On May 11, 2007, families, friends, supporters and staff gathered at the Seaport Hotel to celebrate the Federation for Children with Special Need’s Gala of Possibilities. In addition to the support of the more than 350 attendees, we are grateful for the generous support of our Presenting Sponsors: Cushman & Wakefield of New Jersey/Metropolitan Area Capital Markets Group, Fidelity Investments, Holt Lunsford Commercial, JP Morgan Chase, David & Michele Mittelman, and Morgan Stanley.

The evening began with a reception in the Plaza Lobby and a Very Special Silent Art Auction that exhibited local talent, in addition to artwork created and donated by children whose families we have helped to achieve “possibilities.” The collection was inspired by “What I want to be when I grow up,” illustrating the hopes and dreams of

“Future Dog Trainer” - John, age 7
Submitted for this year’s silent auction

The world of families of children with special needs lost a great champion when Mike Daly died of complications from Melanoma in early June.

In the early 1970’s, Mike was the state representative from Brighton. As House Chairman of the Committee on Education, Mike was the key sponsor and political architect behind both the Bilingual Education Act in 1971 and Chapter 766 in 1972 - Massachusetts’ comprehensive special education law. As Newsline readers know, Chapter 766 preceded the federal special education law - IDEA - and in some ways, despite recent amendments, it still provides a higher standard of protection to children than IDEA. Without the work, the commitment and the political savvy of both Mike and the bill’s co-sponsor, Speaker David Bartley, it is likely Massachusetts would never have adopted such comprehensive and child-centered protections for students with disabilities. It is even possible that IDEA would not exist, since Chapter 766 is the model for much of the original federal special education law.

A former teacher, Mike served as a member of the Task Force on Children Out of School (now known as the Massachusetts Advocates for Children). He cared deeply about the problems the Task Force identified: the widespread exclusion of both non-English speaking children and children with disabilities from school or, if they attended, their relegation to third-rate and neglectful programs within the schools. He brought a wide

In Tribute: Mike Daly, 1940-2007

By Attorney Robert K. Crabtree

Continues on page 8
APPLE Institute

By Barbara Popper, Co-Director, APPLE Project

The Federation’s APPLE (Advanced Parent/Professional Leadership in Education) Project conducted a third Institute in conjunction with the Institute for Community Inclusion (ICI) at the University of Massachusetts-Boston. The goal of this project is to help build better relationships between parents and schools around issues of special education. In addition to providing training to parents and special education personnel, this project has a research component. Our research partners at ICI follow up with the participants to learn if their involvement with APPLE is helpful in building partnerships between their school administrations and the Parent Advisory Committees (PACs) in their towns.

Participants in this latest Institute, held May 17-19, included teams of parents whose children have IEPs (Individualized Education Programs) and one special education professional from the Harvard, Milton, Pentucket Regional and Foxboro Regional Charter School districts; three Special Education Directors attended as part of their district’s team.

For three days, the teams engaged in a variety of teambuilding activities. Participants identified barriers to the parent/professional relationship and brainstormed ways to overcome those barriers. They learned about forming relationships that enhance parent/professional collaboration, goal setting, creating action plans, and about starting new PACs or re-energizing established PACs. The favorite activity was identifying resources and strategies for both advancing personal leadership skills of parents serving on PACs and for supporting parent/professional collaboration. Parents, in particular, enjoyed getting to know other parents who have faced similar difficulties in special education, and learning more about how to have “Respectful Conversations.” Everyone left feeling energized and committed to the action plans they developed. A main goal of each district’s plan is to increase parent involvement in their PACs over the next year. During that time, each team is encouraged to request technical assistance from the Federation, and the Federation will incorporate their ideas into future Institutes.

In addition to the four recent participants, 10 other communities have participated in APPLE Institutes: Maynard, Cambridge, Ashland, Everett, Framingham, Canton, Billerica, Medfield, Gardner, and Grafton. Federation staff worked with several of these PACs on follow-up activities, including conducting a True Colors™ workshop at a parent retreat hosted by the Grafton PAC. This fabulous training promotes teamwork; participants learn about individual learning and communication styles, and how to work with people with different styles.

Currently, APPLE staff is recruiting parents and special education professionals for a spring 2008 Institute. If you are interested in having your town participate, please have your PAC Chair or SPED Director call Barbara Popper at the Federation at 1-800-331-0688, ext. 322 or e-mail bpopper@fcsn.org.

In Tribute: Mike Daly, 1940-2007 (continued from page 1)

and hopeful vision to a legislature that would not acknowledge the limitations of a bureaucracy that held such narrow views of children’s prospects. He exercised a special, from the ground up, organizing genius and built powerful coalitions behind the dramatic changes offered by both the Bilingual Education Act and Chapter 766.

In later years, Mike served as an Associate Commissioner at the Massachusetts Department of Education and then as a political representative of school superintendents’ and special education administrators’ organizations. He did everything he could to moderate the effects of a weakened economy and politics that threatened to reduce the hard-won and fundamental rights of children who would otherwise be left out of the mainstream of education.

I had the great good fortune to work with Mike as the Research Director for the Committee on Education. I know that Mike approached everything he did with a sharp political intelligence, a passion for justice that he hid behind a wry wit and ready humor, and a humility that left him without the enduring recognition that he might otherwise have had for his revolutionary accomplishments in the field of civil rights for children. More to the point, had it not been for Mike’s work, the lives of thousands of children would have taken a different course. Change might have come eventually, but because of Mike’s dedication and genius, and his sense of urgency, it came quickly and comprehensively in a way that truly empowered those thousands of children and their parents and enabled them genuinely to partake of the promise of education.
You may know that Massachusetts was the first state in the nation to pass a comprehensive special education law, known as Chapter 766. You may also know that the federal special education law, now known as IDEA (Individuals with Disabilities Education Act) was passed three years later and was based on the Massachusetts state law. But, did you know that the original name of this law was the Bartley-Daly Act?

