Phyllis Sneirson Retires

By Amanda Green, Parent Training & Information Project

Anyone who knows the Federation for Children with Special Needs knows Phyllis Sneirson. Executive Director Rich Robison recollects, “Countless people have called here in a panic, and Phyllis has talked them off the ledge. They were confused and distraught, but Phyllis was able to help them make sense of the situation, figure out a game plan, and go forward with confidence.”

Long-time advocate Donna Murphy remembers, “Without Phyllis’s support I would not have had the courage to advocate for what my daughter needed. She helped me to ask the right questions, and cared enough to ask how things turned out afterwards. Today it continues to amaze me that if anyone has a question, Phyllis always remembers just where to put her hands on the answer.”

It was with our heartfelt gratitude for all the families she has helped, our awe at her expertise and our admiration for her unflagging energy these past 30 years, that the Federation family and friends wished Phyllis a smooth transition to the next phase of her life when she retired on January 15, 2008.

Phyllis did not begin her career at the Federation as the confident expert she later became. “I was bringing my son to the Youville Hospital in Cambridge for physical and occupational therapy, and there was another young woman there who was working at the Federation. She asked me if I’d like to volunteer in the morning for just a few hours, I said, ‘fine,’ – and I never left!” Phyllis’s first paying job was at the reception desk. “I hadn’t worked in a long time, so I got my paycheck for $3 an hour and I thought it was wonderful!”

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**Inclusion’s New Frontier: Concurrent Enrollment**

*By Amanda Green, Parent Training and Information Project*

When Andrew Sinclair announced his intention to go to college like his brother and sister, his parents and teachers embarked on a quest to help him reach his dream. Andrew, who has Down syndrome, signed up for the state-funded pilot grant program called Inclusive Concurrent Enrollment (ICE), through which students who have significant disabilities, ages 18 – 22, can enroll in credit or non-credit college courses while still receiving services from their local school districts. Now in its second pilot year, ICE provides students with a chance to have an inclusive post-secondary experience. Andrew and his IEP Team at Belchertown High School, partnered with Holyoke Community College (HCC), and arranged for him to take college classes in nutrition, job exploration, painting, and music. Because Andrew needs extra assistance, his educational coach helps him by pre-teaching, reviewing notes, and working on reading comprehension, typing, math, and social skills. Otherwise, Andrew’s daily experience is pretty much that of a typical college student. He works out and makes friends in the college gym – and he has even realized his dream of becoming an actor by dressing up as the school’s mascot, the cougar! To help students get to know each other, HCC arranges a social program on Wednesday afternoons. ICE students mix with other students on campus who drift in to enjoy the barbecues and bands. Andrew attends HCC five days a week; other ICE students attend part-time, and supplement their academics with high school classes or with work experience.

Ginny Bilz, Andrew’s teacher at Belchertown High School, says, “ICE has improved Andrew’s social skills and made him more independent. He arranges his own transportation, finds his way around campus, and he has made some friends.” In addition, the students are not the only ones who benefit from this program. The college art teacher, though hesitant at first, soon realized that Andrew painted without inhibition and now holds up his work as an example to others.

Westfield High School teacher Sherry Elander, who has also placed ICE students at HCC, says, “Our students are treated just like every other student on campus. The professors have gone out of their way to make them feel comfortable.” Ms. Elander’s students are “building resumes, learning work skills, and developing self-esteem.” Most importantly, says Ms. Elander, these young adults are, “able to remain in the community where they feel they should be.”

Of course, a program like the one at HCC involves planning, vision, and determination. Ms. Elander advises, “When you allow yourself to think outside the box, and if you’re thoughtful in enlisting people with the knowledge that can support you, anything can be achieved. You have to be ready to be flexible, to hit the wall, to get back up and go around it. You can’t give up.” At Westfield High School, Ms. Elander works with a planning team of twenty members, which includes Maureen Conroy, the Director of Disability Services at HCC, as well as representatives from the Department of Mental Retardation, the Massachusetts Rehabilitation Commission, the Regional Employment Board, the New England Business Association, Mercy Hospital in Springfield, and Community Resources for People with Autism. Says Ms. Elander, “You have to be a risk taker to do what we’re doing and you have to have the confidence of your families and your administration to back you up. Other teachers in other systems are always amazed by the amount of support we have from our administration, and HCC has been phenomenal.”

Continues next page
In the fall 2007 issue of Newsline, I shared my concerns about the “Team 5 Investigates” television news report that stated “Special Education is cheating regular ed.” I disagreed with the report and detailed some of the issues, unrelated to special education costs, which affect school budget cuts. Several readers responded in kind that the report was misleading. I was particularly heartened to receive the following, thoughtful response from Ralph E. Hicks, Ed. D., the Superintendent of the Spencer-East Brookfield Regional School District. His excellent points about federal and state funding mechanisms for public education reminds us that the issue of rising education costs is a problem for all school districts. Singling out and blaming special education students and their parents is not a solution. The solution lies in collaboration and in changing funding formulas to meet every school district’s needs.

In support of all students,

Richard J. Robison

With Dr. Hicks’ permission, excerpts from his letter appear below:

Dear Mr. Robison:

I share your concern that the Channel 5 story on special education will pit regular education against special education. You are right that “neither special education students nor their parents are cheating the educational system.”

