



# NewsLine

The Federation for Children with Special Needs

Volume 25, Number 2, Fall 2004

617-236-7210 • 800-331-0688 • www.fcsn.org



Patricia Blake retires on September 9, 2004, after 28 years at the Federation.

**"It is totally empowering for a parent to hear from another parent whom they respect that their child is first and foremost a child. Children are precious, whether they have disabilities or not."**

—Patricia Blake

## Patricia Blake— Farewell and Thanks

My son Michael was seven years old when he experienced complications during open-heart surgery. The stroke caused learning disabilities, he lost use of his left side, and he needed a pacemaker. In the midst of providing medical care for Michael at home and dealing with my own emotional distress and fear, I felt frustrated, isolated and alone as I tried to access, organize, and negotiate an overwhelming array of unfamiliar medical services and systems. In the 1970s, when I began my journey into the world of special needs, there was little support for families and no coordination of care.

In 1975, a friend introduced me to a local parent support group. It was the first time I had contact with other parents who had children with disabilities. During one of the

parent gatherings, it was announced that a new parent organization in Boston had received a grant from the U.S. Department of Education to run a pilot parent training program. I decided to attend.

After participating in the training, I understood the importance of being involved not only in managing Michael's medical needs, but also in understanding the new laws that would protect Michael's right to an education. It was at these workshops that I met Martha Ziegler, the Founder and former Executive Director of the Federation. Martha helped me realize that Michael was a **child** with special needs and not a **special needs child**. As a result of this training, and the people I met, I was enthused with a new sense of empowerment. I was eager to be part of this exciting parent movement and called the Federation and asked to volunteer.

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## Parent Leadership: A Historical Perspective

by Richard J. Robison

Rosemary Dybwad was not the parent of a child with disabilities, but in a way, she helped birth the parent leadership movement. She had a way of inspiring parents of children with disabilities. In 1990, on the occasion of her 80th birthday, her husband, Professor Gunnar Dybwad and other colleagues published a collection of her speeches as a book entitled *Perspectives on a Parent Movement*. In it we find the earliest beginnings of parent-to-parent efforts, parent-driven programs and parent-professional partnerships. It has been said that Rosemary "was among the very first to insist that individuals with special needs were people first, human beings with rights, fellow citizens rather than objects of charity or compassion".

Rosemary writes, "It was the autumn of 1957 that my husband, then new Executive Director of the National Association of Retarded Children (today known as ARC US) requested that I help out with an accumulation of letters that had reached the Association from various countries. [I learned] that for families having a child with special needs was a matter of shame and guilt, something to hide, even from one's relatives. I discovered that by the early 1950's there were parents who had found each other. We had contacts in some 40 countries yet it was unclear how it all started; there was 'no visible force' or organization specifically active in linking these parents."

"In England, for instance, in 1947, Judith Frye, the mother of a daughter with severe retardation, placed an advertisement in a magazine called *Nursery Times*, asking for contacts with other mothers with similar

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## Worth Mentioning

### MOVING ON

After 17 years with the Federation, and having made innumerable contributions to various projects, most recently as director of the Early Intervention Training Center, we say farewell to our colleague Ruth-Ann Rasbold. Ruth-Ann has taken a position with Head Start. We wish her a smooth transition to this exciting new phase of her professional life.

Personal changes are the cause of another personnel change. Diana Rocha was Parent's Place training and outreach coordinator for the Latino population. She has a new baby, and her husband has taken a new job in California, so her family has moved west. We wish them the best of luck.

### MOVING IN

We are excited to announce that Rhea Tavares has recently joined the PTI (Parent Training and Information Project) staff. Rhea, a person with a disability, has volunteered for many years at the Federation. She is very familiar with our mission and is already hard at work supporting families, especially those who speak Portuguese. Rhea works out of the Boston Office and can be reached at 800-331-0688 or [rtavares@fcsn.org](mailto:rtavares@fcsn.org).

We are pleased to announce that Margaret (Peggie) O'Hare, PT, M.Ed. has been appointed Director of the Early Intervention Training Center. Peggie has been a part of the Training Center for over four years, serving most recently as the Senior Training Consultant. She brings to the Training Center many years experience as a direct service provider to young children and their families and as an adult educator and trainer. Her years as an early interventionist, a teacher and a supervisor will serve the Early Intervention Training Center well. Peggie welcomes hearing your suggestions and ideas on how the Training Center can better serve the early intervention community. She can be reached at 617-236-7210 or via e-mail at [mcohare@fcsn.org](mailto:mcohare@fcsn.org).

### ANNOUNCEMENTS

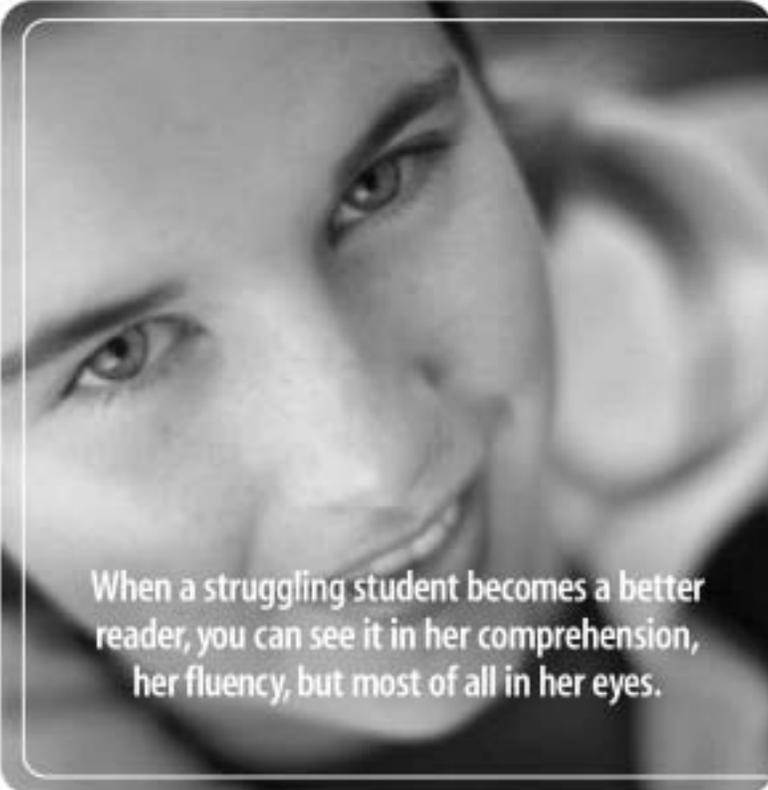
Massachusetts has been awarded a three-year, \$3.4 million state improvement grant through the U.S. Department of Education's Office of Special Education Programs. These funds will be used to develop professional development programs to help ensure students with disabilities develop sound career goals and learn skills to help them after high school. The Federation for Children with Special Needs is proud to join the Massachusetts Department of Education

and the University of Massachusetts at Boston's Institute of Community Inclusion as a collaborator on this grant.