Mike Daly, former Chair of the Massachusetts Legislature’s Education Committee, whose name is attached to this landmark legislation, passed away recently (see tribute by Bob Crabtree on page 1). With his loss, I realize that a generation of leaders who advanced the rights of children with special needs and their families is passing from the scene. Their advocacy, leadership and influence established the legacy that all students with special needs, regardless of the severity of their disability, were entitled to receive a public education that enabled them to have equality of opportunity alongside their non-disabled peers. For the first time in more than 300 years of public education, students with disabilities were to be welcomed into the same schools they would attend if they did not have a disability. They could now go to school with their sisters and brothers, be taught to read, to write, to do math, and to anticipate a life beyond school that would welcome them into our society as equal partners.

Phyllis Sneirson’s speech (see page 9) at this year’s Federation Gala outlined how her expectations as a parent evolved and that her own son, Robert, would eventually achieve a graduate education from a major university despite the fact that he was born with cerebral palsy. This is what Daly and others could only dream of when they framed their legislation. Attorney Steve Rosenfeld was also honored at the Gala, not only for previous accomplishments, but also for his continuing vision and work to ensure that students today will inherit this same legacy.

It seems to me we are at a crossroads in this journey. Some argue that this legislation has gone too far, costs too much, and needs to be cut back. Those of us who are parents of students with special needs who have accomplished more than we ever dreamed they would - due to this law - have inherited a legacy that needs to be preserved for the next generation. Daly’s passing is a reminder that hard fought battles are not just fought once, but rather each and every day, student by student, family by family, and that all means all!

Many of us did not realize Mike Daly is gone and that a generation of students with special needs has lost their champion. Let’s all take a moment to give thanks for this caring individual and to work to ensure his vision endures.

Best wishes,

Richard J. Robison

Rich Robison
Executive Director
Champions for Children with Special Needs

Celebrating the Potential in Us All

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Smart choices about the education of children and young adults with life challenges make all the difference in fostering their abilities to reach their full potential. Seven Hills Academy at Devens and Seven Hills Academy at Groton open the doors of opportunity that lead to brighter futures.

Seven Hills Academy at Devens, located in Devens, MA provides DOE-approved, academic and behavioral education to children and young adults, 22 years of age and under, with autism spectrum disorders, dual diagnosis, mental retardation, and severely challenging behaviors. The Academy is operated by Seven Hills Clinical Associates, an Affiliate of Seven Hills Foundation.

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**New Statewide Parent Involvement Survey**

By Amanda Green, Parent Training and Information Project

Parents, are you considered an equal partner with teachers and other professionals in planning your child’s educational program? Does your child’s Individualized Education Program (IEP) document all of your concerns and recommendations? The Massachusetts Department of Education (DOE) wants to know.

In response to a federal directive, the DOE has developed the Massachusetts State Performance Plan, which uses 20 Performance Indicators to measure the state’s progress in implementing the requirements of the Individuals with Disabilities Education Act of 2004 (IDEA 2004). (Learn about all 20 Performance Indicators at www.doe.mass.edu/sped/spp/.) To lessen the data collection burden on school districts, DOE divided the state into four Cohorts, with the exception of Boston, and is staggering the years in which data is collected for each indicator. Until the spring of 2009, each Cohort will collect data annually for one or two of these five Indicators: 7 (pre-school outcomes), 8 (parent involvement), 11 (child find), 13 (secondary transition) and 14 (post-school outcomes). Because of its size, Boston will collect data on each Indicator every year. To find out which Cohort your town belongs to, visit www.doe.mass.edu/sped/2006/0522idea.html?section=list.

After consultation with the statewide Special Education Advisory Council and key stakeholders, a workgroup composed of local education officials, parents, DOE representatives, and others decided to survey parents across Massachusetts about Performance Indicator 8 - Parent Involvement. The Massachusetts survey, which parents can look over at www.doe.mass.edu/sped/spp/appxA.pdf, is based on questions developed by the National Center for Special Education Accountability Monitoring. Using the results of this survey, the DOE hopes to compile a list of resources that will help promote parent involvement in schools and create a new set of promising practices to help districts and parents work together more effectively.

The new parent survey was piloted in the summer of 2006. In fall 2006, the DOE mailed surveys in English, Spanish, and Portuguese to all parents of students receiving special education services in Cohort 2. Cohort 4 was surveyed in spring 2007, Cohort 3 will be surveyed in spring 2008, and Cohort 1 in spring 2009.

In Cohort 2, only 17.4% of English surveys, 5.2% of Spanish surveys, and 4.5% of Portuguese surveys were returned. In order to fully understand the extent to which parents are collaborating with schools in the IEP process, it is important that the DOE hear from as many parents as possible.

**Parents, when it's your turn to complete a survey - either on paper or online - please take the time to fill it out. Your participation will make a real difference in developing strategies to include all parents in the special education process.**

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**Promising Parent Involvement Practices: Granby Public Schools**

Granby Director of Pupil Services, John Robert, and Chair of the Granby Special Education Parent Advisory Council, Karina “Tinker” Monroe were partners on the state working group when the new Massachusetts Parent Involvement Survey was being developed. Below is a list of strategies they use to create a positive relationship between parents and schools in Granby.

John Roberts advises, “It’s important to establish a very good relationship with your Parent Advisory Council (PAC). Find positive ways to encourage parent involvement without waiting until there’s a problem...” Not only the special education director, but also student adjustment counselors, psychologists and teachers should interact with the PAC. “If you can show parents the good things that are happening in the district,” says John, “then when budget time comes around, parents can be a very powerful ally.”

Tinker Monroe emphasizes that it’s important for parents to become involved in the special education process, “because it’s the law, ultimately creates less work for the district, and benefits the students.”

