



# NewsLine

The Federation for Children with Special Needs

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

Excerpts from:

## Effective Practices for Involving Families of Children with Disabilities in Schools

(Read the entire article on line at [www.fcsn.org](http://www.fcsn.org).)

Over thirty-five years of research recognizes that when families are involved in their children's education, there are significant effects on children's achievement and positive benefits for schools. While the most of this research did not specifically address parent involvement in the education of their children with disabilities, there is evidence to demonstrate that children with disabilities whose parents are involved in their education are more successful in school than their peers whose parents are not involved. Also, the earlier parents are involved, the greater the benefits for the children.

The Individuals with Disabilities Education Act of 1997 provides procedural safeguards for parents, but it does not facilitate partnerships between families and schools, and many schools fail to involve families of children with disabilities in the education of their children. However, Congress, through the Elementary and Secondary Education Act, requires schools receiving Title 1 monies to build partnerships with families and The Elementary and Secondary Education Act, now reauthorized as the No Child Left Behind Act of 2001, has a renewed emphasis on partnerships with families.

Dr. Joyce Epstein at the Center on School, Family, and Community Partnerships at Johns Hopkins University, created a model that broadens the discussion about family partnerships. Her research shows that family involvement takes many forms and that any family involvement benefits both educational outcomes and relationships with the schools. The model includes partnerships around: parenting, communicating, volunteering, learning at home, decision-making, and collaborating with community.

Dr. Mavis Sanders, another researcher at Johns Hopkins, supports Dr. Epstein's model and recognizes that there are some challenges to creating parent involvement opportunities for parents of children with disabilities. However, creating successful partnerships is generally the

same for all families, whether or not the child has a disability.

Using Dr. Epstein's model, parents, principals, special educators, special education directors, special education lawyers, and researchers provided examples of effective practices for facilitating and supporting the engagement of families of children with disabilities in their children's education, through a broad range of activities.

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**The greatest benefit of school, family, and community partnerships is that partnerships can help children succeed in school and in life.**

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Dr. Sanders describes how the Lois T. Murray Elementary School in Baltimore, Maryland empowers families and communities to be partners in the education of children with disabilities: "The school's Action Team for Partnerships, which is responsible for planning and implementing the school's partnership program, was extremely impressive. It was composed of parents, grandparents, teachers, paraprofessionals, the principal and vice principal,

### Assistant Secretary Sclafani Sworn In



Federation staff members and friends attend swearing in ceremony for Dr. Susan Sclafani as Assistant Secretary of Education for Adult and Vocational Education in Washington, DC on March 1, 2004.

and a social worker. I also was impressed with the variety of activities offered and the care, knowledge, and sensitivity that went into the planning and implementation of these activities. The school also did a great job in evaluating the activities and making necessary changes and improvements. The experience taught me a great deal about the possibilities of partnerships for students with disabilities."

Dr. William Henderson is principal of the Patrick O'Hearn School, an elementary school in Dorchester, Massachusetts. Under Dr. Henderson's leadership, the O'Hearn School has become a fully inclusive, high performing nationally recognized school. Students in regular education, students with special needs, and students considered gifted and talented learn together and from each other. Teachers and

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**Bulletin**

Parents Learning About Children's Education



# New Policy Update: MCAS Appeals

The MCAS appeals process for students with disabilities has changed. The process was amended by the state legislature under Chapter 140 of the Acts of 2003, Section 119. On January 27, 2004 the state Board of Education unanimously adopted regulations implementing these amendments. The most notable change is that, in order for a student with a disability to be eligible for an appeal, a minimum score of 216 is no longer required. Other eligibility requirements still stand:

1. The student must have had a 95% attendance rate;
2. The student has to have taken the grade 10 MCAS test at least 3 times (2 times for those taking the MCAS alternate assessment); and
3. The student must have participated in any available MCAS tutoring or academic support services (unless lack of participation is related to the disability).

Another key revision is that, if the parent of an eligible student with a disability so requests, a superintendent is now required to file an

appeal. (Previously, the decision of whether or not to file an appeal rested with the superintendent.) Students with disabilities who are 18 or older can also request an appeal themselves. Furthermore, all appeals for students with disabilities now require parental consent.

To demonstrate that the student making the appeal meets the competency determination standard, the typical MCAS appeal involves comparing the student's grade point average with other students who took the same set of courses and passed the 10th grade MCAS. For the comparison to be meaningful, the group must consist of more than six students. It is common for the group to be too small. In these cases, a portfolio of the student's work can be submitted instead. However, under the new regulations, if the district has not maintained a portfolio for the student, then one can be developed for submission, or the superintendent may submit "other supporting information," including work samples, documentation of having been accepted to college courses, documents showing scores on other standardized tests, and other documents that address the student's achievement in the subject area. With parental

consent, a student's IEP team can also now have the superintendent insert additional documents that the team believes support the appeal (i.e., work samples).