The problem is in the funding, which relies increasingly on local property taxes. It is high time that both Congress and the Great and General Court of Massachusetts step up to the plate. In 1975, Congress promised to eventually pay 40% of the cost of special education. Thirty plus years later, they pay a paltry 15%. Massachusetts doesn’t do much better, with Circuit Breaker reimbursing 75% of the costs that exceed four times the Foundation budget and nothing towards the cost of special education transportation.

Yes, students with special needs have not cheated regular education students, but the federal and state governments have. There is no question in my mind that special education in Massachusetts has, in many communities, been financed on the backs of regular education students. I see a backlash coming, and I don’t like it. This needs to be recognized by all of us.

Thus, we need to work together to see that this “rob Peter to pay Paul” attitude becomes a thing of the past. Congress needs to start living up to its 40% promise. The Great and General Court needs to put a more realistic formula in place for both Circuit Breaker and Chapter 70, which caps special education students at 4.75% of the total school population. Lastly, Circuit Breaker needs to include transportation, for without it many children with special needs would not receive the services they need. I hope the Federation agrees with these premises and will fight to see they are enacted.

Sincerely,

Ralph E. Hicks, Ed. D.
Superintendent of Schools

Note: For more information about Circuit Breaker, Chapter 70 and Foundation budget visit http://finance1.doe.mass.edu/seducation/ and http://finance1.doe.mass.edu/chapter70/.

Inclusion’s New Frontier: Concurrent Enrollment continued from page 2

Around the state, six colleges have partnered with twenty-four school districts in the ICE program, with the goal of developing promising practices to support college and work success for students with disabilities. The participating colleges are Mass Bay Community College, Mt. Wachusett Community College, Quinsigamond Community College, Holyoke Community College, Bristol Community College, and UMASS – Boston. The Federation for Children with Special Needs is now collaborating with these colleges to provide information and training about Transition topics, both to families whose students are involved with the ICE project, and to other interested families in ICE school districts. In a similar way, the Institute for Community Inclusion is providing information and training to district and college personnel.

Andrew’s mother, Julie Sinclair, says, “As parents, we recognize that it is more about the process than the product. It’s more about the journey than the destination. We are thankful to the legislators who funded this program and who believe that all students should have the opportunity to try. We’re also grateful to the Massachusetts Department of Education for enabling school districts to support students in their vision for post-secondary education. Andrew loves going to college, and is helping to create the paradigm shift to be included and to belong – just like everyone else!”
Delores Qualls Selected for AIDS Alliance Leadership Training

Delores Qualls, Project Coordinator for the MassCARE Family Support Initiatives at the Federation, was selected from more than 100 applicants to participate in the AIDS Alliance Corps Leadership Program in Baltimore, Maryland. The goal of this train-the-trainer program is to teach consumer leaders the skills they need to develop leaders in their own states.

The first of the three training sessions was December 2 – 6, 2007. Participants learned how to go into communities and teach consumers about accessing resources. This includes finding housing, medical care, and support groups. Participants did lots of role-playing, an activity Delores enjoys. In addition, Delores noted, “We received lots of support and learned good outreach techniques that would work with a variety of populations. The training model is applicable to a variety of settings. This carries over to any grassroots project that needs to identify and mobilize consumer involvement.”

The other participants also work in Part D Title IV Ryan White programs throughout the country. Delores has attended many intensive trainings, but this one set a new standard for intense! Still, it was “fabulous” and she is looking forward to the next session in April.

MassCARE Update: Common Visions Conference & Teen Supports

The Massachusetts Department of Public Health, in collaboration with the Boston Pediatric and Family AIDS project, and the MassCARE Family Support Initiatives at the Federation, hosted the Common Visions Conference on November 27 and 28, 2007. Delores Qualls, Project Coordinator for the MassCARE Family Support Initiatives at the Federation, gave the keynote presentation on the first day of this conference, which was for providers and consumers. The second day was for consumers only. They talked about consumer participation and getting involved with local and statewide Family Advisory Networks and Consumer Advisory Boards, stressing the importance of having a voice in the services consumers need and receive.

Consumers participated in the workshops, and one remarked that when she first came to the U.S. she had no support services. After she got involved in the MassCARE program, she received social and medical supports not only for herself, but also for her children. She is now active in MassCARE, in her community, and is a support person for other families affected by HIV/AIDS. She described her experience using the following analogy, “When I first came here, I didn’t know how to ride a bicycle and now I can drive a car. The MassCARE program has meant that much to me.”

In the next few months, the MassCARE Teen Advisory Network (TAN) will be organizing a 2nd event for adolescents and young adults from the MassCARE program and teens from the other Title IV HIV/AIDS programs: Dimock, Boston Pediatric Family AIDS program, the Justice Resource Institute, and the Latino Health Institute. This cross-program event will bring young people together to learn leadership skills and discuss topics of mutual interest.

Delores and Linda are working with teens to identify unmet needs, which include information about transition from school to work and post-secondary educational opportunities, as well as transition from pediatric to adult medical care, and teen support groups.