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**Tips to Increase Parent Involvement:**

- Build on existing relationships and offer different types of participation (electronic, volunteering in person).
- Involve parents in planning PAC meetings.
- Use a telephone tree or phone messaging system to let parents know about PAC meetings.
- Invite the Federation for Children with Special Needs to give a Basic Rights training.
- At least once a year, invite the PAC to talk to the School Committee about special education needs.
- Provide transition meetings so that parents can learn about their children’s move from one school to the next - from elementary to middle, from middle to high school.
- Encourage staff to reach out to parents, instead of waiting for parents to call.
- Be flexible about Team meeting times, and use technology to facilitate teleconferencing.
- Given advance notice, provide childcare and interpreters during meetings.
- Invite PAC members to assist in interviewing potential new special education staff.
- Encourage teachers to attend PAC meetings. Offer PDPs (Professional Development Points) to teachers who present at PAC meetings.
- Listen to families, and be responsive to their needs.
- Use the Internet; develop a website and post on electronic forums.
- Thank parents when they help.

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The Kids' Project is a program of Pine Tree Society
Nueva Encuesta para Padres que se Involucren

Por Amanda Green, Proyecto de Entrenamiento e Información para Padres

El padre, es considerado como un socio común igual con las maestros y otros profesionales para planear el programa educativo del hijo? El IEP documenta todas sus preocupaciones y recomendaciones? El Departamento de Educación de Massachusetts quiere saber.

En respuesta a un directive federal, el Departamento de Educación ha desarrollado en el estado de Massachusetts un Plan de Ejecución, que usa 20 Indicadores para medir el progreso del estado en implementer los requisitos del Acto Educativo de Individuos con Discapacidades del 2004 (IDEA 2004). (Aprenda sobre los 20 Indicadores de Ejecucion en el www.doe.mass.edu/sped/spp/.) Para disminuir la carga de recolección de datos en los distritos escolares, El Departamento de Educacion dividió el estado en cuatro secciones, con la excepcion de Boston, y gradualmente por años donde los datos se han recolectado para cada indicador. Hasta la primavera del 2009, cada sección recolectará los datos anualmente para uno o dos de estos cinco Indicadores: 7 (metas pre-escolares), 8 (participacion de los padres), 11 (child find), 13 (transicion secundaria) y 14 (metas despues que terminan la escuela). Por su tamaño, Boston recolectará los datos en cada Indicador cada año. Para encontrar que cantidad le pertenece a su pueblo, visite al www.doe.mass.edu/sped/2006/0522idea.html?section=list.

Después de la consulta con el Special Education Advisory Council del estado un grupo de trabajo compuesto de oficiales locales de educación, padres, representantes del Departamento de Educacion Especial, y otros decidieron hacer una encuesta a los padres en todo Massachusetts sobre los 8 Indicadores de Funcionamiento-e

Involucrar a los Padres. La encuesta de Massachusets, que los padres pueden ver en el www.doe.mass.edu/sped/spp/appxA.pdf, esta basada en preguntas desarrollada por el Centro Nacional para la Supervision de las Responsabilidad de la Educacion Especial. Usando los resultados de esta encuesta, El Departamento de Educacion espera hacer una lista de recursos que ayudara a promover la participacion de los padres en las escuelas y crear un nuevo conjunto de practicas que promete ayudar a los distritos y los padres a trabajar juntos mas efectivamente.

La nueva encuesta de padres fue desarrollada en el verano del 2006. En el otoño del 2006, el Departamento de Educación envio las encuestas en ingles en español, y en portugues a todo los padres de estudiantes que reciben servicios de educacion especial en la seccion 2. En la seccion 4 estuvo en la encuesta en la primavera del 2007, En la seccion 3 hecha en la encuesta en la primavera del 2008, y la seccion 1 en la primavera del 2009.

La seccion 2, solamente el 17.4% de las encuestas eran en ingles, el 5.2% de las encuestas en español, y el 4.5% de las encuestas en Portuges fueron devueltas. Para poder entender como los padres estan colaborando con las escuelas en el proceso del IEP, es importante que el Departamento de Educación escuchen comentarios de los padres.

Padres, cuando sea su turno para llenar la encuesta - por papel o por internet - porfavor tomese el tiempo y complete la encuesta. Su participacion hara una diferencia real en el desarrollo de estrategias para incluir a los padres en el proceso de la educacion especial.

Por Amanda Green, Proyecto de Entrenamiento e Información para Padres
Nova Pesquisa sobre o Envolvimento dos Pais em todo o Estado

Por Amanda Green, Projeto de Treinamento e Informações aos Pais

Pais, vocês são considerados parceiros em igualdade com os professores e outros profissionais, no planejamento do programa de educação de seu filho? O Programa Educacional Individualizado, Individualized Education Program (IEP) de seu filho, documenta todas as suas preocupações e recomendações? O Departamento de Educação Massachusetts, The Massachusetts Department of Education (DOE) gostaria de saber.

Em resposta à uma diretriz federal, o DOE desenvolveu o Plano de Desempenho do Estado de Massachusetts, Massachusetts State Performance Plan, que usa 20 Indicadores de Desempenho, Performance Indicators para medir o progresso do estado, na implementação dos requisitos da Lei Educacional para Indivíduos com Deficiência, Individuals with Disabilities Education Act, de 2004 (IDEA 2004). (Aprenda sobre todos os 20 Indicadores de Desempenho no www.doe.mass.edu/sped/spp/). Para diminuir o peso da coleta de dados nos distritos escolares, o DOE dividiu o estado em quatro Regiões, Cohorts, com exceção de Boston, e está alternando os anos nos quais os dados são coletados para cada indicador. Até a primavera de 2009, cada Cohort fará a coleta de dados anualmente, para um ou dois destes cinco Indicadores: 7 (resultados do pré-escolar), 8 (envolvimento dos pais), 11 (descoberta da criança), 13 (transição secundária) e 14 (resultados da pós-escola). Por causa de seu tamanho, Boston coletará dados de cada Indicador a cada ano. Para averiguar sobre qual Cohort a sua cidade pertence, visite o www.doe.mass.edu/sped/2006/0522idea.html?section=list.