Two crucial parts of the appeals process remain the same for **all** students: First, any appeal has to be filed by the superintendent. Second, the superintendent can, at her or his discretion, request the waiver of any of the eligibility criteria.

Finally, one change has been made to the appeals process for **all** students. The Department of Education prepares form letters for superintendents to mail to parents so parents will now receive notification letters stating the decision of the performance appeals board.

Contact the PTI project at the Federation if you have questions or would like additional information. You can also visit the Massachusetts Department of Education's appeals website at [www.doe.mass.edu/mcasappeals](http://www.doe.mass.edu/mcasappeals), or call the Appeals Hotline at 781-338-3333.



**Aspire  
Achieve  
Empower**

**Partners™ for Youth with Disabilities**

Now Recruiting youth, young adults and mentors with disabilities to participate in our one-to-one, group, and online mentoring programs. Mentors really can make a difference. **Visit our website at [www.pyd.org](http://www.pyd.org) or call (617) 556-4075 x18 to learn more about how you can get involved.**

## Tools for Life: Parents Learning about Assistive Technology

Easter Seals is offering a series of hands-on workshops for parents of children with disabilities on using assistive technology in the classroom.

Workshops are offered at \$40 each.

Contact Thao Duong:

800-244-2756 x328 for more information

- An Introduction to Boardmaker April 1
- Practical Supports to Promote Participation, Independence and Success April 3
- Introduction to Alternative Access April 29
- Intellitools for Parents May 1
- Speaking Dynamically Pro May 20
- Writing Aids for Students with Disabilities May 22



Workshops are sponsored by a generous grant from the Carl and Ruth Shapiro Family Foundation

## From the Executive Director

# 30 Years: Then and Now!

It's spring 1974. The Massachusetts special education law (Chapter 766), passed in 1972, was still in its first months of implementation. It focused on access to public education by students who in some cases had been excluded by law or practice or both. Parents were the prime movers behind this law, believing always that even students with the most significant disabilities had a fundamental right to receive a public education that would enable them to maximize their own potential. Working with educators, administrators, policy makers and others, parents formed unprecedented coalitions to ensure passage of this law. For students with special needs, it was an optimistic time as a 20-year struggle to guarantee every single student a high quality public education had come to fruition.

Prior to the enactment of Chapter 766, some Massachusetts' students with special needs had more rights than others. For example, there were specific laws to protect students who were blind or deaf. The Task Force on Children Out of School (later the Mass Advocacy Center and now Mass Advocates for Children) found out through a comprehensive study in Boston that thousands of other children had been kept out of school due to issues of race, culture, behavior and disability.

Chapter 766 was the first comprehensive state law in the nation that sought to address these complicated issues by guaranteeing that all students would be entitled to a free appropriate public education. Chapter 766 called for "non-categorical" eligibility. Any child who needed services and supports to be successful in school would be able to receive them without regard to their type of disability. In 1975, the Federal government followed suit with the law we know today as IDEA (Individuals with Disabilities Education Act).

Thirty years ago the Federation was born out of the strong commitment to parents and their crit-

ical role in ensuring that schools would fulfill the promise of the law. Parents of children with special needs created a way to help other parents understand their rights under the law as well as learn the most effective methods of supporting their children with special needs. This parent-to-parent and parent-to-professional model continues today as we continue to pursue the Federation's commitment to quality education and protecting the rights of all children.

### Thirty years ago the Federation was born out of the strong commitment to parents and their critical role in ensuring that schools would fulfill the promise of the law.

Phyllis Snieron, a veteran Federation staff member and parent of an adult son with disabilities, was one of those early parent pioneers. I fondly recall her telling me, "we thought once everyone knew that the law had been passed, our job would be over! Six months or a year would be enough time." Today, 30 years later, we remain focused on many of the same issues, but with notable progress.

In 2004 it is the law of the land. Every child is entitled to a free appropriate public education with appropriate supports and services.

Education reform efforts at the state and national levels hold schools accountable for fully including all children with disabilities not just in the school building, but also in the school's general curriculum.

Students with disabilities are surpassing the expectations of their parents, teachers and the



Richard Robison

public in general. We can boast about a new generation of individuals with disabilities who are living, working and thriving in their own communities like never before.

Mary Ann, a person with autism lives independently. Jessica, a woman with CP (cerebral palsy), is an artist with her own company and website. Meghan, who also has CP, has met the same educational standards as all other students. Amy, a young woman with Down syndrome attends a community college.

The Federation's commitment remains the same, but even our expectations have been raised. Fighting for access to school has become a fervent battle for high educational standards for even those students with the most severe cognitive disabilities. Teaching new parents about the rights, critical history and promising practices is our daily endeavor. Last year we responded to more than 26,000 phone and email inquiries and over 50,000 people visited our website each month.

