adults, “What do you think I do well?” Explore the Internet together to find online Career Interest Inventories and websites that describe the abilities required for specific jobs. The U.S. Department of Labor produces the Occupational Outlook Handbook, which describes thousands of jobs, and the skills needed to perform them. Find it at your local library or browse it online at www.bls.gov/oco/home.htm.

Encourage her to identify activities she does well and enjoys, as well as tasks she dislikes doing and should avoid. What does she like to do in her free time? What are her favorite school subjects, and why? Does she like to work with her hands or use a computer? Is she artistic? Does she like to be alone or in a group? Would she be best suited for outdoor or indoor work? Does she need structure and predictability? Is she a good listener, speaker, reader, or writer? What household chores does she do well? Can she handle money, find her way around town, drive a car, or travel on a bus? What does she need help to do, and what can she do independently?

The answers to these questions can help you and your child find a satisfying job. For example:

- If your child is organized - she may enjoy stocking supermarket or food pantry shelves, doing office filing, organizing books at the library, or doing summer maintenance at her school.

- If your child is friendly and helpful - some large stores employ greeters. Your child could also usher at a theater or stadium, be a guide at a park, a summer camp counselor in training, or a nursing home volunteer.

- If your child enjoys doing Internet research or entering information into a database - your local newspaper or nonprofit might need her talents.

Another way to identify summer job possibilities is to walk down the main street of your town with your teen. Are there businesses that might be potential summer work sites? Have your child introduce herself to the people who work at your local library, grocery or clothing store, pharmacy, farm stand, medical office, YMCA, or bakery. Ask if they need help, and help them to think creatively about ways your child could fit in. Even if these businesses can’t accommodate your child this summer, you will have made a connection for the future. And, don’t forget about volunteer opportunities! Your child does not have to make money to gain valuable work experience. In fact, her willingness to work in exchange for an opportunity to learn and gain experience might encourage an employer to make a place for your child.

What supports need to be in place so your teen can succeed? Providing needed supports may be key to your child’s success at a summer job. If possible, obtain help from other employees or friends. Consider assistive technology such as electronic calendars, tape recorders, and talking word processors, especially if your child uses them at school. If your child’s IEP Team determines that her summer job is a needed part of her vocational education, the school may provide a job coach. Finally, consider supplying your child with a safety net: a cell phone so that she can call you if she gets stuck. This will give both of you peace of mind.

In autumn, your child will return to class with new skills, new community connections, better self-knowledge, and an important addition to her resume!

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Visions of Community 2008 (Continued)

time,” he cautioned us not to let, “bud-
get crises or lack of motivation get in
the way of educating the next genera-
tion,” because if we, “under educate a
whole segment of our population, we
short change the ‘stewards’ of our fu-
ture.”

In addition to the keynotes, the Fed-
eration continued the tradition of
inviting representatives from the Ex-
ecutive Offices of Health and Human
Services (EOHHS) and the state dis-
ability agencies. Dr. Judy Ann Bigby,
the Secretary of EOHHS, extended
greetings from Governor Patrick,
thanked the Federation for all the
work it does and said she was pleased
to attend the conference because it is,
“an important event.”

Commissioner Heidi Reid, from the
Massachusetts Commission of the
Deaf and Hard of Hearing, recognized
the Federation as a great collaborator.
Larry Tumino, Deputy Commissioner
at the Department of Mental Retarda-
tion (DMR), stated the department
was excited about their Community
First initiative, dedicated to creat-
ing a full life for all. Secretary Jean
McGuire, also from DMR shared that
she was also a parent and pleased to
have interacted with the Federation.
Commissioner Angelo McClain stat-
ed the Department of Social Services
is committed to supporting children
by strengthening families. Assistant
Commissioner Sally Fogarty, from the
Department of Public Health, shared
greetings from the Medical Director
Dr. Lauren Smith and Commissioner
Auerbach, and expressed their com-
mitment to being responsive to fami-
lies’ needs and to continued collabo-
ration with the Federation.

Community Partnership Awards

Each year, the Federation gives Community Partnership Awards to recognize the “unsung heroes” – those parents, educators, advocates, health professionals and community leaders, who have made a significant impact for children with special needs. This year’s recipients were:

**Mark Kelly**, the Director of Special Needs for the Newton Parks and Recreation Department. Mark has brought quality therapeutic and educational recreational activities to Newton area special athletes. Mark said that, “working with the athletes and watching them grow over the years is the most fulfilling part of the job.” He accepted the award on behalf of the department and all the community partners, volunteers, coaches, parents and sponsors who make the program possible."