Depois da consulta com o Conselho de Assessoria em Educação Especial, Special Education Advisory Council, de todo o estado e com os depositários de dinheiro significantes, com um grupo de trabalho composto de funcionários para a educação local, com os pais, com os representantes do DOE e outros, decidiram avaliar os pais em todo o estado de Massachusetts, sobre o Indicador de Desempenho 8 - Envolvimento dos Pais. O questionário de Massachusetts, que os pais podem examinar no www.doe.mass.edu/sped/spp/appxA.pdf, está baseado em questões desenvolvidas pelo Centro Nacional para Monitoração da Responsabilidade da Educação Especial, National Center for Special Education Accountability Monitoring. Usando os resultados deste questionário, o DOE tem esperança de compiler uma lista de fontes que ajudarão a promover o envolvimento dos pais nas escolas e a criar um novo conjunto de práticas para ajudar os distritos e os pais a trabalharem juntos e com mais eficácia.

A novo questionário sobre os pais foi experimentado (estudo-piloto), no verão de 2006. No outono de 2006, o DOE enviou pelo correio os questionários em inglês, espanhol e português, para todos os pais de alunos que estavam recebendo os serviços de educação especial na Cohort 2. A Cohort 4 foi examinada na primavera de 2007, a Cohort 3 será examinada na primavera de 2008 e a Cohort 1 na primavera de 2009.

Na Cohort 2 foram devolvidos somente 17.4% de questionários em inglês, 5.2% de questionários em espanhol e 4.5% de questionários em português. Com o intuito de compreender totalmente a extensão pela qual os pais estão colaborando com as escolas no processo IEP, é importante que o DOE colha informações da maior quantidade possível de pais.

Pais, quando chegue a sua vez de completar o questionário - seja no papel ou on-line - por favor, preencha-o devagar. Sua participação fará uma grande diferença no desenvolvimento de estratégias para incluir todos os pais no processo de educação especial.

Inclusive Schools Week...

The 7th Annual Inclusive Schools Week will be observed from December 3-7, 2007. This year’s theme, “Lessons from the World: Including All Children,” will focus on activities and resources that promote inclusive education for all children, all around the world. The Federation for Children with Special Needs is, once again, a proud partner in this celebration. This issue, as well as the next issue of Newsline, will highlight sections of the Inclusive Schools website.

Talk to your school administrators about Inclusive Schools Week and work with them to plan activities. To help you get started, download the checklist and planning form at www.inclusiveschools.org/involved.asp#get. For great ideas for promoting inclusive schools, the home page at www.inclusiveschools.org has a “Tip of the Month.” Click on this link to read the featured tip as well as to access the archived tips. These include information about school and household routines, promoting social relationships, and engaging families in classroom activities.
John Nadworny and Cynthia Haddad are not only professional financial planners but also have family members with special needs (John has a son with Down syndrome; Cindy has a brother with intellectual and developmental disabilities). These two authors share their personal and professional expertise in this informative and practical book, which carefully explains why planning really does matter, and then provides the necessary tools.

The Special Needs Planning Guide provides a clear framework for planning that takes family issues, emotional needs, financial issues, legal considerations and government benefits into account. It includes helpful checklists, forms, a glossary of terms that helps parents understand the financial planning process, and a CD-ROM with a financial planning timeline. Parents can communicate key information, concerns and desires to a future caretaker using the printable Letter of Intent. Marty Wyngaarden Krauss, Provost and Senior Vice President of Academic Affairs at Brandeis University, says, "This book educates, encourages, and empowers families.” It acknowledges the complexity of the process, but gives a useful structure so that families can create a comprehensive and sustainable plan.

MassCARE News: Teen Advisory Network

By Margarita Diaz, Program Coordinator, MassCARE Family Support Initiatives

The MassCARE Teen Advisory Network (TAN) met for the second time on April 13, 2007, at the United Church of Christ Conference Center in Framingham, MA. Fifteen teens from Lawrence, Lowell, Springfield and Worcester attended a job readiness workshop, co-presented by Margarita Diaz and a Human Resource Specialist from Jordan’s Furniture. When the TAN originally met in December 2006, teens received preliminary information about finding employment. At their request, this workshop provided the more in-depth knowledge they wanted about applying for summer jobs, filling out applications, being successful at interviews and learning about employment laws that pertain to teens. In a second workshop, these ambitious youth learned how to create resumes that highlight their unique talents and skills.

To celebrate and reward the participants’ hard work, Just Us, a Boston-based, award-winning teen dance duo, treated the teens to a surprise performance. Their mix of hip-hop, break dance and ballet amazed and inspired the kids. This dance team performs free, not only to give back to the community, but also to encourage kids to believe in themselves, work hard and have big dreams.

Currently, the TAN is planning activities for the annual Family Networking Day, which will take place in August.

If you know a teen affected by HIV/AIDS who would like to participate in the TAN, call Delores at 1-800-331-0688, ext. 311. TAN meetings coincide with school vacations and new participants are always welcome.

AIDS Alliance Conference

By Delores Qualls, Coordinator, MassCARE Family Support Initiatives

The AIDS Alliance for Children, Youth and Families sponsors an annual Voices conference for consumers, case managers and program administrators. MassCARE was proud to sponsor seven Massachusetts family members to attend Voices 2007. Five adult and two adolescent consumers, who demonstrated outstanding leadership at Family Advisory Network (FAN) events and in their communities, traveled to Arlington, Virginia to participate in this national conference on May 18-20, 2007.

Everyone attended the plenary sessions, which highlighted current HIV/AIDS public policy issues. Adult consumers chose from a variety of learning labs where they shared information about their state programs. Massachusetts attendees spoke about how the Massachusetts Title IV program was instrumental in helping them live stronger and healthier lives. Youth-only breakout sessions were an opportunity for teens to speak privately and freely among their peers.

In a separate but related event, everyone went to Washington D.C. on May 21 to participate in Capitol Hill Advocacy Day. This was an opportunity to meet with our Massachusetts congressional delegations and make our voices heard about issues and concerns related to HIV/AIDS.