For more information about MassCARE and to learn how you can be involved, call Delores or Linda at 1-617-236-7210 or e-mail dqualls@fcsn.org or lspinner@fcsn.org.

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Darla Gundler and her husband Greg are parents of two outstanding children. Tiffany, their 14-year-old daughter, was born prematurely and has a profound hearing loss. Tiffany received early intervention services and Darla actively participated in those services. She also became a parent leader at her local early intervention program and at the state level, working alongside professionals to ensure the parent voice was included in policy development, and expanding leadership opportunities for all parents. Darla became an effective advocate not only for Tiffany, but also for all children and families served by early intervention programs in Massachusetts and across the nation. Every year, in recognition of an outstanding commitment to parent leadership in the early intervention field, the IDEA Infant & Toddler Coordinator’s Association confers a National Parent Leadership Award. This year’s recipient was Darla Gundler!

For the past 10 years, Darla has been the Director of the Massachusetts Early Intervention Parent Leadership Project. Darla and her staff work in partnership with the Massachusetts Department of Public Health (the lead agency for early intervention (EI) services), EI program staff and families served by the EI system. They make sure families are knowledgeable about the services their young children are entitled to receive, and have opportunities to participate at the program, state and national level.

Darla’s colleagues note, “Darla is a true collaborator and partner. When asked to participate she only considers how her involvement can help shape the system for better, not how much time it will take or what’s in it for her.”

“As Darla has been influential as a parent at so many levels – on behalf of her daughter, as a parent appointed to the Massachusetts ICC [Interagency Coordinating Council], and as Director of the Massachusetts Parent Leadership Project. She is among the best resources for states hoping to develop or improve their parent involvement and leadership.”

Upon acceptance of the award, Darla thanked her family for their support and encouragement. She also stated, “One of my mentors told me long ago that working with emerging family leaders is one of the most challenging jobs that she ever had. I totally agree; however, it is also the most rewarding job that I have ever had.”
Phyllis Sneirson Retires continued from page 1

What was truly wonderful was the commitment and compassion Phyllis brought to her work, which gradually branched out from the reception desk to direct advocacy for families, to developing a first-of-its kind institute to train parent advocates. “Before we started to train advocates,” recalls Phyllis, “it was really awful. Parents would call here looking for an advocate, and you couldn’t get people to do it.” “However,” says Rich Robison, “Phyllis has been the inspiration and mentor for hundreds, if not thousands, of parent advocates, having run the advocacy training that became our Parent Consultant Training Institute since the early 1980s. In addition, she has the ability to keep up with them! She knows all the advocates personally, and she created a database so that the Federation can match them up with callers. That’s a real gift, not just to the individuals but really to the whole special education field.”

What parting advice does Phyllis have for families? “Know your rights! It’s absolutely essential!” Now, more than ever, Phyllis believes that parents need to educate themselves about the law and the special education process. “When the law [Chapter 766] was first passed, I used to say that we’re going out of business because we have this wonderful law. Unfortunately, it’s more difficult now than it used to be. There are many more children needing services, and shrinking budgets are an underlying factor in the sometimes contentious situations we see between parents and schools.”

Why has Phyllis stayed with the Federation? Parent Training and Information Director Robin Foley thinks Phyllis’s dedication has its roots in Phyllis’s own family. “Her connection to other families is rooted in her love for her son Robert, and that’s why she’s done what she does all these years. Her support for families is unwavering because of her own unwavering love as a mother.” Phyllis says that the support and flexibility of the Federation staff always allowed her to take care of her own family’s needs. Good friend and fellow staff member Terri McLaughlin can’t imagine the office without her. “To me, Phyllis has been an inspiration every day. I know that when I see her, whether I am happy or sad, she will listen and make me feel better. Like countless others who have been lucky enough to know Phyllis, I have enjoyed her wonderful sense of humor, listened intently to her stories, appreciated her strength and sense of fairness, and admired her strong commitment to family, friends and faith.”

Currently, Phyllis does not have definite plans for her retirement; we hope we can persuade her to come back to the Federation and then to share her wisdom and indomitable spirit. We wish her happiness and success in her future endeavors, and rather than say “good-bye,” we say, “until we meet again.” Most importantly, on behalf of all Massachusetts families who have children with special needs, we say, “Thank you.”

Parent Consultant Training Institutes

Do you find yourself wishing you knew more about laws that support your child or student? The Federation’s Parent Consultant Training Institutes offer Massachusetts parents and professionals the opportunity to learn more about state and federal special education laws and processes. We believe that educated parents and professionals are better able to collaborate effectively to develop supports and services that enable students with disabilities to succeed.

Tuition for parents is $325, professionals $425. Limited scholarships are available for parents. Family members can contact the Massachusetts Developmental Disabilities Council (MDDC) at 617-770-7676 to apply for Consumer Empowerment Funds. For more information about the Institutes and an application, visit http://fcsn.org/pti/advocacy/becomeanadvocate.php.

Spring 2008

Worcester

Meeting dates are on Friday, April 4, 11, 18, May 2, 9, 23, 30, June 6 from 9:00 a.m. to 2:30 p.m. Location TBA. Applications will be accepted after March 21. For more information, please contact Dotty Robison at 1-800-331-0688 ext. 315 or drobison@fcsn.org.