**Donna Rosso**, special education director in the Melrose Public Schools is eager to help children maximize their potential and to support families. She believes that when schools partner with parents, the best interests of children are served.

**Julianne Kelley** is the mother of three young boys on the autism spectrum and a parent advocate. She was instrumental in re-organizing her district’s special education advisory council, and, as a member of the school committee, advocated for an inclusive pre-school and improved van safety. Julie organizes monthly parent support groups, and helps parents learn about opportunities. She has also formed special needs sports teams so children can participate in a safe and nurturing environment.

As a single parent raising three children, **Elaine Crowley** needed to make money to support her family. However, her heart belonged to children who have special needs. For 23 years, Elaine volunteered to help children with disabilities at her local bowling alley, teaching them to play the game, and keep score. When her own children were grown, Elaine turned her volunteer experience into paid work and became a professional aide in the Shrewsbury Public Schools where she guides, encourages and supports the independence of students with disabilities in grades 3-8.

**Sara Soulard** is a 4th grade teacher at the Hemenway School in Framingham, where she creatively involves students with disabilities in every aspect of the general curriculum. She communicates with parents so they always know what is happening in the classroom and can follow through at home. She uses computer technology to ensure all her students are on the ‘same playing field,’ develops modifications that foster students’ independence, and sees each student as an individual with unlimited potential.

**Tracy Johnston and Marynell Henry** are both parents of children with special needs. They put their heads, hearts, and work experience together to create a vision of inclusive programming for special education students in Situate. Together they founded the Scituate Community of Resources for Special Education, raised $90,000 in 20 months and created collaborative partnerships with community members, and touched the lives of numerous children, families and educators.
Ajudando o Seu Adolescente a Encontrar um Trabalho Durante o Verão

Por Amanda C. Green, Especialista de Informação, Projeto de Informação e Treinamento para os Pais

O verão está chegando. É hora de pensar sobre um trabalho para seu adolescente com deficiência. Durante os anos de Transição, de 15–22 de idade, um trabalho durante o verão pode ser uma forma importante para que seu filho/sua filha faça contatos com a comunidade, descubra que tipo de trabalho gosta de fazer, aprenda e pratique hábitos de trabalho e descubra as habilidades que necessitará no futuro. Esta também é uma boa oportunidade para ajudar a promover o crescimento de independência de seu filho/sua filha, ajudando-o(a) a aprender a proteger-se por si só. Como adulto, ele/ela necessitará compreender suas capacidades e fraquezas e poderá ser capaz de explicar quais os apoios dos quais necessitara para ser tornar bem sucedido(a). Trabalhando juntos para encontrar emprego de verão para seu filho/sua filha, ajuda a antecipar estes objetivos.


Encoraje-o(a) a identificar as atividades que faz bem e com prazer, bem como as obrigações das quais não gosta de fazer e deveria evitar. O que ele/ela gosta de fazer em suas horas livres? Quais são suas matérias favoritas e por quê? Ele/ela gosta de trabalhos manuais ou de usar o computador? Ele/ela tem aptidões artísticas? Ele/ela gosta de estar só ou em um grupo? Estaria melhor adequado a um trabalho em recinto fechado ou aberto? Ele/ela necessita estrutura e previsibilidade? Ele/ela é um bom ouvinte(uma boa ouvinte), orador(a), leitor(a) ou escritor(a)? Quais as obrigações caseiras que ele/ela faz bem? Ele/ela sabe lidar com dinheiro, encontrar fácil um endereço pela cidade, dirigir um carro ou viajar de ônibus? De que ajuda necessita para fazer algo e o que pode fazer sozinho(a)?

As respostas a estas perguntas podem ajudar você e seu filho/sua filha a encontrar um trabalho satisfatório. Por exemplo:

- Se seu filho/sua filha gosta de animais de estimação - faça amizade com os vizinhos que têm cachorros e descubra se eles necessitam empregar alguém para passear com o cachorro. Se seu filho/sua filha se perde facilmente, providencie para que esteja acompanhado de um amigo que saiba usar bem os mapas e eles podem trabalhar em par. No final do verão, seu filho/sua filha poderá aprender a melhorar sua capacidade de direção e se familiarizar mais com a sua cidade. Alternadamente, seu filho/sua filha poderia se voluntariar para um abrigo de animais ou uma clínica veterinária.