MassCARE (Massachusetts Community AIDS Resource Enhancement) is one of 58 programs throughout the country that is funded under Title IV of the Ryan White Care Act. The program ensures that children, adolescents, women and family members living with or affected by HIV/AIDS have access to coordinated, comprehensive, family-centered, culturally and linguistically competent counseling, testing, and care. MassCARE, a program of the Massachusetts Department of Public Health, has a Family Support Initiatives component, which is coordinated through the Federation for Children with Special Needs. To learn more about MassCARE and the Family Support Initiatives, contact Delores Qualls at 1-800-331-0688, ext. 311 or via e-mail at dqualls@fcsn.org
our children with disabilities. We were pleased to welcome Boston Globe Sports Columnist and award winning author Dan Shaughnessy, who emceed the dinner and award ceremony, in addition to donating two sets of personalized books. A vocal group from The Carroll School performed a moving ensemble of songs from their musical, *Breaking Through*, written to illustrate how Dyslexia feels from a student’s point of view. Somerville-based comedian Jimmy Tingle closed the evening with humorous social and political commentary.

The Gala is also a time to acknowledge the significant contributions of outstanding advocates. The *Martha H. Ziegler Founder’s Award* is given to individuals who have had a tremendous impact in improving the quality of life for children and students with special needs. The Federation presented the 2007 Ziegler Award to attorney Stephen Rosenfeld for his many years of advocacy for children with special needs, and for his particular role in improving the accessibility of health care services for these children. Steve is currently the Volunteer Legal Director at Health Law Advocates where he has launched a Children’s Mental Health Campaign to advance reforms that remove the barriers children and families face when seeking treatment.

In March 2005, the Federation’s Board of Directors voted to establish the *Patricia Blake Advocacy Award* in honor and recognition of the legacy of advocacy Pat has given to parents of children with disabilities and self-advocates. This year, this honor was bestowed upon Phyllis Sneirson, Information Specialist and Coordinator of Parent Consultant Training Institutes at the Federation. Over the past 30 years, Phyllis has taken thousands of calls from distraught parents in their quest for information, guidance, and advice. She provides assistance rooted in personal experience, as an advocate for her son Robert, who was born with cerebral palsy.

Proceeds from the Spring Gala provide the critically needed funds to support the work of the Federation. Over the past year, staff, volunteers, and board members worked together to ensure the financial success of this annual event. It is a collective effort and we are pleased to announce that we exceeded our fundraising goal of $200,000.

The Federation commends our artists, donors, volunteers, program participants, and supporters who help us to inform, educate and empower parents. We are honored by your commitment to the Federation’s mission and grateful for your support.

**Special Thanks to Our Silent Art Auction Contributors...**

- Willem Ackman
- Allie
- Leaifael Arias
- Bren Bataclan
- Eric Bissell
- Bill Commerford
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- Billy Mitchell
- Ivan Polanco
- Danny Ricci
- Vinicio Rosario
- Luis Sanchez
- Nicole Schram
- Adam Schwartz
- Kayli Ana Whittenburg
- Joseph Williams
In the early 1970’s, it was not the norm for youngsters with disabilities to attend their local public schools. Children like my son were “lucky” to attend schools such as the Industrial School for Crippled Children or the Massachusetts Hospital School in Canton. Many parents, me included, thought these segregated schools were the only alternatives. The words “mainstreaming” and “integration” were not part of anyone’s vocabulary.

After attending a segregated pre-school, I wanted my son to attend our neighborhood school. I was apprehensive and wondered if I had any rights under a recently enacted law.

“As a parent of a child with special needs, I felt isolated and alone. Where could I get the knowledge, support, and assistance I so desperately needed?”

Under the guidance and leadership of Martha Ziegler, a strong parent advocate who envisioned a center where parents could obtain the latest information about legislation as well as support for their advocacy efforts, the Federation was born. There was now a place where I could get the help I needed. If it were not for the help and guidance of an advocate at the Federation, my son’s entire education might have taken an entirely different route and he might not have been prepared to attend a first-rate university where he received a Bachelors of Arts degree and later a Master’s degree in political science. Placing him in our community school was the best decision I ever made.

This is only my story. Every day, parents who desperately need information and support call the Federation and knowledgeable staff is there to help guide them. The Federation’s commitment to helping parents remains constant.

It is with humility and respect for the dedicated staff of the Federation that I accept this award. Thank you very much for this honor.

A Very Special Yard Sale Weekend

The contents of Bay Staters’ basements, attics, and garages proved very valuable the last weekend of April when families from Weymouth to Hadley hauled their hidden treasures onto their front lawns, affixed price tags, and sold their goods to passersby to raise money for the Federation for Children with Special Needs. The Very Special Yard Sale Weekend provided everyone in need of a little spring-cleaning with the opportunity to fund the crucial programs and services of the Federation. Although the initial group of families who participated in yard sale was modest, the event raised more than $3,000.00. Even more important was the priceless public relations the Federation received through local news coverage.
Thank You for Your Support

The Federation’s mission is to provide parent-centered information and support to families. We work with more than 40,000 families and professionals each year throughout the Commonwealth on all issues related to their children with special needs. In addition, the Federation receives more than 1.5 million visitors per year to our websites, and our mailing list includes more than 35,000 families and professionals. We are grateful for the generosity of our Friends, Foundations and Corporations who provide the much needed funding to sustain the work of the Federation. This list includes donors who gave between November 1, 2006 - June 15, 2007.

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Comings and Goings at the Federation

It is difficult to see people move on from the Federation, but at the same time, it affords us the pleasure of offering opportunities to new parent leaders. Parents PLACE, the Massachusetts Parent Information and Resource Center, is pleased to welcome two new Outreach Coordinators and Training Specialists, Lee Soto and Roxanne Hoke-Chandler. Lee is new to the Federation. Many of you may know Roxanne, the former Boston Parent Coordinator for the Family TIES project. We’ll miss Roxanne at Family TIES, but are pleased to have her remain an integral part of the Federation’s work.

The Parent Training and Information Project (PTI) welcomes Adriana Castro, a Project Assistant, and Dotty Robison, the Information Specialist and Training Coordinator for Central Massachusetts.

Good-bye and best wishes to: Jane Wolfson, Director of Development, Andrea Watson, Coordinator for Parents for Residential Reform, and Karen Douglass, Family TIES Southeast Parent Coordinator.