Summer 2008

Boston

Meeting dates are Monday through Friday, June 23, 24, 25, 26, 27 from 9:00 a.m. to 3:30 p.m., at the Federation Offices, 1135 Tremont St, Suite 420 in Boston. Applications will be accepted after April 1. For more information, please contact Dotty Robison at 1-800-331-0688 ext. 315 or drobison@fcsn.org.

Winter 2008

Western Massachusetts

Meeting dates are on Tuesday, February 26, March 4, 11, 18, and Thursday, February 28, March 6, 13, 20 from 9:00 a.m. to 2:30 p.m. Location TBA. The application deadline is February 18. For more information, please contact Julie Sinclair at 413-323-0681 or sinclair@fcsn.org.

Fall River Area

Meeting dates are on March 24, 26, 31, April 2, 7, 9, 14, 16 from 9:00 a.m. to 3:30 p.m. at the Fall River Boys & Girls Club, 803 Bedford St., in Fall River. For more information, please contact Terri McLaughlin at 1-800-331-0688 ext. 336 or tmclaugh@fcsn.org

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Planning Summer Fun for Children with Special Needs
By Mary Castro Summers, Director, Family TIES of Massachusetts

With the winter holiday season behind us, many parents turn their attention to the next most stressful time of year - summer vacation. Nearly all children look forward to the end of school. Often, parents share that feeling and enjoy a break from early morning struggles to get to school on time, wardrobe challenges, and homework checking. Unfortunately, this change in routine can also leave parents anxiously seeking creative ways to keep their children entertained and busy with activities that inspire learning and creativity, build skills, and deplete seemingly boundless amounts of energy. Add to this a parent’s own demands to meet work schedules and personal needs, and it’s no wonder you’re starting to worry about summer.

Parents of children with special needs have additional hurdles to consider, as they must find programs that not only fit their children’s interests, but also meet their child’s physical, developmental, emotional, and/or behavioral needs. Are you looking for a single solution to fill the entire summer for your child, or do you want to find several different programs to meet the growing interests and abilities of your son or daughter? Speak frankly with camp staff about your child’s special needs and the supports that will help your child enjoy each camp experience. Remember to ask about the staff-to-camper ratio, who oversees first aid and medical situations, and if the camp or family provides transportation. Once you’ve gathered information about programs that you think could meet the scheduling demands, include your child in the selection process. Ask if their friends are going to programs that might be of interest to them. Help your child get excited about summer programs, a must for success.

Begin summer planning by exploring the possibilities in and around your city or town. Are there any low-cost camps for children? Many programs let families create a plan to meet their children’s special needs as well as their needs for recreation, socialization, and fun – at an affordable cost. Check with your local Recreation Department; many have weekly programs that offer inclusive activities for children, and some even have programs designed just for children with special needs.

Ask if your local school district hosts summer recreation programs, and connect with your Special Education Parent Advisory Council. Other parents are a great source of information and ideas and can share what has worked for their own children. Don’t forget to check with the local YMCA (www.ymca.net/find_your_ymca/) and Boys and Girls Clubs of America (www.bgca.org/clubs/). Look in the Yellow Pages for camp listings, read local newspapers as many camps advertise, and try to attend a summer camp resource fair. The Federation publishes a yearly Summer Fun Guide (www.fcsn.org) with listings.

In addition to looking at program options, you need to consider the costs and funding sources. Many programs offer scholarships; most are need-based and parents should apply early. Check to see if your town Recreation Department offers scholarships or sliding-scale fees. Many faith-based communities, disability-specific organizations like United Cerebral Palsy, local Autism Support Centers, the Asperger’s Association of New England (www.aane.org; 617-393-3824), and state agencies may be able to provide some funding for summer programs.

Families have come up with creative ideas to help defray the cost of summer programs. These include:

- Organize an annual yard sale, and advertise that the money will pay for your child’s summer camp. Neighbors, family and friends contribute items and not only benefit from the opportunity to get rid of unused items, but also enjoy knowing the money will help a neighborhood child enjoy a summer of fun.

- In lieu of birthday or holiday gifts, ask family and friends to contribute to your child’s ‘camp fund.’

- If your child is old enough, consider having him or her contribute by earning some money by walking a neighbor’s pet, watering gardens, or doing other small odd jobs.

- Call your Family TIES Regional Coordinator at 1-800-905-TIES (8437) for additional information and for other funding ideas.

As you begin to develop summer plans, don’t forget about services through the public schools. Does your child qualify for an extended-school year (ESY)? Children who have an Individualized Education Program (IEP) may qualify for summer programming if the lack of consistent services throughout the summer would result in a regression or loss of skills gained during the academic year. Summer goals and objectives should be included in the IEP, if the Team decides that your child needs these services. Visit the Massachusetts Department of Education website at www.doe.mass.edu/pqa/ta/iesp_qa.html for more information.

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7
MassHealth Commonhealth – Program Eligibility & Application

Often, families whose children have special health care needs have lots of medical expenses. In addition to their health insurance premiums, they are also paying deductibles, co-payments, and for services their children need, but have exceeded the service limit set by their health insurer.