The Federation for Children with Special Needs is proud to unveil its new website. Still located at [www.fcsn.org](http://www.fcsn.org), the site hosts the same great information, but the new look was created to make it easier for our on-line visitors to find information about our various projects and opportunities, resources and links.

### AND FINALLY

As this issue of Newsline is devoted to parent leadership, here's one parent's perspective on the importance of the parent leader role: "Being part of the Parent Leadership movement has been a way to 'give back' to families for all the times they have stood behind me. It enables me to share my experience with the agencies that support our families on what works and what wastes our time. Most of all it has given me a sense of self-respect, and helped me to become a better advocate for my own children. Becoming involved is definitely a commitment, but if you don't bother to buy the Cracker Jacks, then you'll never get the prize!" [Shared by Joanne Spencer, Family TIES Parent-to-Parent and Outreach Coordinator.]



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## From the Executive Director

# The Federation: A Uniquely Parent Perspective!

In this edition of Newsline, we focus on parent leadership—parents who have emerged as leaders due to their advocacy efforts on behalf of their, and all, children with special needs.

When the state and federal special education laws were passed in the 1970s, one of the most important safeguards was the provision for parents' rights. The crafters of the legislation knew that it would always be a struggle to ensure the inclusion of students with disabilities. They wanted to ensure that parents knew their rights and were knowledgeable about the laws. They also knew these same parents would be the most qualified to help other parents assume leadership roles and help them advocate on behalf of their children. This was the best way to ensure that children with special needs would be fully included in public education and gain full access to high quality health care.

This is how the Federation was born and what fuels its ongoing mission: parents helping other parents learn the lessons experience has taught them. There is no college track or PhD program to teach these lessons. There is no career ladder to climb. Parent leaders are created out of the reality that our world has not yet fully embraced children with special needs and their differences. Parent leaders emerge out of a fundamental struggle for

justice and equality for all our children in our society. Like any other human rights struggle, safeguarding the rights of vulnerable citizens becomes a passion. Parent leaders hold a precious vision of a world where every



Richard Robison

parent leaders create alliances, partnerships, coalitions and teams with school, community, health care and government personnel who join them in their dream.

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**We dedicate this issue to all parents, with a particular focus on those parents who have taken a courageous step to move beyond their own struggle and share the life lessons they have learned with other parents who are just beginning their journey. We invite those who are reluctant to embark, and those who have just started down the road, to join us on this incredible journey.**

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child, even their own, can experience choice, live freely and pursue happiness.

We recognize that parents cannot ultimately prevail without professional allies and friends along the way. For vision to become reality,

*Richard J. Robison*

Richard J. Robison

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## Parent Leadership: Vision to Reality

by Janet Vohs, Co-Director of Parents' PLACE

Today, "parent involvement" is recognized as one of the pillars of education reform. Thirty years ago, a conviction about the importance of parents in every aspect of their children's care and education led to the founding of the Federation. Over those years, we also thought a lot about leadership. As we began to develop projects to support parents as leaders, we asked, "What would it take for parents to assume stronger leadership roles and to be viewed as leaders by others?" In the 1980s and '90s, business leaders began stressing the power of vision. A compelling vision, they said, is key to creating success. This article tells our story of the power of vision and its unfolding in our lives.

My daughter Jessica, now 33, has cerebral palsy and is severely disabled. Thirty-three years ago, special education rights and the participation of people with disabilities in every part of society were new concepts. Many of us were still being advised to institutionalize our children. As the mother of a tod-

dlar with disabilities, I soon realized that the world was not necessarily a welcoming place for her, and that things were likely to get worse as she grew. At that time, people with severe disabilities, like Jessica, were institutionalized. Ghastly reports of the horror of those places were becoming widely known. What would happen to her? I was afraid of the future and of what lay ahead.

I realized that the future I wanted for Jessica would take more than just my efforts, and I began to build a network of friends and supporters. Work here at the Federation also put me in touch with inspired leaders from across the country, all devoted to reshaping society and securing civil rights, inclusion, and social justice for people with disabilities. The movement was fueled by love for our friends and children and a passion to transform what was possible for them.

The vision was inclusion and belonging—the everyday reality was that Jessica was isolated and segregated at school and we were living in an inaccessible 4th floor walk-up apartment. After Jessica became too heavy for me to get her upstairs into our apartment, she attended school in an institutional setting, only coming home on weekends and in the summer. After

a few years, when she was high school age, Jessica began to insist on coming back to her hometown school. With the help of advocates from the Federation and friends, the local high school enrolled Jessica on a part-time basis.

Jessica was assigned to the special education classroom, and from there she went around to different offices to do odd jobs such as dust tables and water plants. But when Jessica would come home everyday, she would open her communication book, point to the icon of a classroom, and then emphatically point to herself. She knew that being part of the high school meant taking classes with the other students, not being the janitor!

Inspired and spurred on by Jessica's vision, I met with the Special Education Director and asked for classes for Jessica. The response was that the classes, even the special education ones, were far too advanced for her. I expressed the importance of Jessica being able to participate with the other students and how she needed to have opportunities to learn and make friends. The administrators assured me that Jessica would not fit into any of the classes, nor would she need to make friends because most of the students would go off to college and not be around. "Anyway," they said, "we don't know where Jessica will live after she leaves school. It depends on what town has a facility with an open slot."

The idea of Jessica ending up in a slot in a distant town was not our vision of belonging. Shocked, I immediately declared a new vision—really Jessica's vision—that would guide us: Jessica *will* attend regular high school classes, she *will* make lifelong friends, and she *will* live in and be a valued member of this community. I was not going to settle for choosing an existing option. I was taking a stand for creating something new. I insisted on designing an educational program to support Jessica's vision.