- Se seu filho/sua filha é organizado – pode divertir-se organizando o estoque de um supermercado ou prateleiras de comida de uma despensa, organizando arquivos em um escritório, organizando livros em uma biblioteca ou fazendo manutenção de verão em sua escola.

- Se seu filho/sua filha é amigoável – algumas lojas de porte empregam pessoas para receber os clientes. Seu filho/sua filha poderia também indicar lugares (lanterinha) em um teatro ou estádio, ser um conselheiro em treinamento em um acampamento de verão ou um voluntário em uma clínica de repouso para idosos.

- Se seu filho/sua filha aprecia fazer pesquisas na internete ou colocar informações em bancos-de-dados – seu jornal local ou uma organização não lucrativa poderá necessitar de seus talentos.

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Making Social Connections: Share Your Ideas!

Making social connections in high school can be challenging for kids with disabilities. Have you developed a successful strategy to help facilitate social connections for your teen, learn the art of conversation and other social conventions so he can develop and maintain a social network? We want to hear your ideas!

Have you helped your son to set up a monthly movie club? Have you worked with your school’s guidance counselor to establish an after school club around your daughter’s interests? Does your child’s speech therapist have a successful model for teaching social pragmatics? Have you developed an effective script to help your teen make phone calls?

Let us know the solutions that have worked for your family, and we’ll share your stories on our website at www.fcsn.org. Send your ideas to Amanda Green at agreen@fcsn.org. Thanks!
How Can Special Needs Trusts Be Used?

By Neal A. Winston, Moschella & Winston

Clients often ask about the kinds of expenses that their child’s Special Needs Trust can pay for without reducing or making a child ineligible for government benefits. A trust can pay expenses for a wide range of items or services. These include:

- **Medicines and Medical Devices** such as prescription and nonprescription medications, supplemental dietary needs, eyeglasses, hearing aids, prosthetic devices, wheelchairs, modified scooters and for the maintenance of these devices.

- **Medical Services** – These include a private room, private nurses, home health care, therapies, rehabilitation, hospice care, psychological counseling, respite care and room and board during a medical confinement.

- **Dental check-ups** and all other oral health needs.

- **Educational training** and associated expenses such as: tuition, books, supplies, computers and software.

- **Recreation** – The trust can provide funds for hobbies, attendance at cultural and athletic events and vacation travel (including the cost of a companion if needed) for visits with relatives and friends.

- **Transportation** – Special Needs Trusts may be used for transportation, or to purchase a car (including insurance, gasoline and maintenance) if it is necessary for the beneficiary to perform essential daily activities, or for a specially equipped vehicle such as a modified van.

- **Insurance** – The trust can pay the premiums for term life insurance and supplemental health insurance.

- **Certain housing items and related costs** – The trust can provide funds for payment of goods and services that add pleasure and quality to life: audio and video equipment, videos, CDs, DVDs, furniture, gardening expenses, home improvements such as ramps and rails to accommodate the beneficiary’s physical condition and similar items.

The Supplemental Security Income (SSI) program requires a partial benefit reduction if the trust pays for food and shelter, like rent or mortgage payments. Reductions only affect the SSI benefit; as long as an individual is eligible for SSI, he is eligible for MassHealth/Medicaid.

A special needs trust can pay expenses for a wide range of items or services.

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Jewish Family & Children’s Service

JF&CS Services for People with Disabilities provides an array of programs for adults and youth.

Contact us to learn more about our programs for people with disabilities including:

- **Preparing for Independence After School Program**
- **Sunday Respite Program**

For more information call 781-647-JFCS (5327) or visit our website at jfcsboston.org.
Imagine being among thousands who share your deepest passions and concerns. Imagine finding all the information you need on your most important challenges in a single place. Imagine it all coming amid a spirit of friendship, joy and celebration.

You’ll find it all in Boston at the 36th annual National Down Syndrome Congress (NDSC) Convention, July 11–13, 2008.

Learn

The NDSC is dedicated to enhancing the lives of people with Down syndrome. Information — current, accurate, sometimes revolutionary — is the key. Through the NDSC annual convention you can connect — meet, hear and learn from the best minds in our community on virtually every aspect of Down syndrome. From keynote speeches to workshops and on to casual gatherings of parents and professionals, you will discover exactly what you need to meet challenges, present and future.