The Medicaid program in Massachusetts is MassHealth. There are many different types of MassHealth programs. Two of these programs, MassHealth Standard and MassHealth Commonhealth, can help families of children with special needs with out-of-pockets costs, even if they have private health insurance. Program eligibility depends on many factors. These include income, access to other health insurance, and if the child meets federal disability criteria.

If family income is less than 150% of the Federal Poverty Level (FPL), or $30,984 for a family of four, the children will be eligible for MassHealth Standard based solely on family income. If family income is more than 150% FPL, a child may be eligible for MassHealth Commonhealth if she meets the federal disability criteria. Read the listing of childhood impairments at http://www.socialsecurity.gov/disability/professionals/bluebook/ChildhoodListings.htm.

There is a sliding-scale premium for Commonhealth; the higher your family income, the higher the monthly premium. However, if the monthly premium is less than what you are paying out-of-pocket, purchasing Commonhealth can be a cost effective way to supplement health insurance coverage for a child with special health needs*.

Applying for MassHealth Commonhealth

The Medical Benefit Request or MBR is the single application for all the MassHealth programs. To find the application online, go to www.mass.gov/masshealth. On the left-hand side, under Programs & Services, click on Individuals, Families, & Children, and then click on How to Apply. You have the option of downloading the application or you can call a MassHealth Enrollment Center at 1-888-665-9993 (V) or 1-888-665-9997 (TTY) and request an application in the mail.

Fill out the application, being sure to provide information about each family member, as family size is used to compute family income as a percent of FPL. Even though you list each family member, when asked ‘is this person applying’ check ‘yes’ only for the individual with a disability. Make sure you fill out the blue Supplement B: Injury, Illness or Disability Questions part of the application for the child with a disability. In order to be eligible for Commonhealth, the child must meet federal disability criteria.

A separate Disability Evaluation Services (DES) Unit makes the disability determination, which can take up to 90 days. You can expedite this process by providing additional documentation with your MBR.

1) Download and fill out the MassHealth Child Disability Supplement at http://www.mass.gov/Eeohhs2/docs/masshealth/appforms/mads_child.pdf. Include information for all providers, even a provider your child saw only once, as everything is factored into the disability determination.

2) Fill out a MassHealth Medical Release Form for each health care provider. This gives the DES Unit permission to contact your child’s doctors for information. The form is at http://www.mass.gov/Eeohhs2/docs/masshealth/appforms/mh_mrr.pdf.

3) Follow up with your child’s doctors and confirm that they have provided information to the DES Unit.

4) There is a citizenship requirement. Include a copy of your child’s birth certificate.

5) Make a copy of the application and supplemental materials before you mail it.

*For information about the CommonHealth premium structure, or questions about MassHealth for a child with special health care needs, call the Massachusetts Family-to-Family Health Information Center at 1-800-331-0688, ext. 210 or e-mail massfv@fcsn.org.

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Rosie D. v. Patrick Update: MassHealth Improves Mental Health Screenings

By Kathryn Rucker and Santina Sciaba-Douglas, Attorneys, Center for Public Representation

Over the next two years, important changes will occur for MassHealth enrolled children with “serious emotional disturbances.” These changes include improvements in screening and assessment for behavioral health conditions and the development of new home-based behavioral health services.

These changes are in response to the federal class-action lawsuit, Rosie D. v. Patrick. This suit includes thousands of MassHealth eligible children who experience serious emotional or behavioral health conditions and, as a result, may be stuck in hospitals, at risk of hospitalization or out-of-home placements, or otherwise not receiving the mental health services they need to remain successfully in their homes and communities.

As of January 1, 2008, MassHealth requires pediatricians to offer brief mental health screenings in addition to the other medical and developmental screenings conducted during routine well child visits. Families can also request these screenings at other times if they suspect a problem.

The new screening process is voluntary. The intent is to identify concerns early and to provide an opportunity for parents and primary care providers to discuss all aspects of a child’s health, including mental health. The screening tool is a simple questionnaire or checklist completed by the parent or child, depending on the child’s age. If the screening raises concerns, parents and pediatricians can choose an appropriate plan of action, by either developing strategies to handle the problem within the primary care setting, or referring to a specialist.

As implementation of the court-ordered remedial plan proceeds, MassHealth and its managed care companies will use member notices, enrollment guides, handbooks, trainings, and bulletins to update families and providers. These updates will include information on standardized mental health evaluations (available after November 31, 2008) and the creation of a new behavioral health service system (available in June 2009).

Over the next sixteen months, a network of regional Community Service Agencies (CSAs) will be developed. These CSAs will offer and coordinate access to home-based services that are family-centered, strength-based, individualized, and delivered in a child’s home and community. The child and family will actively participate in and guide care and treatment services.

New home-based services are expected to include mobile crisis intervention, crisis stabilization, in-home behavioral support, and in-home therapy and mentor services. Children with serious emotional disturbances will also be eligible for intensive care coordination, and a treatment planning process, which establishes a single team and a single plan for services, developed and delivered in partnership with families.

For more information about changes in screening, and behavioral health services currently available to your child, speak with your primary care or behavioral health providers, or call MassHealth Customer Service at 1-800-841-2900 (1-800-497-4648, TTY) or your MassHealth managed care plan. Details on the Rosie D. case, including relevant court decisions and implementation updates are at www.centerforpublicrep.org.