Speaking it gave the vision power. The same members of the education/transition team who had been most negative embraced the vision. When I would waver or prepare myself to accept some compromise, a team member would call me back to the vision! It was no longer just Jessica's vision or my vision—it belonged to and empowered everyone, and everyone had a role in shaping it.

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## Parent Leadership: Many Recipes, Endless Outcomes

by John Sullivan

"She'll never walk, she'll never talk, and she probably won't live into her teens." Those words, spoken by our obstetrician, still make me cringe. Twenty minutes after the birth of our first child, the doctor not only declared the future of my baby girl with Down syndrome, he went on to say that since we were such young parents, our options were, "1) place her in an institution to live out her days, 2) put her up for adoption, there are many families who adopt 'kids like these,' or 3) bring her home with you." That's right, the advice from this health professional was, "bringing your child with a disability home from the hospital was a last resort." Although this sounds like advice from the 1940s or '50s, the year was 1987.

Had that been the only opinion provided that day, life would be incredibly different now. Thankfully, it was not the only information shared. Immediately after the doctor left the room, a nurse, who had been listening quietly, told us there was someone else she wanted us to hear from. A few moments later a second nurse entered the room carrying a couple of photographs. She was the parent of a 10-year-old daughter with Down syndrome and said we should forget everything the doctor had just told us. She showed us pictures of her daughter and spoke with pride of the many

activities her daughter participates in. Although she warned there would be challenges, she acknowledged it was all worth it.

This issue of *NewsLine* is dedicated to parent leadership. That nurse is an example of how valuable one parent's experience can be to

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another parent. While the ability to help other parents resides in all of us, it is sometimes unclear how to develop that skill. The concept of being a parent leader can be even more elusive.

At a Massachusetts Families Organizing for Change event in 1994, I listened as Michael Kendrick, formerly the Assistant Commissioner for Program Development for the Office of Human Services in the State of Massachusetts, spoke on what it means to be a leader.

Mr. Kendrick explained in clear, simple terms the many ways leadership manifests itself. Some are common and understood by all: the leader standing at the front of the pack screaming, "Charge!" or the cheerleader encouraging her charges to accomplish their mission. Leadership, however, can be achieved with less flash and noise by simply providing the tools, information, and resources needed by others to accomplish the goal. Leadership is not about receiving credit; it is about moving all towards the common good. The opportunity to lead is about helping the cause, not requiring being the "lead" character. Everyone has the ability to lead. Whether it is done by giving an inspiring speech to a room full of parents, talking privately to new parents devastated by news upon the birth of a child, or providing information so others can benefit, is not important. What is important is that parents connect with other parents to continue to expand awareness about the potential of children with special needs and their right to participate fully in their community.

As my daughter climbed to the top of a cheerleading pyramid during a dance recital a few years ago, I thought back to the day of her birth and thanked one parent for making a difference.

## Vision to Reality

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Jessica had a very exciting last couple of years of schooling! When there were no teachers who would accept Jessica, a high-school honors student came forward and asked if she could help. She found teachers who were willing and eager to include Jessica in advanced placement classes. After graduation, Jessica became the first person with severe disabilities to join City Year, and be part of the inaugural class of America Corps. She then took classes at Massachusetts College of Art and the School of the Museum of Fine Arts, and became part of an art studio in Boston.

Today, Jessica is truly living the vision laid out in that pivotal meeting. Her accessible apartment is in her hometown. She has the support she needs to live there. She has friends and family who care about her. She is a respected artist, known across the country for her beautiful handpainted silk scarves and watercolor paintings. She was recently featured in a 2-page article in the *Boston Globe Magazine*. Jessica, through her participation in school, her community, and her work, is a role model today—a success story for other parents and children of what is possible. Jessica's art teacher Kate Finnegan wrote about this in her yearly report of Jessica's progress:

"This year I heard from two teachers of watercolor classes in Boston who each have a disabled student in their classes that Jessica is a kind of "hero" to them. Not because she is a genius, unique, different, or special, but because she is an inspiration. . . Jessica is an inspiration to what the word "possibility" means. By example, Jessica and her mother have shown what is possible through hard work, determination, and consistent effort. They inspire other people to seek out greatness in themselves."

For me, an important part of being a parent leader means *listening* for the child's vision, *believing* that it is possible, and *using* it as a guiding star.

# Becoming a Self-Advocate: Mentoring for Success

by Holly-Anne Neal, Information Specialist and Coordinator of Trainings

Growing up with a disability is hard. I know because I grew up with learning disabilities and ADHD (Attention Deficit/Hyperactivity Disorder). At times, everyone struggles with decision-making, but when you have learning disabilities, it can be even more difficult to make good choices. It is also difficult to always know the right things to say and appropriate times to say them. However, in order to stand up for yourself and be successful, you need to learn to be your own champion. In other words, you need to learn how to advocate for yourself.

Being a self-advocate does not mean that you have to be alone! It can be helpful to discuss your options with someone else first. There has been a lot of research on the best ways to advocate for yourself. Each of these studies says that picking at least one mentor is helpful.

The right mentor is an important support to help ensure your success. This person will listen to you, and provide coaching, advice and encouragement. A mentor can help you make good decisions, which will enhance your ability to self-advocate.

Choosing a mentor may be tricky. It is important to choose someone that will help you in positive ways. You can have more

than one mentor. Your mentor(s) might be a parent, a brother, sister or other relative, a friend, counselor, teacher or other school staff, a community leader, or even a colleague from work. Before you choose a mentor, ask yourself:

- Who do you trust?
- Who you look up to/whose decisions do you respect?
- Who would be willing to be your mentor?
- Who is good at things you would like to be good at?
- Who listens to you when you talk?
- Who would be willing to role-play new situations with you?
- Who do you enjoy spending time with?
- Who is good at setting goals and working on reaching them?
- Who can give you advice with out being too critical?
- Who is good at sticking up for his or herself?
- Who takes you and your interests seriously?

Once you have picked someone you'd like as your mentor, let him or her know why s/he is important to you, that s/he is some-

one you respect and ask if it would be okay to come and talk to him or her when you have questions or worries. Sharing your hopes and dreams as well as hobbies and interests with your mentor is also a good idea. Sometimes mentors can get you involved in activities and opportunities where you can practice important self-advocacy skills. However, in order for this relationship to be beneficial, you must be open to trying new things.

When you ask your mentor for help, tell him or her what you are concerned about and why. Your mentor is there to encourage and advise you; you shouldn't feel embarrassed, as everyone has issues with which they struggle.