Goodbye and Hello to Our State Partners

One of the Federation’s goals is to model parent/professional partnerships, and we strive to set an example by the partnerships we have built with the commissioners of various state agencies. With a new administration in place, it is a time of transition for many of the state agencies as well. We say farewell to old friends and look forward to making new ones.

Goodbye and good luck to Gerry Morrissey, Commissioner for the Department of Mental Retardation (DMR), Harry Spence, Commissioner of the Department of Social Services (DSS), Beth Childs, Commissioner at the Department of Mental Health (DMH), Elmer Bartels, of the Massachusetts Rehabilitation Commission (MRC), and David Driscoll, Commissioner for the Massachusetts Department of Education (DOE). After more than forty years in education, eight of them as commissioner of education for the Commonwealth, Mr. Driscoll is retiring.

We welcome Commissioner Elin Howe to DMR, Commissioner Charlie Carr to MRC, Commissioner Angelo McLean to DSS, and Commissioner John Auerbach, Department of Public Health (DPH).

Congratulations to Commissioner Heidi Reed, reappointed to the Commission for Deaf and Hard of Hearing and to Commissioner Jane Tewksbury, reappointed to Department of Youth Services (DYS).

We look forward to working with you!

Employment Opportunity...

The Federation is seeking a qualified professional to diversify and expand its funding sources. We assist 40,000 families and individuals annually to gain access to educational, medical and support services through information and referral, training and technical assistance.

The Director of Development is responsible for developing and implementing a development plan, planning and executing appeals and events, targeting and cultivating corporate/individual donors, preparing grant proposals and supervising development operations. The position reports to the Executive Director and is liaison to the Development Committee of the Board of Directors.

Qualifications include 5 to 7 years of relevant experience, superior organizational, verbal and writing skills, familiarity with disability policy. Cover letter and resume to: Richard J. Robison, Executive Director at rrobison@fcsn.org. Parents of children with special needs and persons with disabilities are encouraged to apply.

The National Center for Cultural Competence

The ability to design supports and services that are culturally and linguistically appropriate for everyone is just one aspect of cultural competence. Cultural competence also means adopting behaviors and attitudes that are free of bias and assumptions on the part of the providers, families, and other partners, as well as policies that are flexible enough to meet people’s needs, regardless of culture and that truly value diversity. For families with children and youth with special health care needs, which includes mental, behavioral and emotional needs, cultural competence has another facet - understanding disability from the family, child and youth perspective.

Two of the many projects of the National Center for Cultural Competence (NCCC) at Georgetown University in Washington, D.C. work to ensure health and mental health programs are designed and implemented to deliver culturally competent health and mental health services to families with children and youth with special health care needs.

Visit the NCCC website at http://www.w11.georgetown.edu/research/gucchd/nccc/ (in English en Español) to learn about the various projects, and access resources and tools. These include a resource database, excellent publications and promising practices. Of particular interest are the self-assessment checklists for providers, as families can also use these as a starting point for questions to ask potential providers and to assess the physical environment of the office to see if the practice will be a welcoming place and that the provider will be a good match for their child.

The promising practices include ideas anyone can implement in their community. For example, one community started a book club as a way to understand issues from different points of view, talk about attitudinal change, expand participants’ views of the world and promote understanding.
Fall Parent Consultant Training Institutes

The Parent Consultant Training Institute is an opportunity for parents and professionals to learn more about state and federal education laws and to effectively manage their child’s and/or client’s special education program.

The Institute consists of 8 day-long sessions and an optional 50 hour internship. Topics include special education laws, mediation, inclusion, transition, communication skills as well as other issues relating to special education.

Fee (includes materials): $325.00 for parents of children with special needs, $425.00 for professionals. Limited amounts of scholarships are available. Parents of children with special needs can also apply to the Massachusetts Developmental Disabilities Council for Consumer Empowerment funds at www.mass.gov/mddc/documents/cefp_application.doc; you must apply at least 45 days in advance of the Institute you plan to attend.

Boston:
Meeting dates: October 2, 9, 16, 24, 30, November 6, 13, 20.
Times: 9 am - 3:30 pm
Federation Offices: 1135 Tremont Street, Suite 420, Boston.
For more information, call Phyllis Sneirson at 617-236-7210 or e-mail phyllis@fcsn.org.

Worcester:
Meeting dates: October 5, 12, 19, 26, November 2, 9, 16.
Times: 9 am - 3:30 pm
Location to be announced.
For more information, call Dotty Robison at 617-236-7210, ext. 220 or e-mail drobison@fcsn.org.

IEP Clinics

The Federation is pleased to announce fall IEP (Individualized Educational Program) Clinics in English, Spanish and Portuguese. These clinics, conducted by experienced Federation staff and/or trained parent consultants, assist families whose children receive special education services. Attend a clinic if you are concerned that:

- The services and supports on the IEP are not fully supporting your child’s ability to make effective academic progress,
- Your child’s IEP does not reflect your vision and does not include appropriate goals.

The Boston Clinic will meet on Saturday, October 13, from 10 am - 2 pm at the Federation offices at 1135 Tremont Street, Suite 420.
The Worcester Clinic will meet on Saturday, December 1; time and location to be announced.

NOTE: Pre-registration is required for the IEP Clinics and limited space is available. For more information, please contact Rhea Tavares at 617-236-7210, ext. 329 or rtavares@fcsn.org.

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For more information call 781-647-JFCS (5327) or visit our website at jfcsboston.org.
News from the Massachusetts Family-to-Family Health Information Center

By Beth Dworetzky, Project Coordinator, Mass Family Voices/MA Family-to-Family Health Information Center

**New Funding:** The Mass Family Voices Conference project at the Federation for Children with Special Needs is the recipient of a 3-year award from HRSA - the Health Resources and Services Administration - to expand and enhance the services currently offered through the Massachusetts Family-to-Family Health Information Center (F2F HIC). This parent-run center was created in 2004 with funding from the Centers for Medicare and Medicaid Services. We are pleased to be able to continue to assist families of children and youth with special health care needs and their professional partners in understanding private health insurance benefits, eligibility criteria for and access to state and federal public benefits, medical advocacy and activities that promote a family’s ability to partner at all levels of decision-making. This includes but is not limited to a family’s participation on their child’s medical team, on committees, task forces, grant reviews, etc.