For more information call:
617-236-7210, ext. 374
or visit fcsn.org.

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MassHealth Commonhealth – Programa de Qualificação & Formulário

Informação do Centro deInformação de Saúde de Família-para-Família, um projeto do Vozes das Famílias de Mass

Frequentemente, as famílias das crianças que têm necessidades de cuidados especiais de saúde têm muitas despesas médicas. Além das apólices de seus seguros de saúde elas também estão pagando as deduções, pagamentos-compartilhados e pelos serviços que seus filhos necessitam, mas se excederam no limite do serviço estipulado por sua seguradora de saúde.


Se a renda familiar for menor do que 150% do Nível de Pobreza Federal, Federal Poverty Level (FPL), ou $30,984 se destinar a uma família de quatro pessoas, as crianças estarão qualificadas para o MassHealth Standard tendo como base somente a renda familiar. Se a renda familiar for maior do que 150% do FPL, uma criança poderá ser qualificada para o MassHealth Commonhealth se ela estiver enquadrada nos critérios de deficiência federal. Leia a lista de limitações das crianças no http://www.socialsecurity.gov/disability/professionals/bluebook/ChildhoodListings.htm.

Existe uma escala-móvel de pagamento da apólice para o Commonhealth; quanto maior for sua renda familiar, maior será o pagamento mensal da apólice. Entretanto, se o pagamento mensal da apólice for menor do que as despesas pagas pelo segurado, a compra do Commonhealth poderá ser uma maneira de custo eficaz para suplementar a cobertura do seguro de saúde para uma criança com necessidades especiais de saúde*.

Solicitação para o MassHealth Commonhealth

O Pedido de Benefícios Médicos, Medical Benefit Request, ou MBR é um único formulário para todos os programas do MassHealth. Para encontrar o formulário online, visite o www.mass.gov/masshealth. No lado esquerdo, sob o nome de Programs & Services, clique em Individuals, Families, & Children e depois clique no How to Apply. Você tem a opção de carregar o programa do formulário ou pode telefonar para um Centro de Inscrição do MassHealth, MassHealth Enrollment Center, no 1-888-665-9993 (V) ou 1-888-665-9997 (TTY) e pedir um formulário através do correio.

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Supporting Children’s Learning at Home: What the Research Says

Janet Vohs, Director of Publications, Massachusetts Parent Information & Resource Center (Mass. PIRC)

Today’s families are busier than ever. Time is precious. To support their children’s development and learning, families are eager to choose actions that are effective, and that fit into everyday life. Research sheds light on the kinds of involvement that can make the biggest difference for all kids, no matter what special learning needs they may have or language they speak. Here’s Mass. PIRC’s “Top 10 List” of ideas that have been found to have a powerful impact on children’s learning.

Top 10 List

1) **Hold high expectations.** Parents’ expectations and aspirations for their children have a profound, positive impact on school success. Encourage your children’s dreams. Have confidence in their abilities and teach them to believe in themselves. Find ways to praise their efforts. For some fun ideas, visit www.mnsu.edu/comdis/kuster/gjohnson/101ways.html.

2) **Be a positive role model.** Let your child see you enjoy reading and learning. The high value you place on education and learning has a tremendously positive impact on your children.

3) **Seize the moment.** Every day brings opportunities to talk with and listen to your children. In fact, just talking and listening contribute greatly to students’ school successes. Find out what amuses, excites, and inspires your child. When you and your children are walking, driving, shopping, or waiting for an appointment, talk about the things you see and hear.

4) **READ! READ! READ!** No skill is more significantly linked to academic success than reading. Read to and with your child as often as possible. Read in the language of the home or whatever language you are comfortable using. Keep books, magazines, and newspapers in the house and be a reading role model. Visit the Reading is Fundamental website at www.rif.org/ for activities to promote reading, literacy games, and book lists.

5) **Encourage math and science.** Talk about math and science during everyday activities. Cooking, gardening, sewing, using a calculator, playing board games, estimating distances and amounts, and recognizing patterns in design and music all offer opportunities for conversation.

6) **Be a positive voice for your child.** The more families speak out for children and support their progress, the better their children do, and the longer they stay in school. If you need help and support, the Federation provides many opportunities for parents to learn the skills they need to be effective advocates.

7) **Find out what your children are learning at school.** Ask your children’s teachers what they are teaching and what you can do at home to help. Ask them to send home learning kits or homework sheets with instructions. Family reading and math nights at school are good times to find out what your children are learning. Even if you can’t attend, ask teachers how you can help. Students in elementary grades through high school whose parents stay well informed and have high expectations for them have higher grades, complete more academic credits, and are more likely to attend college.

8) **Support your children’s learning at home.** What families do at home to reinforce their children’s learning has a greater effect on student achievement than more general types of involvement, such as volunteering for class trips or attending school meetings. The key is for families to link what they do at home to what is being taught in the classroom.

9) **Make sure your child gets to school – and on time.** The adage that 90% of success is just showing up is true for school too! Students who attend school regularly learn more and are more successful than students who do not. Students with chronic illnesses that may require them to stay at home must still have the support they need to keep up with their studies. “Showing up” also means that students get the sleep and nutrition they need to be awake and able to participate.