As you start making more decisions for yourself it is great to know you have a team behind you, someone on your side who cares about you. As you begin to choose your mentors, you start to become more independent. Remember, the most successful people always look for the support of others.

## Parent Leadership: A Historical Perspective

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concerns. A year later Anne Greenberg placed an ad in the New York Post: "To mothers of retarded children: Are you interested in forming a cooperative nursery school for your children?" A mother in New Jersey had placed a similar ad in the Bergen Evening Record. Ten years later, Mrs. Nam Hong Choi in Korea had the same idea and placed an ad in a newspaper in Seoul. In each case, the advertisement led to the estab-

lishment of a local group of parents determined to develop a range of programs\*."

Rosemary devoted her life to linking parents and sympathetic professionals with each other to create international networks of people working for change. By 1971, the United Nations General Assembly unanimously adopted the "Declaration on the Rights of Mentally Retarded Persons." In 1972, Massachusetts enacted Chapter 766, the first comprehensive special education law in the nation. Three years later the U.S. Congress followed suit with the passage of IDEA (the Individuals with

Disabilities Education Act).

Rosemary credited parents for their world changing leadership. She was our coach and mentor in so many ways. Her leadership inspired hundreds of parent leaders around the world. May we not lose her legacy!

*\*Perspectives on a Parent Movement, The Revolt of Parents of Children with Intellectual Limitations*, by Rosemary F. Dybwad, Brookline Books, 1990. (Limited copies are available, for purchase or to borrow, through the Federation.)

# Declaration of Rights for Parents of English-Language Learners

Under *No Child Left Behind*, parents of English-language learners can expect:

1. To have your child receive a quality education and be taught by a highly qualified teacher.
2. To have your child learn English and other subjects such as reading, language arts and mathematics at the same academic level as all other students.
3. To know if your child has been identified and recommended for placement in an English-language acquisition program, and to accept or refuse such placement.
4. To choose a different English-language acquisition program for your child, if one is available.
5. To transfer your child to another school if his or her school is identified as "in need of improvement."
6. To apply for supplemental services, such as tutoring, for your child if his or her school is identified as "in need of improvement" for two years.
7. To have your child tested annually to assess his or her progress in English-language acquisition.
8. To receive information regarding your child's performance on academic tests.
9. To have your child taught with programs that are scientifically proven to work.
10. To have the opportunity for your child to reach his or her greatest academic potential.

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Prepared by the U.S. Department of Education, Office of English Language Acquisition

For copies of these rights in Spanish and Portuguese, and/or to find out more about workshops to help immigrant families understand their children's educational rights, please contact Parents' PLACE at the Federation. Call, toll-free, 877-471-0980.

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## **Patricia Blake**

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Thus began my 28-year relationship with the Federation for Children with Special Needs. Over the next three decades, I would hear daily reminders of the power that comes from parents helping parents. This spirit of peer support and parent empowerment has infused the parent movement, led by the Federation in collaboration with other organizations, that has swept the nation since the 1970s. The model established by the Federation's first pilot parent-to-parent training and information program in 1975 has since become established in federal law, and similar programs now exist in every state and U.S. territory.

I was blessed to have found the Federation when I desperately needed help and information for my son. I feel honored to have worked with the many dedicated staff (past and present), families, and the Board of Directors to help carry out the Federation's mission and values for families who have children with special needs.

The Federation has helped change the world for children with disabilities by helping "one family at a time." My experience of getting help and information for my son Michael affected my immediate and extended family, next-door neighbors, teachers, friends, Boy Scout leaders, baseball coaches and the general public. Anyone that touched our lives learned to value Michael for himself, a delightful child who happened to have a disability. Multiply that by the thousands of families that the Federation helps each year and imagine the ripple effect for the millions of people who now think differently about people with disabilities because of the Federation. I am so proud to have been part of changing the world.

And now, my own life is changing. I am sad to leave this special and unique organization, but it is time to move on to a new, different and challenging part of my life – retirement.

## Declaração dos Direitos para os Pais com Filhos que estão Aprendendo Inglês

**Sob a lei *Nenhuma Criança Deixada Para Trás*, os pais com crianças que estão aprendendo inglês têm o direito de:**

1. Que a sua criança receba uma educação de qualidade e que seja ensinada por um professor altamente qualificado.
2. Que a sua criança aprenda inglês e outras matérias, tais como leitura, línguas e matemática no mesmo nível acadêmico dos outros alunos.
3. Saber se a criança foi identificada e recomendada para um teste para alocação no programa de aquisição de inglês, e aceitar ou recusar tal alocação.
4. Escolher um programa de aquisição de inglês diferente para a sua criança, caso haja um disponível.
5. Transferir sua criança para outra escola se a escola que ela estuda for identificada como "precisa de aperfeiçoamentos".
6. Aplicar para receber os serviços suplementares, tais como um tutor, caso a escola de seu filho seja identificada, por dois anos seguidos, como "precisa de aperfeiçoamentos".
7. Fazer com que seu filho seja testado(a) anualmente para verificar o rendimento na aquisição da língua inglesa.
8. Receber informações sobre a performance dos testes acadêmicos de seu filho.
9. Solicitar que seu filho seja ensinado com programas cientificamente comprovados que funcionam.

10. Ter a oportunidade para que a sua criança alcance o mais alto potencial acadêmico.

Realizado pelo Departamento de Educação dos EUA, Secretaria de Aquisição da Língua Inglesa.

Para cópias destes direitos em espanhol e português, ou para saber mais sobre os workshops para ajudar as famílias de imigrantes sobre os direitos educacionais de seus filhos, por favor, contacte o Clube dos Pais na Federação. Ligue grátis: 877-471-0980.

## Rhea Tavares começou a trabalhar para o PTI

Nós estamos felizes em anunciar que Rhea Tavares recentemente começou a trabalhar para o PTI (Projeto de Informação e Treinamento para os Pais). Rhea, é uma pessoa que possui uma deficiência, e que voluntariou-se para a Federação por muitos anos. Ela está bem familiarizada com a nossa

missão e já está trabalhando apoiando as famílias, especialmente aquelas que falam Português. Rhea trabalha no escritório em Boston e pode ser encontrada pelo telefone 800-331-0688 ou email [rtavares@fcsn.org](mailto:rtavares@fcsn.org).