**Annual Joining Voices Conference:** The F2F HIC will host its annual Joining Voices conference on Thursday, November 29, 2007 at the UCC Conference Center in Framingham. This is a free day of networking and learning for families of children and youth with special health care needs.

Dr. Suzanne Bronheim from the National Center for Cultural Competence (see article on page 13) will give the keynote presentation. In addition, there will be workshops about legislative advocacy, the Children’s Mental Health Legislation, Title V programs, and family partnerships with primary care physicians. The conference brochure and registration forms will be posted at www.massfamilyvoices.org; visit often for conference updates.

**SCHIP:** In 1997, Congress created the State Children’s Health Insurance Program, commonly referred to as SCHIP. The goal of SCHIP was to bridge the gap in health insurance coverage for children whose family incomes were too high to qualify for Medicaid, but too low to afford employer-sponsored or other private health insurance. The program was initially enacted with strong bi-partisan support for 10 years. It is set to expire in September 2007.

Based on a federal formula, each state receives an SCHIP funding allocation. Massachusetts’ SCHIP dollars are used in combination with Medicaid funds to support MassHealth programs. Most recently, as part of the new health care reform, SCHIP funds were used to expand MassHealth eligibility to provide health insurance to even more children. This has been instrumental in both reducing the number of uninsured children and dramatically improving their health. Without continued SCHIP funds, the state would be in a difficult financial situation.

Currently, Congress is debating SCHIP. Both the House and Senate budgets have set aside $50 billion to support SCHIP over the next 5 years, and both chambers are debating a number of provisions to enhance the program. It is important that SCHIP is reauthorized before the end of September and that the full $50 billion is allocated to support this program. This is especially important for families of children and youth with special health care needs as it ensures support for public health insurance programs, and encourages the state to make sure all eligible children are enrolled.

Contact your congressional representative and senators and share your point-of-view about SCHIP reauthorization, and if applicable, how the program has helped ensure your child’s access to health care. You can learn more about SCHIP reauthorization by visiting the New England Alliance for Children’s Health web site at www.childrenshealthne.org.

Contact information for your congressional delegation is available at the Family Voices Legislative Action Center at http://capwiz.com/familyvoices/home/.

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Back-to-School: Tips from Family TIES of Massachusetts

By Mary Castro Summers, Director, Family TIES of Massachusetts

Family TIES of Massachusetts is a statewide information and support network for families of children with special needs. It is a project at the Federation for Children with Special Needs, funded by the Massachusetts Department of Public Health (DPH), Division for Perinatal Health, Early Childhood and Special Health Needs. Regional Coordinators provide information, referrals, and training. The Parent-to-Parent Program matches parents with other parents whose children have similar disabilities and circumstances and who face similar challenges and joys in raising a child with special needs.

Back-to-School: The school nurse will be better able to meet your child’s medical needs during the school day if she has up-to-date health information. If you do not already have an Individualized Health Care Plan or IHCP for your child, the start of the school year is the perfect time to create one or to update an existing plan. The IHCP summarizes your child’s important health information, medications, equipment and treatment needs, allergies, and contact information for medical providers. It lists the types of medical situations your child may face, why they may occur, and how to ensure the health and safety of your child at school. The student’s parents or guardians, primary physician, and the school nurse work together to develop this plan and ensure that all of the information is complete, accurate, and easy to understand. The school nurse will identify the designee and alternate who are responsible for your child’s care and provide information and training. Signed copies of the IHCP should be included in the child’s medical file at school and attached to his IEP (Individualized Education Program), if one is in place. Many school districts offer their own version of this comprehensive tool, or you may contact Family TIES at 1-800-905-TIES to receive a standard version.

For students who require medical technology during the school day, such as an insulin pump, intermittent catheterization, or a ventilator, parents are encouraged to contact MASSTART - the Massachusetts Technology Assistance Resource Team. Staff of this free consultation service, sponsored by the DPH, provides education and training to local school nurses to facilitate the transition to public, private or faith-based schools for children, birth-22 years, with complex medical needs. For more information, or to access services, call the MASSTART program in your region:

Greater Boston and Northeast: 857-218-4333
Southeast: 800-608-8200
Central: 508-856-4155
West: 413-794-3406

Additional information about creating an IHCP is available at the Mass Family Voices website at www.massfamilyvoices.org/ihcpbrochure.pdf. For information about special health care needs and the IEP process, visit www.fcsn.org/pti/topics/medconcerns/index.html.

Need more resources? Don’t forget to access the 10th Edition of the Family TIES Directory of Resources for Families of Children with Special Needs and regional support group listings at www.massfamilyties.org or by calling 1-800-905-TIES (8437).
**Getting Set for the School Year**

Parents and guardians can do some homework now to prepare their families for the school year ahead. The timeline below will help your family be aware of key dates. Each school district sets exact dates, like the first day of school. Watch your mail for a district calendar, check the school website or call the school.

### August 2007

Around August 30, the Massachusetts Department of Education (MA DOE) will send preliminary notices to school districts as to whether or not their schools have met their Adequate Yearly Progress (AYP) goals.

### September 2007

**Notice of AYP status:** Parents receive notice of the school’s AYP status. Parents of children whose Title I school did not meet AYP goals must be notified of the school’s status if it means the school must offer School Choice (the student may transfer to a better performing school) or if the school must offer free tutoring (see SES).

**First day of school:** Exact date varies across the state.

**Back-to-school events:** Find out the schedule for Open Houses, Back to School Nights, meetings of the Parent/Teacher Conferences, Parent Teacher Organization (PTO), School Site Council, Parent Advisory Council (PAC) for special education and for English Language Learners.

**Parent-Guardian MCAS Report:** Late September to early October, families receive their child’s spring 2007 MCAS test results. Students with disabilities who took the MCAS-ALT also receive a report.

### October 2007

**October 1 - 26:** Students who have Limited English Proficiency (LEP) take the (MELA-O), the oral portion of the Massachusetts English Proficiency Assessment (MEPA).