Meet

The NDSC convention is a giant family reunion. It is a time when people from across the nation and around the world gather to reconnect with old friends and make new connections. Sincere warmth is palpable and the concern genuine and heartfelt.

Celebrate

We know how to party! From the opening reception through workshops and keynotes and on to the banquet gala, you’ll celebrate the lives of individuals with Down syndrome and your pride in their accomplishments. You will laugh, applaud, cheer. And, you may shed a few tears as you revel in the richness, diversity and accomplishments of a wonderful, caring community.

Cómo Ayudar a su Adolescente a Encontrar un Empleo de verano

Por Amanda C. Green, especialista en información, Proyecto de Capacitación e Información para Padres

Pronto llega el verano. Es hora de pensar en un trabajo para su adolescente con discapacidades. Durante el período de transición, entre los 15 y 22 años, un empleo de verano puede ser una manera importante para su niño de conectarse con la comunidad, explorar qué tipos de trabajo le gustan, aprender y practicar destrezas laborales y descubrir las habilidades que necesitará en el futuro. Es también una buena oportunidad para promover la creciente independencia de su niño ayudándole a aprender a defender sus intereses. Como adulto, deberá entender sus propias fortalezas y debilidades y ser capaz de explicar los apoyos que necesita para tener éxito. Buscar juntos un trabajo de verano con su niño le ayudará a avanzar hacia estas metas.

Averigüe si la escuela ha realizado alguna evaluación de transición relacionada con el empleo (p. ej., una Evaluación Funcional Vocacional). Use los resultados de guía para hacer con su niño una lista de sus fortalezas y debilidades. Aliéntele a que pregunte a sus maestros y demás adultos de confianza “¿Qué cosas creen que hago bien?” Exploren juntos la Internet para encontrar pruebas de orientación vocacional y sitios web que describan las habilidades requeridas para empleos específicos. El Departamento de Trabajo de EEUU publica el Occupational Outlook Handbook, que describe miles de empleos así como las habilidades necesarias para realizarlos. Puede encontrarlo en su biblioteca local u hojearlo en línea en www.bls.gov/oco/home.htm.

Aliente a su niño a identificar las actividades que hace bien y le gustan así como las tareas que le desagrada y debería evitar. ¿Qué le gusta hacer en su tiempo libre? ¿Cuáles son sus materias favoritas en la escuela y por qué? ¿Le gusta trabajar con las manos o usar computadoras? ¿Tiene inclinaciones artísticas? ¿Le gusta estar solo o en grupo? ¿Prefiere el trabajo al aire libre o bajo techo? ¿Necesita estructura y una rutina previsible? ¿Tiene buenas habilidades de escucha, habla, lectura o escritura? ¿Cuáles tareas del hogar hace bien? ¿Sabe manejar dinero, orientarse por la ciudad, conducir un auto o tomar el autobús? ¿En qué necesita ayuda y qué puede hacer en forma independiente?

Las respuestas a estas preguntas pueden ayudar a usted y su niño a encontrar un trabajo que le dé satisfacción. Por ejemplo:

When it comes to life there are no limits.

Day school
Residential school
Adult services

Michelle Markowitz 781-829-1205 mmarkowitz@coletta.org

continúa en la página 14
Children’s Mental Health Campaign Update
By Matt Noyes, Children’s Health Coordinator, Health Care For All

Nationally, 20% of all children and adolescents (15 million) have a diagnosable mental illness. Of these young people, one in ten suffers from a mental illness severe enough to cause significant impairment.

In Massachusetts, more than 140,000 young people need mental health services every year, but more than 100,000 do not get the care they need.

Mental illness is connected to school drop outs (50% of students with mental illness leave school before graduation), juvenile justice (70% of kids involved with the Department of Youth Services have a mental disorder), and suicide (90% of children who die by suicide have a diagnosable and treatable mental illness at the time of their death).

This year, the Massachusetts’ Legislature has taken significant steps toward passing legislation that will significantly reform the children’s mental health system and expand access to behavioral health services for children in need.

Senate Bill (SB) 2518 An Act Relative to Children’s Mental Health, will help children living with mental illness by:
- Promoting early identification of mental illness;
- Improving insurance coverage for mental health care;
- Providing tools to early education settings and schools to help students with behavioral health needs;
- Ensuring that children are treated in the least restrictive, most appropriate care settings;
- Reforming state agency structures to improve the provision of care for children

The bill, sponsored by Representative Ruth Balser and Senator Steven Tolman, enjoys strong, bi-partisan support in the State House; more than 105 legislators have signed on as official supporters. Additionally, the broad-based Children’s Mental Health Campaign coalition, made up of nearly 100 endorsing organizations across the state, backs SB 2518. For more information about the Campaign, visit their website at www.ChildrensMentalHealthCampaign.org.