## EXPANSÃO DOS SERVIÇOS

Family TIES tem o prazer de oferecer serviço de intérprete para famílias cuja primeira língua é o Espanhol ou o Português. Quem procurar nossa assistência poderá entrar em contato com os números de telefone a seguir e deixar uma mensagem com o seu nome, a razão pela qual ligou e um número de telefone em que possa ser encontrado(a) durante o dia. Nossos intérpretes verificarão o recebimento de mensagens nas segundas, quartas e sextas-feiras. Uma vez tendo feito contato com a pessoa que ligou procurando assistência, o intérprete consultará o apropriado membro da equipe da Family TIES para a obtenção das informações sobre serviços adequados. Famílias que procuram orientação em Espanhol podem ligar para 800-331-0688, ramal 222 e deixar uma mensagem para Sara. Para aquelas que procuram orientação em Português o número é 1-800-331-0688, ramal 195 e a mensagem deve ser deixada para Renata. Os folhetos informativos da Family TIES encontram-se agora disponíveis em Inglês, Espanhol e Português. Muitos de nossos outros materiais informativos estão também sendo agora traduzidos.

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# Declaración de Derechos

## para los Padres de Estudiantes que están Aprendiendo Inglés

**El Presidente George W. Bush tuvo la visión de que todos los alumnos podían superarse académicamente recibiendo una educación de alta calidad. Sabía que se tenía que tomar acción concreta para cerrar la enorme brecha que existe entre los alumnos minoritarios y sus compañeros de escuela. Con la ley Que Ningún Niño Se Quede Atrás (No Child Left Behind), ustedes, los padres de estudiantes que están aprendiendo inglés, pueden esperar lo siguiente:**

1. Su hijo/a recibirá una educación de calidad y será enseñado por maestros altamente capacitados.
2. Su hijo/a aprenderá inglés y todas las materias tales como la lectura, la expresión oral y escrita, y las matemáticas, al mismo nivel académico que todos los demás alumnos.
3. Sabrá si se ha determinado y recomendado que su hijo sea colocado en un programa de aprendizaje del idioma inglés y, podrá aceptar o rechazar tal colocación.
4. Podrá elegir otro programa educativo de aprendizaje del inglés para su hijo/a, si hay uno disponible.
5. Podrá trasladar a su hijo a otra escuela si su escuela ha sido clasificada como una escuela que "necesita mejoramiento".
6. Podrá solicitar servicios suplementarios para su hijo, como la tutoría si su escuela ha sido clasificada por dos años consecutivos como una escuela que "necesita mejoramiento".
7. Recibirá información sobre el rendimiento de su hijo/a en los exámenes académicos.
8. Su hijo/a tomará un examen cada año para evaluar su progreso en el aprendizaje del idioma inglés.
9. Su hijo será enseñado con métodos cuya eficacia ha sido comprobada científicamente.
10. Su hijo/a tendrá la oportunidad de alcanzar su máximo potencial académico.

---

La ley *Que Ningún Niño Se Quede Atrás*— una nueva era en la educación pública.  
[www.ed.gov](http://www.ed.gov), 800-USA-LEARN  
 Oficina Para el Aprendizaje del Idioma Inglés, enero 2004

## Expansion de Servicios

A Family TIES les place ofrecer apoyo de interpretes para aquellas familias que su primer idioma es Español ó Portugués. Todas las personas que necesitan nuestra asistencia pueden llamarnos a los numeros siguientes y dejar un mensaje con su nombre, telefono, y razon de su llamada. Nuestros interpretes estaran chequeando sus mensajes los Lunes, Miercoles, y Viernes. Cuando el contacto inicial este hecho con la persona que llamo, el interprete se pondra en contacto con el personal apropiado de Family TIES para el seguimiento de servicios.

Las familias que necesitan apoyo en Español pueden llamar al 1-800-331-0688 ext.222 y dejar un mensaje a Sara. Aquellos que necesitan apoyo en Portugués pueden llamar al 1-800-331-0688 ext.195 y dejar un mensaje a Renata. Los folletos de Family TIES estan disponible en Ingles, Español, y Portugués, al igual que mucho de nuestros materiales estan siendo tradicido.

## NewsLine

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*NewsLine's* mailing list is occasionally made available to organizations in which we believe our readers may have interest. If you wish your name to be withheld, please call or write the Federation's Boston office to inform us.

## The Federation for Children with Special Needs, Inc.

**Our Mission:**  
To provide information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

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# The Parent Consultant Institute

## Enroll Now for this Parent Leadership Opportunity

by Julie Sinclair

Have you ever wondered what school personnel were talking about at your child's IEP (Individualized Education Program) meeting? Do you know what a 504 Plan is? Do you wish you knew more about state and federal special education laws so you could help other parents of children with special needs?

The PTI (Parent Training and Information Center) at the Federation invites you to enroll this fall in one of three Parent Consultant Institutes offered throughout the state. This is an exceptional parent leadership opportunity. PTI staff and expert professionals such as lawyers, educators, social workers, and a neuropsychologist present each seven-week Institute. Participants will learn about special education laws, court decisions, the mediation and appeals process, how to write

measurable goals, objectives and benchmarks, as well as how to access general education curricula. Understanding evaluations, transition from early intervention into preschool programs and from high school to post-secondary education and/or work and other adult-life options, effective communication, parent professional partnerships and other relevant topics will also be discussed. New topics include positive behavioral supports, and advocacy for medical and mental health supports. Tuition is \$300; scholarships are available.

The Basic Rights and Turning Three workshops, also offered through the PTI, are required prior to enrolling in the Parent Consultant Institute. Check the PTI workshop schedule at [www.fcsn.org/pti](http://www.fcsn.org/pti) or call the Federation at 800-331-0688 for infor-

mation about the dates and times of these workshops at a location near you.

The dates for each of the Institutes, and the PTI contact for more information, appear below:

**Boston:** October 13, 19, 26, November 2, 9, 16, 23. Contact Phyllis Sneirson at 617-236-7210 or e-mail: [Phyllis@fcsn.org](mailto:Phyllis@fcsn.org).

**Central:** October 1, 8, 15, 21, November 5, 12, 19. Contact Mary Loughlin 508-798-0531 or e-mail: [mloughlin@fcsn.org](mailto:mloughlin@fcsn.org).

**West:** September 28, October 5, 12, 19, 26, November 2, 9. Contact Julie Sinclair 413-323-0681 or e-mail: [sinclair@fcsn.org](mailto:sinclair@fcsn.org).