10) **Establish a regular time and place for homework.** Carving out a time and place for homework may also require limiting TV time or computer game time. Look over homework every day.

Being involved doesn’t have to be hard! These are just a few of the powerful ways parents can make a positive difference in their children’s education. You and your children will enjoy the benefits!

The Massachusetts Parent Information and Research Center (Mass. PIRC) is a Federation project devoted to helping parents of all children participate as equal partners with educators in their children’s education. We have a wealth of resources and are eager to share! Call us toll free at 1-877-471-0980 or visit us at www.pplace.org if you’d like more suggestions for supporting your children’s learning at home. We are here to help.
Preencha o formulário, certificando-se de providenciar informações sobre cada membro da família, pois o tamanho da família é usado para calcular a renda familiar como uma porcentagem do FPL. Mesmo que você assinale cada membro da família, quando lhe for perguntado ‘está esta pessoa solicitando’ marque ‘sim’ somente para o indivíduo com uma deficiência. Certifique-se de que preencheu o Suplemento B azul: Perguntas sobre Lesão, Doença ou Deficiência que faz parte do formulário para a criança com uma deficiência. Para que a criança seja qualificada para o CommonHealth, deverá enquadrar-se nos critérios de deficiência federal.

Uma Unidade separada de Serviços de Avaliação de Deficiência, Disability Evaluation Services (DES) fará a determinação da deficiência, o que poderá levar até 90 dias. Você poderá agilizar este processo fornecendo documentação adicional com o seu MBR.


3) Mantenha contato com os médicos de sua criança e confirme que eles forneceram informações para a Unidade do DES.

4) Existe uma exigência de cidadania. Inclua uma cópia da certidão de nascimento de sua criança.

5) Faça uma cópia do formulário e dos materiais suplementares antes de enviá-los pelo correio.

*Para obter informação sobre a estrutura da apólice do CommonHealth ou para perguntas sobre o MassHealth para uma criança com necessidades especiais de saúde, telefone para o Centro de Informação de Família-para-Família de Massachusetts no 1-800-331-0688, ext. 210 ou mande um e-mail para massfv@fcsn.org.
The DME Access Project

Would you like to participate in a study on durable medical equipment?

The Massachusetts Consortium for Children with Special Health Care Needs invites parents to participate in a research study about families’ experiences getting durable medical equipment (DME) for their kids.

Read on for details then contact Chris Fluet at 617-574-9493, ext. 1 or cfluet@neserve.org if you might be interested in participating.

What is DME?
DME – or durable medical equipment – are products that can be used over an extended period of time, are used at home, and are designed to fulfill a medical need. Some examples are wheelchairs, hospital beds, and oxygen concentrators.

What is the purpose of the study?
The process for getting DME can involve a lot of people – you and your child, your child’s pediatrician, specialists, physical therapists, home nurses, your insurer, the DME vendor and manufacturer, etc. That can make it complicated. The DME Access Project wants to see where the process is working smoothly for families, and where it could be improved.

Who can participate?
To be eligible, you must be the parent or guardian of child aged 0-18, and your child must have a new recommendation or prescription for a piece of DME.

What would I have to do?
As a participant, you would use a special online diary to track your child’s DME until it is delivered to your home. For example, you would note down when you spoke to the pediatrician, or when you received a letter from your insurer, or had a visit with the physical therapist. If you prefer, you can use a paper diary instead.

What’s in it for me?
In addition to the knowledge that you’ve helped improve an important part of the health care system for families, you’ll receive a stipend, plus fun incentive prizes.

How can I learn more?
Please contact Chris Fluet at 617-574-9493 or cfluet@neserve.org.
MassHealth Commonhealth – Requisitos del programa y proceso de solicitud

Informe del Centro de información de salud del programa De familia a familia (Massachusetts Family-to-Family Health Information Center), un proyecto de Mass Family Voices

A menudo, las familias de niños con necesidades especiales de cuidado de salud tienen muchos gastos médicos. Además de las primas de sus seguros médicos, pagan deducibles, copagos y los servicios que sus niños necesitan, pero han excedido el límite de servicios que fija su seguro de salud.

En Massachusetts, el programa de Medicaid se llama MassHealth. MassHealth tiene muchos programas diferentes. Dos de ellos, MassHealth Standard y MassHealth Commonhealth, pueden ayudar a las familias con los gastos de su propio bolsillo aunque tengan un seguro de salud privado. Los requisitos del programa dependen de muchos factores, por ejemplo, ingresos, acceso a otro seguro de salud y si el niño cumple con los criterios de discapacidad federales.

Si los ingresos de la familia están por debajo del 150% del nivel federal de pobreza (FPL, por sus siglas en inglés), o de $30,984 para una familia de cuatro, los niños cumplen los requisitos para MassHealth Standard en base sólo a los ingresos familiares. Si los ingresos de la familia están por encima del 150% del nivel federal de pobreza, un niño puede cumplir los requisitos para el programa MassHealth Commonhealth si cumple los criterios de discapacidad federales. Lea la lista de discapacidades infantiles en http://www.socialsecurity.gov/disability/professionals/bluebook/ChildhoodListings.htm.