SB 2518 was reported out of the Health Care Financing Committee in February and is currently pending action by the Senate Ways and Means Committee. Your help is needed to keep the bill moving forward. Contact your State senator and tell him or her that you support SB 2518 and that you want the Senate to pass this legislation. Contact information for your state senator is available at www.wheredoivotema.com.

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For more than 45 years HMEA has provided specialized supports to children and adults with developmental disabilities
- Early Intervention – home-based ABA services
- School-age – home & school behavioral consultation
- TRACS — vocational assessment, school-to-work training and independent living skills development
- The Darnell School for Educational and Behavioral Services in Hudson, MA – serving children with autism or developmental disabilities – ages 9 to 22

“We believe in the power of dreams, NOT the limitations of disabilities”

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E-mail: hmea@hmea.org
Web site: www.hmea.org
Ajudando o Seu Adolescente a Encontrar um Trabalho Durante o Verão

(continuação da página 10)

Uma outra forma de identificar possibilidades de trabalhos de verão é andar pela rua principal de sua cidade com seu adolescente. Existem negócios que poderiam ser lugares em potencial para trabalho de verão? Seu filho/sua filha já se apresentou para as pessoas que trabalham na sua biblioteca local, loja de alimentos ou roupas, farmácia, banca de mercado, consultório médico, YMCA, ou padaria? Pergunte-lhes se necessitam de ajuda e ajude-os a pensar com criatividade sobre maneiras pelas quais seu filho/sua filha poderia estar adequado para a posição. Mesmo que estes negócios não possam acomodar seu filho/sua filha neste verão, você terá feito um contato para o futuro. E, não se esqueça das possibilidades do trabalho voluntário! Seu filho/sua filha não precisa ganhar dinheiro para ganhar uma experiência valiosa de trabalho. Na verdade, a sua boa vontade de trabalhar em troca de uma oportunidade de aprender e ganhar experiência poderá encorajar um empregador a encontrar uma posição para seu filho/sua filha.

Que apoios são necessários de serem estabelecidos para que seu adolescente possa ser bem sucedido? Providenciar os apoios necessários pode ser a chave para o sucesso de seu filho/sua filha em um trabalho durante o verão. Se possível, obtenha ajuda de outros empregados ou amigos. Leve em consideração a tecnologia de assistência tais como os calendários eletrônicos, gravadores e processadores de ajuda à fala, especialmente se seu filho/sua filha já os usa na escola. Se o Time IEP determinar que um trabalho de verão para seu filho/sua filha é uma parte necessária para a sua educação vocacional, a escola poderá providenciar um orientador para trabalho. Finalizando, considere fornecer a seu filho/sua filha um ambiente seguro: um telefone celular para que possa chamá-lo/la se encontrar-se em uma situação difícil. Isto trará paz de espírito para vocês dois.

No outono, seu filho/sua filha retornará às aulas com novas habilidades, novos contatos na comunidade, conhecimento melhor de si próprio(a) e um acréscimo importante ao seu currículo!

Cómo Ayudar a su Adolescente a encontrar un Empleo de Verano

(continuação de la página 12)

• Si a su niño le gustan las mascotas, hable con sus vecinos que tengan perros y pregunte si les gustaría contratar a alguien para que los saque a pasear. Si su niño se pierde fácilmente, sugiera que colabore con un amigo que sepa usar bien los mapas y emprendan algo en conjunto. Para el final del verano, su niño tal vez mejore sus habilidades para orientarse y conozca mejor su ciudad. Otra posibilidad es que su niño se ofrezca como voluntario en un refugio para animales o una clínica veterinaria.

• Si su niño es organizado, tal vez le guste abastecer los estantes en un supermercado o una despensa de alimentos, archivar documentos en una oficina, organizar libros en una biblioteca o hacer trabajo de mantenimiento en su escuela.

• Si su niño es cordial y le gusta ayudar, algunas tiendas grandes contratan a personas para que den la bienvenida a los clientes. También podría trabajar de acomodador en un teatro o estadio, ser guía en un parque, recibir capacitación como consejero en una colonia de vacaciones u ofrecerse como voluntario en un hogar de ancianos.