## Interagency Coordinating Councils: Leadership Development for Parents

by Barbara Popper

The National Parent Leadership Development Project for ICCs (Interagency Coordinating Councils), a project of the Federation for Children with Special Needs, is a leadership support project for parents of children with disabilities serving on their state Interagency Coordinating Councils throughout the country. These parents play an important role in developing policies and designing programs for children with disabilities and their families. Our goal is to enhance leadership skills and offer direct support that will be useful to parents serving on ICCs.

Some of the project supports include:

- A collection of training materials, by-laws, conference agendas, contact information, and any other resources which have proven useful in supporting the work of parents serving on councils across the country.

- A "leader-to-leader" network, which links parent leaders to each other around common interests.
- An annual 3-day Leadership Institute for state teams that offers specific training on areas such as communication, cultural diversity, conflict resolution, and personal leadership style.
- *Leadership Notes*, a national newsletter of current information on national and local trends affecting ICC parent leaders.
- Conference calls on requested topics for parent leaders who are serving, or who have served, on ICCs.

For more information about this parent leadership project, visit <http://iccparent.org>.

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Go to [www.fcsn.org](http://www.fcsn.org) for details.*

# Pathways for Parents

## Support for Families Served by Mass DSS

by Gwen Healey

Pathways for Parents, a project developed to inform and support families served by the MA Department of Social Services (DSS), recently celebrated its first anniversary as a project of the Federation. Data shows that although a high percentage of DSS served children receive special education services, their parents tend not to be active in the Federation's projects and programs. While all projects at the Federation provide information and support to parents, Pathways for Parents is uniquely focused on reaching and engaging these underserved families.

By providing support, information, guidance and referral, Pathways seeks to strengthen parents' abilities to effectively participate in their child's education and successfully access

emotional and behavioral support services on their behalf. The Pathways project collaborates with other Federation projects and with community-serving agencies to support parents via phone and e-mail communications and with outreach presentations. The Pathways coordinator is actively seeking to collaborate with community-based, family-serving agencies in order to provide outreach to parents.

The Pathways for Parents project also strives to empower parents with skills to practice supportive parenting and to focus on making positive and proactive choices to enable more effective goal achievement. Partnering with DSS as a "voice for parents" the Pathways coordinator is a participant in

workgroups currently undertaking the momentous task of cultural and organizational restructuring of the DSS System of Care. Participants are working to incorporate the newly adopted *Core Practice Values: Child-Driven, Family-Centered, Community-Focused, Strength-Based, Committed to Diversity and Cultural Safety and Committed to Continuous Learning*, into the new DSS philosophy for working with families.

Pathways for Parents brochures have been distributed to DSS Area Offices, community organizations and local health centers. DSS resource coordinators can access information by contacting Pathways on behalf of parents, or parents can contact the Pathways coordinator directly for support, information, guidance and referral.

For more information, or to sponsor a workshop, contact Gwen Healey, the Pathways for Parents Coordinator, at 800-331-0688, ext. 116.

# Holiday Gift Fund Event

## a Success

by Richard J. Robison

On Friday, June 25, 2004, Parents for Residential Reform (PFRR) and the Federation for Children with Special Needs hosted their Annual Holiday Gift Fund event at Anthony's Pier 4 in Boston. Each year, PFRR presents the "Powerful Friends" Award to individuals who, either personally or professionally, advocate on behalf of youth with disabilities. This year's honorees were State Auditor Joe DeNucci, and television sportscaster Steve Burton, WBZ-TV.

The Holiday Gift Fund Silent Auction, which raised over \$12,000, was part of the evening's festivities. This money is donated to the Department of Social Services and is used to purchase holiday gifts for youth in residential placements. Andrea Watson, founder of PFRR, established the Holiday Gift Fund and organizes this annual event in response to her daughter's experiences in residential care. She discovered that many youth did not receive gifts during the holiday season and urged her mother to take action. The Fund is in its 6th



L to r: Powerful Friend Honoree 2002 Richard Sheola, Governor Michael Dukakis, & Richard Robison

year and has raised nearly \$100,000. You can help support this fund by writing a check to: Holiday Gift Fund, and mailing it to: PFRR/FCSN, 1135 Tremont St. Suite 420, Boston, MA 02120 or by visiting [www.pfrr.org](http://www.pfrr.org).

Next year's Holiday Gift Fund Event will be June 17, 2005, honoring Barry and Elliot Tattelman for their many years of commitment to advocacy and to making a difference in the lives of children.

Parents For Residential Reform is a project of the Federation for Children with Special Needs, which provides support, information, referral, and other information to parents and professionals regarding residential educational settings and group home care.



L to r: Powerful Friends Honorees Ginni and Steve Burton, Barbara DeNucci, and Powerful Friend Honoree the Honorable A. Joseph DeNucci.



L to r: Event Co-chair Kathy Betts, Master of Ceremonies and Boston Radio Legend J.J. Wright, Oldies 103.3, Actor David Chokachi, and Andrea Watson

PFRR has developed a network of families in similar situations throughout MA and now nationwide. For more information, call our Hot Line at 800-672-7084, 617-236-7210, ext. 145 or email [pfrr@fcsn.org](mailto:pfrr@fcsn.org).



## Health News

at the Federation for Children  
with Special Needs

### Mass Family Voices

#### Supporting Parent Leaders in their Advocacy Roles on Behalf of Children and Youth with Special Health Care Needs

by Beth Dworetzky

Massachusetts Family Voices at the Federation is proud to help support and advance the Federation's commitment to parent leadership. Realizing that it is not

always possible for parents to travel to trainings and workshops, we host a statewide listserv. The Mass Family Voices listserv provides an on-line forum where participants can exchange resources and information, post questions, hear from the collective expertise of our diverse membership and support each other in our advocacy efforts on behalf of children and youth with special health care needs. As professionals are also welcome to participate, it serves the dual purpose of also helping to connect parents with leadership and advisory opportunities and build parent-professional partnerships. A parent-professional recently shared her experiences with the listserv, saying, "I love the listserv! It has been an effective way to pass the word along about opportunities. It's like a chain reaction—the information

always gets to at least one person to whom the connection is important."

Mass Family Voices also hosts an annual Joining Voices conference. This daylong event provides a networking and learning opportunity to help support parent leaders and emerging leaders in their advocacy roles. We are currently in the planning stages and welcome your ideas for workshop topics that would help support you in your leadership roles.