La prima del programa Commonhealth se calcula mediante una escala móvil; cuanto más altos son los ingresos de la familia, más alta es la prima mensual. Sin embargo, si la prima mensual es menos de lo que usted paga de su propio bolsillo, comprar el programa Commonwealth puede ser una manera económica de suplementar la cobertura del seguro médico de un niño con necesidades especiales de cuidado de salud.

Cómo solicitar MassHealth Commonhealth

La solicitud de beneficio médico (Medical Benefit Request o MBR en inglés) es la única solicitud para todos los programas de MassHealth. Para descargar una copia de Internet, visite www.mass.gov/masshealth. A la izquierda, bajo “Programs and Services” (Programas y servicios), haga clic en “Individuals, Families & Children” (Individuos, familias y niños) y luego en “How to Apply” (Cómo solicitar). Tiene la opción de descargar la solicitud o de llamar a un centro de inscripción en MassHealth (MassHealth Enrollment Center) al 1-888-665-9993 (voz) ó al 1-888-665-9997 (TTY) y pedir que le envíen una por correo.

Complete la solicitud asegurándose de dar información de todos los miembros de la familia, ya que el tamaño de la unidad familiar se usa para calcular los ingresos familiares como porcentaje del nivel federal de pobreza (FPL). Aunque debe incluir a cada miembro de su familia, en la parte donde se pregunta “¿Es ésta la persona que solicita los servicios?”, responda “Sí” solamente para la persona que tiene la discapacidad. Para el niño con la discapacidad, asegúrese de completar la parte de la solicitud llamada “Supplement B: Injury, Illness or Disability Questions” (Suplemento B: Preguntas sobre lesiones, enfermedades o discapacidades) o suplemento azul. Para tener derecho al programa Commonhealth, el niño debe cumplir los criterios de discapacidad federales.

Una unidad separada de Servicios de Evaluación de Discapacidad (Disability Evaluation Services o DES) toma la determinación de discapacidad, lo cual puede tomar hasta 90 días.

1) Descargue y complete el Suplemento de Discapacidad de MassHealth (MassHealth Child Disability Supplement) en http://www.mass.gov/eeohhs2/docs/masshealth/appforms/mads_child.pdf. Incluya información para todos los proveedores, aunque se trate de un proveedor que ha visto a su niño una sola vez, ya que al tomar la determinación de discapacidad, se tiene todo en cuenta.

2) Para cada proveedor de cuidados de salud, complete un formulario separado de MassHealth para autorizar a que comunique información médica (MassHealth Medical Release Form).

3) Comuníquese con los médicos de su niño para confirmar que le han dado la información a la unidad de Servicios de Evaluación de Discapacidad (DES).

4) Uno de los requisitos es ciudadanía. Incluya una copia de la partida de nacimiento de su niño.

5) Haga una copia de la solicitud y los materiales suplementarios antes de enviarlos.

*Para recibir información acerca de la estructura de primas del programa CommonHealth o si tiene preguntas sobre MassHealth para un niño con necesidades especiales de cuidado de salud, llame al Centro de información de salud del programa De familia a familia, al 1-800-331-0688, ext. 210, o escriba por correo electrónico a massfv@fcsn.org.

Easter Seals Camp
Programs for Youth & Young Adults with Disabilities to Enjoy the Experience of Camp
(800) 244-2756 ext 410
www.eastersealsma.org
Told from the point of view of Jody, a young girl whose brother Josh has autism, this sweet children’s story, written for ages 4 – 8, explains several aspects of family life when a child has autism. It depicts both Jody’s understanding of her brother’s rigid behaviors and rules, and her frustration with dealing with those behaviors, as well as provides a visiting relative with insights into why Josh acts the way he does. And, it accomplishes this without Jody ever saying her brother has autism, preferring to tell her great aunt that Josh “has his own rules.” For example, he is slow to warm up to new people, prefers to stare at the underside of his baseball cap rather than look directly at his great aunt, and even though he can talk, he reverts to using his PECS (Picture Exchange Communication System) to ask for things he wants. Using the following analogy, Jody aptly explains, “Josh doesn’t like new people for the same reason he doesn’t like new shoes. They both rub him the wrong way. New people give Josh blisters in his head.”

Jody even respects Josh’s rules. When their aunt mistakenly moves one of Josh’s animals out of their specific order, he screams. Jody comments that she doesn’t like it either when people mess up the rainbow order of her crayons, but she can cope with the annoyance better than her brother can. Another nice element of this book is that Jody doesn’t spend the entire visit with her aunt running interference for her brother. Jody indulges in her own childish behaviors, eating a lollipop that she shouldn’t, cheating at a board game, and in a display of un sporting behavior, does a victory dance when she wins, complete with hooting and hollering, loud noises she knows will disturb Josh.

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

Link to Amazon.com through our website www.fcsn.org and up to 6% of your purchase will help support the Federation.
Mark your calendars for these upcoming Federation Events

Visions of Community Conference
Seaport World Trade Center • Boston, MA
March 1, 2008

Belonging & Becoming...
Opportunities for All

Spring Gala
May 2, 2008

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

INFORMING, EDUCATING, EMPOWERING FAMILIES