• Si a su niño le gusta investigar temas en la Internet o ingresar información en bases de datos, su periódico o alguna organización local sin fines de lucro podría necesitar de sus habilidades.

Otra manera de identificar posibilidades de trabajo de verano es dar un paseo con su adolescente por la calle principal de su ciudad. ¿Hay comercios que sean posibles fuentes de empleo durante el verano? Haga que su hijo o hija se presente a las personas que trabajan en su biblioteca, bodega, tienda de ropas, farmacia, puesto de productos de granja, consultorio médico, YMCA o panadería. Pregúntele si necesitan ayuda y ayúdelas a pensar en forma creativa en maneras en que su niño podría ser útil. Aun si estos comercios no tienen empleo para su niño este verano, habrá hecho una conexión para el futuro. ¡Y no se olvide de las oportunidades de servicio voluntario! Su niño puede adquirir una experiencia laboral valiosa aunque no gane dinero. De hecho, su voluntad de trabajar a cambio de la oportunidad de aprender y adquirir experiencia puede ser un aliento para que un empleador considere darle trabajo en el futuro.

¿Qué clases de apoyo necesita su adolescente para poder tener éxito? Contar con los apoyos necesarios puede ser la clave que su niño tenga éxito en un empleo de verano. De ser posible, pida ayuda a otros empleados o amigos. Considere el uso de tecnología asistiva, como calendarios electrónicos, grabadores y procesadores de texto a voz, especialmente si su niño los usa en la escuela. Si el equipo a cargo del IEP (plan educativo individualizado) de su niño determina que su empleo de verano es una parte necesaria de su educación vocacional, la escuela podría proveerle un tutor laboral. Por último, considere brindarle a su niño una red de seguridad: un teléfono celular para que pueda comunicarse con usted si tiene cualquier problema. Esto les dará tranquilidad a los dos.

En el otoño, su niño retornará a la escuela con nuevas habilidades, nuevas relaciones en la comunidad, mejor conocimiento de sí mismo e importante información para añadir a su currículum vitae.
It can be difficult to recognize underlying medical, physical and mental health conditions in individuals who have a primary diagnosis. A misdiagnosis or failure to recognize symptoms of a new medical concern is a problem for anyone. It is an even bigger concern for individuals who have limited communication skills or who have difficulty coping with stress in healthy ways.

Adults with Down syndrome achieve healthy mental health the same ways as other adults. They want to be accepted, have choices, enjoy a lifestyle that includes good nutrition and regular exercise, be part of and contribute to their community, and have the opportunity to do interesting and satisfying work.

When these things are absent, it can intensify behaviors, such as a tendency to be methodical, and lead to a misdiagnosis of a mental illness when the person is really coping with stress in an unhealthy way.

If you need help understanding the strengths, challenges, and behaviors of an adult with Down syndrome, this easy-to-read and well organized book provides wonderful insight. Readers will learn the difference between behaviors and mental illness. There are excellent tips for what to watch for, when to be concerned, when to get help, and how to choose a mental health provider.

Teaching Children with Down Syndrome about their Bodies, Boundaries, and Sexuality. A Guide for Parents and Professionals

By Terri Couwenhoven, M.S.
Woodbine House Special Needs Collection 2007

Terri Couwenhoven is a certified sexuality educator who works with individuals with intellectual disabilities and is a mom to two daughters, one with Down syndrome.

With an emphasis on helping children develop healthy sexuality, Ms. Couwenhoven has written a wonderful guide that not only explores the myths about sexuality and people with disabilities but also provides gentle prompts for teaching a child about his or her body and the changes to expect. There’s a chapter devoted to helping parents identify why they have a difficult time teaching their child about sexuality, which provides guidelines for how much information to provide at specific times. Other chapters include excellent activities for teaching children about social skills and friendships, dating, healthy relationships and safety, accompanied by visuals parents can use to teach their children about their bodies. And, don’t forget to read through the resource section with excellent supplementary materials for parents, children, teens, self-advocates and professionals.

Woodbine House has donated a copy of these books, and other titles from their Topics in Down Syndrome series, to the Federation. Call 617-236-7210 to borrow a book or review the entire Woodbine House catalogue at www.woodbinehouse.com.
Mark your calendars for these upcoming Events

National Down Syndrome Congress
36th Annual Convention
Seaport World Trade Center • Boston, MA
July 11-13, 2008

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

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

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