For more information about the conference and/or the listserv, please contact Mass Family Voices at 800-331-0688 ext. 210, e-mail [massfv@fcsn.org](mailto:massfv@fcsn.org) or visit us on-line at [www.massfamilyvoices.org](http://www.massfamilyvoices.org).

### MassCARE: Family Advisory Network News

by Sara Miranda

MassCARE—Massachusetts Community Aids Resource Enhancement—is a statewide program, run by the Department of Public Health (DPH). MassCARE clinics provide care at community sites across the state to women, children and families affected by HIV/AIDS. As with so many DPH programs, there is a family advisory component; DPH contracts with the Federation to run the MassCARE Family Advisory Network (FAN). FAN offers many ways for families living with HIV to support each other and become involved in various leadership opportunities by participating in program planning at the local, state and national levels. Regional and statewide meetings, a newsletter and other events, such as a family networking day and an annual conference are examples of activities offered through the FAN.

*Discovering New Choices* was both the name and theme of this year's MassCARE conference, hosted by the MassCARE Family Advisory Network (FAN). On June 25, 2004, 100 adults and teens came together to hear a fabulous, motivational keynote address by Lavern Saunders from Families FIRST at Wheelock College. Afterwards, adults and teens participated in separate activities, which were selected based on the results of a con-

sumer survey. Adults could choose from a series of workshops on nutrition, advocacy, and things children do to make us crazy—understanding motivation and behavior. There were additional workshops about alternative therapies, reflexology, and making quilt squares. Teens could attend a workshop to talk about issues of disclosure, or hear a

presentation by WAETOC (We Are Educators with a Touch of Class). This is a group of teens from Boston who help other teens deal with issues of sex, disclosure, and domestic violence. There was also a Raw Art workshop, taught by people who work with different communities to help them express themselves through art.

For more information about becoming involved in the FAN, call the Federation at 800-331-0688.

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# News from Family TIES of Massachusetts

by Mary Castro Aten, Director

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, Division for Special Health Needs. We offer information and referrals for families of children with special needs, direct parent-to-parent support, and trainings.

## STAFFING UPDATE

Family TIES welcomes Michele Wolf, the new Western Regional Coordinator. Michele's background includes serving as an attorney for the State of Minnesota and teaching courses in the areas of ethics, law, and civil rights. However, Michele says, "nothing has prepared me better for my role than adopting [her son] Ethan from Ukraine and obtaining the services and medical care that he deserves." In addition to her 6½-year old son, she is the mother of 14-month-old Spencer. You may reach Michele at the Western Regional Health Office in Northampton at 413-586-7525, ext. 1133.

## EXPANDED SERVICES

Family TIES is pleased to offer interpreter support for families whose primary language is Spanish or Portuguese. Anyone seeking our assistance can contact the following phone numbers and leave a message with your name, daytime telephone number, and reason for the call. Our interpreters check for messages on Monday, Wednesday, and Friday. Once they have made contact with the caller, the interpreter contacts the appropriate member of the Family TIES staff for follow-up services. Families seeking support in Spanish can call 800-331-0688, ext. 222 and leave a message for Sara. Those seeking support in Portuguese can call 800-331-0688, ext. 195 and leave a message for Renata. Family TIES brochures are now available in English, Spanish, and Portuguese. Many of our other materials are also being translated.

## CENTRAL DIRECTORY FOR EARLY INTERVENTION PROGRAMS

Family TIES maintains the statewide Central Directory of Massachusetts Early Intervention (EI) programs. We provide EI program information to parents seeking this valuable service for their young children (birth-age 3), and to professionals who refer families for EI services. For current EI program information, parents and professionals are encouraged to call our toll-free line at 800-905-TIES (8437) or visit our website at [www.massfamilyties.org](http://www.massfamilyties.org).

## PROGRAM ACTIVITIES

The 7th Edition of our Resource Directory for Families of Children with Special Needs is available. Please call your regional coordinator to get your copy! The Directory is also available on our website: [www.massfamilyties.org](http://www.massfamilyties.org). We are always looking for new resources for the next edition of the Directory and our updated listings of regional support groups. Feel free to contact our staff with your suggestions.

The Regional Coordinators are beginning to schedule **Next Steps: Let's Get Organized** workshops for parents. Call your regional coordinator for details or to assist us in arranging a presentation in your community.

## LEADERSHIP OPPORTUNITIES

Family TIES invites parents to share their voices by becoming an advisor to the Massachusetts Department of Public Health. Parents may participate in our Family TIES Advisors activities by attending focus groups or participating in advisory councils, filling out surveys, or reviewing materials and grants. We seek your expertise in a number of areas: Access to Medical Care, Cultural Competency/Diversity, Emergency Medical Planning, Genetic Testing and Genetics, Health Insurance—Public and Private Policies, Medical Home Partnerships, Nutrition for Children with Special Needs, Parent Education Training Opportunities, Respite/Family Supports, Transition Issues—Work and Independent Living. For more information, contact Joanne Spencer, Family

TIES Parent-to-Parent and Outreach Coordinator, at 781-774-6740.

**Parent-to-Parent** continues its mission to bring together families seeking a personal connection with an experienced parent whose child has similar concerns. Matches have included a wide variety of medical conditions and special needs. During three sessions this summer, we provided training for parents who are willing to offer support to others. Some of the diagnoses for which we now have trained parents include: Autism, Cerebral Palsy, complex medical needs, Down syndrome, FG Syndrome, Muscular Dystrophy, Pervasive Developmental Disorder (PDD), Prader-Willi Syndrome, and Trisomy 18.

Additional Parent Support Trainings are scheduled for the Western, Central, and Southeast Regions. We are also offering this training to organized support networks, whose members would be willing to be Support Parents. If you would like to know more about becoming a Support Parent, or if you would like to have an opportunity to be matched with a Support Parent, call Joanne Spencer at 781-774-6740, or e-mail: [joanne.spencer@state.ma.us](mailto:joanne.spencer@state.ma.us).