**October 22 - 26:** LEP students in Grade 3, and only those in Grades 4 - 12 who did not take the spring 2007 MEPA-R/W tests will be tested in their ability to read and write English.

**SES (Supplemental Educational Services) Notice to Families:** Parents of children in Title I schools that have not met AYP goals may begin to receive notice of their child’s eligibility for free tutoring. If your child is in a Title I school, call to see if the school must provide SES.

### November 2007

**Nov. 6 - 8:** MCAS Retests in English Language Arts (ELA) for 11th & 12th Graders, repeating 10th Graders and those out of school who did not pass the MCAS.

**Nov. 14 & 15:** MCAS Retests in Math.

**Student Report Cards:** Schools with 4 marking periods issue report cards mid- to late-November. Students with disabilities will also receive progress reports.

### December 2007

**Student Report Cards:** Schools with 3 marking periods issue student report cards early to mid-December.

**Winter School Vacation**

### January 2008

**Kindergarten Registration for Fall 2008:** Begins in many districts.

**K - 12 Registration:** Registration for 2008-09 school year begins for districts that offer school choice.

### February 2008

**Feb. 25 - March 19:** LEP students in grades K - 12 take MELA-O.

**Mid-Winter School Vacation**

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**AYP or Adequate Yearly Progress:** The amount of progress each school must make each year for all students to become proficient in Math and English by 2014. Each school’s progress for the year is measured, in part, by its students’ Spring MCAS scores.

**CD, or Competency Determination:** Students must attain a Competency Determination as one condition for high school graduation. Students earn a CD when they meet or exceed the Needs Improvement score of 220 on both the English Language Arts and Mathematics MCAS grade 10 tests.

**ELA or English Language Arts:** The subject area that includes Reading, Reading Comprehension, Composition, Language, and Literature.

**LEP or Limited English Proficiency:** Descriptor for students whose native language is not English and who are not yet able to do classroom work in English. English Language Learners (ELL) is also used.

**MCAS or Massachusetts Comprehensive Assessment System:** Tests given to Massachusetts’ public school students to measure their progress toward meeting state educational standards.

**MCAS-ALT or MCAS Alternate Assessment:** Tests designed for the small number of students with the most significant disabilities who are unable to take the standard MCAS tests even with accommodations. MCAS-ALT is a portfolio of a student’s work including work samples, instructional data, videotapes, and/or other supporting information.

**MCAS Retest:** Students in Grades 11 & 12, repeating 10th Graders, and students who are out of school who did not yet earn a passing grade have further chances to pass by taking retests in the spring and fall.

**MELA-O or Massachusetts English Language Assessment-Oral:** The state-mandated assessment of English listening and speaking skills for LEP students in grades K-12.

**MEPA or Massachusetts English Proficiency Assessment:** Annual tests that measure the ability of LEP students to read, write, understand, and speak English, as well as to measure their progress in learning English. MEPA consists of the MELA-O and MEPA-RW.

**MEPA-RW or Massachusetts English Proficiency Assessment-R/W:** Assesses an LEP student’s proficiency in reading and writing at Grades 3-4, 5-6, 7-8, and 9-12.

**NCLB School Report Cards:** The federal No Child Left Behind Act (NCLB) requires states and school districts to provide annual report cards on how well schools are educating their students. The report cards give parents and others a snapshot of student performance and teacher qualifications in their local schools.

**SES or Supplemental Educational Services:** Free tutoring or other extra academic help, outside the school day, for eligible students in Title I schools that have not met their AYP goals for 3 or more years in a row.

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### March 2008

| March 3 - 7: | MCAS Retests in Math and ELA. |
| March 10 - 14: | LEP students in Grades 3 - 12 take MEPA-R/W. |
| March 24 - April 7: | Grades 3, 5, 6, & 8 take MCAS ELA Reading Comprehension. |
| Mar. 25: | Grades 4, 7 & 10 take MCAS ELA Composition. |
| March 26: | Grade 10 takes MCAS Language & Literature, Sessions 1 & 2. |
| March 26 - April 7: | Grades 4 & 7 graders take MCAS ELA Reading Comprehension. |
| March 27: | 10th Graders take MCAS ELA Language & Literature, Session 3. |

**NCLB School Report Cards:** MA DOE set March 30 as the deadline for districts to get these report cards to parents.

### April 2008

| April 2: | Make-up MCAS ELA Composition for students in grades 4, 7, & 10 who missed the March 25 test. |
| April 12: | Due date for MCAS-ALT portfolios for Grade 12 students working for a Competency Determination (CD, needed for High School Diploma). |
| April 18: | Due date for MCAS-ALT portfolios for Grade 12 students not working toward a CD. |

**Spring Vacation**

### May 2008

| May 9: | Due date for MCAS-ALT portfolios for Grades 3 - 8 & 10. |
| May 12 - 29: | Grades 3 - 8 take MCAS Math. |
| May 13 - 29: | Grades 5 & 8 take MCAS Science and Technology/Engineering. |
| May 14 - 29: | Grades 5 & 7 take MCAS History and Social Science. |
| May 14: | Grades 3 - 8 take MCAS Science and Technology/Engineering. |
| May 27 - 29: | Grades 10 & 11 U.S. History MCAS. |

### June 2008

| June 3 - 4: | High School MCAS Science and Technology/Engineering, Sessions 1 & 2. |

**Last Day of School:** Exact date varies across the state.

Visit www.doe.mass.edu/mcas/participation or call the Student Assessment Services office at 781-338-3625 for more information on MCAS and students with disabilities and LEP students.

Additionally, Massachusetts PIRC staff members are available to answer your questions about your child’s education. Call us at 1-877-471-0980.
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Mark your calendars for these upcoming Federation Events

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October through November (Now accepting applications)

Joining Voices Conference
November 29, 2007
Keynote Speaker - Dr. Suzanne Bronheim, National Center for Cultural Competence

Inclusive Schools Week
December 3-7, 2007

Visions of Community Conference
March 1, 2008

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