## FAMILY TIES STAFF

Mary Castro Aten, Director  
781-774-6736

Joanne Spencer, Parent-to-Parent and Outreach Coordinator  
781-774-6740

## Regional Coordinators

**Boston:** Roxanne Hoke-Chandler  
617-541-2875

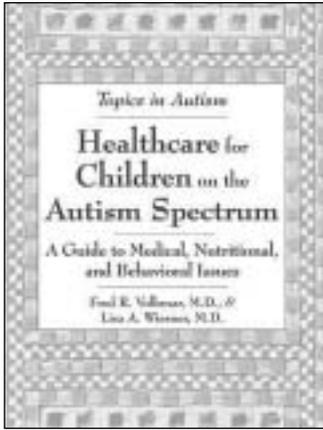
**Southeast:** Karen Douglass  
781-774-6609

**Metrowest:** Lisa Mayer  
781-774-6602

**Central:** Barbara Donati  
508-792-7880, ext. 2337

**Northeast:** Kathy Morin  
978-851-7261, ext. 4018

**Western:** Michele Wolf  
413-586-7525, ext. 1133 or 800-445-1255  
(western region only)



***Healthcare for Children on the Autism Spectrum: A Guide to Medical, Nutritional, & Behavioral Issues***, Fred R. Volkmar, M.D., and Lisa A. Wiesner, M.D. Woodbine House; 1st Edition (February 1, 2004). 348 pp.

## Book Review

by Mary Loughlin

Every parent of a child on the autism spectrum will want to have a copy of *Healthcare for Children on the Autism Spectrum*. It is a well-organized and comprehensive book and each chapter ends with a topic-related, valuable question and answer section. Topics include: an overview of autism and related conditions, getting a diagnosis, raising a healthy child with autism, coping with medical problems, handling visits to emergency rooms and hospitals, growth and nutrition, safety, sleep and sleep problems, seizure disorders, dental care, sensory issues, challenging behaviors, medications, adolescence and sexuality, dealing with developmental deterioration, and complementary and alternative treatments. This book should also be required reading for all professionals because an awareness of these medical, nutritional, and

behavioral issues is critical when working with children on the spectrum and their families.

The book begins with an excellent overview of autism and related disorders. It gives a clear definition of terms such as pervasive developmental disorder (PDD), autism, Rett's disorder, childhood disintegrative disorder (CDD), Asperger's disorder, Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS), and Autism Spectrum Disorder (ASD). It tackles the tough and still unanswered questions of what causes autism and whether or not the frequency of autism is increasing.

According to the authors, various rating scales and checklists cannot replace a skilled clinician's expertise in giving a diagnosis. They discuss getting a diagnosis, the uses and limitations of a diagnosis, and the characteristics of a good diagnostic evaluation, as well as how to understand test results. Because there is no simple laboratory test, parents must rely on "the judgment of (hopefully) experienced clinicians." The authors address the real concern of uncertainty about a diagnosis based primarily on observation and history.

The authors explore various healthcare issues for children on the autism spectrum and why medical care can be more challenging for children on the spectrum as compared to typically developing children. The message throughout the book is one of empowering parents through information in order to strengthen our role on our child's healthcare team and make us more effective advocates. They also emphasize the importance of parents having their children self-advocate whenever possible, making well-informed decisions, and building a strong working relationship with the child's doctor.

Thirteen years ago, when I began my journey as a parent of a child diagnosed with autism, I wish that I had the information in this book to follow. Without this information, I had to reinvent the proverbial wheel, and tried, not always successfully, to prevent my child from becoming "like a butterfly upon a wheel" (William Blake). With this book to guide them, parents and children can softly land and safely travel in the mysterious world of autism.

Woodbine House is a publisher specializing in books about children with special needs. They provide parent-friendly, useful books about disabilities for parents, children, teachers and other professionals. For more information, and/or to receive a catalog, call 800-843-7323 or visit [www.woodbinehouse.com](http://www.woodbinehouse.com).

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### ***Freedom Flight I*** by Jessica E. Vohs

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*Let's open our minds and hearts and fly free  
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*"Having worked in the DME industry in the past I know the difference between a caring, well run company and one that's not. We looked hard to find the right one because we knew with 7 special needs children to care for; we needed a company we could count on. Every single time I had an immediate need, they came out that same day and did so with a smile. There is no comparison. Charm you are the best!"*

**— Bill and Teresa Gately on their children Joshua, Mary, Emily, Charlie, Christopher, Jamie and Alicia - Roslindale, MA**

*"I truly want to thank you at Charm for helping me realize I could get supplies covered for my son Paul. I was unaware, as some other parents may be, that my son's incontinence needs were covered via Mass Health. I thought that because his disability wasn't "physical" that he wouldn't be covered. Charm helped me so much because I was able to stop having to pay for the supplies myself. Please get the word out to other parents and thank you! Thank you, thank you!"*

**— Lisa Nicewicz on son Paul Nicewicz - Chelsea, MA**

*"I'll tell you what, every time I have to make a phone call to Charm, it's almost too easy! Everything else seems to be a fight when dealing with the needs of my child. I can absolutely set my watch to the delivery schedule, which is always on time. Thanks so much for your donation in the fundraiser we held for Megan and also for putting the word out in your "Charm Chatter" newsletter about the fundraiser. I got donations from people I didn't even know! You guys go the extra mile. Thank you so much!"*

**— Kendra Keith on her daughter Megan - Hanson, MA**

*"We are extremely pleased with the service we get from Charm. Their Account Coordinators truly care. In fact, when Allison had a G-button problem they came out IMMEDIATELY and brought her another one without a fuss...2 Days in a row! That just showed our family that we had the right company delivering our medical supplies. Thanks Charm, you guys are the best!"*

**— Karen Stott on her children Aiden, Alison and Abigail - Plymouth, MA**

*"I had been bounced around from DME company to DME company with no success. I was getting so frustrated with the lack of cooperation I was receiving in being able to get Bethany the right equipment. I would spend hours on the phone having to call time and again to try and get it right. When I had finally had enough, I asked a care coordinator at the Department of Public Health to help me find the right DME company. Without hesitation she said... Charm Medical Supply. What a blessing! I could not be any happier with the company, and I sincerely mean that. Their entire staff proved to us that they really do care. From the friendly coordinators to the friendly drivers, they make sure things are done right. They get us what we need, on time, every time. We have finally found a DME company that truly puts our needs first!"*

**— Cindy Sabbag on her daughter Bethany - Medford, MA**



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## Planning a Life:

Making the Most Out of High School

Friday & Saturday,  
October 29 & 30, 2004  
Clarke University,  
Grace Conference Center  
Worcester, MA

**FOR FURTHER INFORMATION,  
CONTACT:**

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## National Inclusive Schools Week

December 5-11, 2004

INCLUSIVE SCHOOLS  
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Supporting inclusive urban communities,  
schools, and families to build their capacity  
for sustainable successful urban education.