Thirty years later and the job is not done! In fact, there is more than ever for us to do. The lessons of history are too easily lost if the results of that history are not constantly lived and appreciated.

Please join us in this 30th year celebration by sharing your stories, volunteering in your community or at the Federation and supporting the efforts of individuals with disabilities to live fully in their communities.

*Richard J. Robison*

Richard J. Robison

**Parents • Pais • Padres**  
**Your input is important!**  
**Sua Participação é importante**  
**Su opinión es importante**

**Help us to help you!**  
 Please go to page 13 to fill out our Needs Assessment Survey.

**Ajudem-nos a ajudá-los!**  
 Por favor, preenche a nossa pesquisa na página 13.

**¡Ayúdenos a ayudarle!**  
 Por favor vaya a la página 13 y llene el cuestionario que estamos haciendo para conocer sus necesidades.

### FEDERATION SEEKS BOARD NOMINATIONS

The Federation is seeking nominations of parents or professionals committed to children with special needs to serve on its Board of Directors. The Board is responsible for the overall direction and policies of the Federation and to ensure its long term stability and growth. We are seeking to add up to three directors with the following areas of interest or expertise: Public Relations, Education and Development. Persons from diverse cultural or ethnic backgrounds are particularly encouraged to apply. A nomination form may be found at [www.fcsn.org/nomination](http://www.fcsn.org/nomination). Self nominations are welcome. For more information contact Richard Robison, Executive Director or write to [rrobison@fcsn.org](mailto:rrobison@fcsn.org).

## A Letter of Thanks

*The Federation for Children with Special Needs helps parents advocate for services and supports for their children. Through Parents For Residential Reform (PFRR), the Federation also helps make a difference in the lives of children who do not have a parental voice to advocate on their behalf. PFRR and the Federation received the following letter in acknowledgment of these efforts.*

Dear Friends,

Once again, the holidays were happier for a large number of youth spending this time in facilities away from their families, and once again it was your hard work and generosity that made this difference. On behalf of all of us acting in the role of parents for these children, I want to thank you from the bottom of my heart for your fundraising efforts [at the 5th Annual Children's Holiday Gift Fundraiser], which resulted in the extremely generous donation to this Department [of Social Services] of \$10,000 for gift cards. I thought I would share a single individual story as one small example of how much these gift cards have helped our youth separated from [their] families during this crucial time of year: For two teenage brothers, suddenly returned to Massachusetts after a failed placement with relatives out of state, it was looking to be a bleak Christmas. First, with little preparation, they were put on a plane with nothing but the clothes on their backs the week before the holiday. Then, the intended placement with relatives in Massachusetts did not work out. Finally, we arranged for their temporary placement in shelter care. While we did pull together some funds to address their immediate clothing

needs and a small amount for presents, the social worker remained concerned about the Christmas holiday for these boys. The older teen was particularly concerned about his younger brother and about having no way to buy his brother a gift. And that's where your efforts made all the difference. With the gift cards, both boys received quality gifts that they wanted and were interested in, including remote control trucks, and "official" NFL jerseys for the teams that they support. In addition, we were able to take the older boy shopping to purchase a gift for his younger brother. The gift cards helped to ease the pain of separation from family for both boys and both were surprised and pleased to receive such generous and personal gifts.

This is just one story of many. You and those who worked with you in this cause are to be commended for your dedication and extraordinary accomplishments. We at the Department very much appreciate your efforts on behalf of the children that we all serve.

Thank you,

Harry Spence

Commissioner of the Department of Social Services, and Assistant Secretary of the Children's, Youth and Family cluster at the Executive Office of Health and Human Services



Federation staff and special guests present \$10,000 check to the Massachusetts Department of Social Services for the Children's Holiday Gift Fund.

Left to right: Susan Getman, Deputy Commissioner DSS; Andrea Watson, PFRR; Patrice Vinci, Comedian; Cassandra Watson; Robin Dawson, Executive Director, Mass Film Bureau; David Chokachi, TV Actor, Baywatch/Witchblade; Laura Yellen, Assistant Mass Film Bureau; Rich Robison, Executive Director, Federation for Children with Special Needs; Jessica Vohs, Artist

*The Children's Holiday Gift Fund benefits children with disabilities living in state custody due to abuse, abandonment and/or neglect. The Fund provides holiday gifts for this population. The 6th Annual Children's Holiday Gift Fund event will be held on June 25, 2004 at Anthony's Pier 4 in Boston. For more information about this year's upcoming event, and how you can help, visit [www.pfrr.org](http://www.pfrr.org).*

## Toll-Free Hotline for Air Travelers with Disabilities

The U.S. Department of Transportation (DOT) hosts a Toll Free Hotline for air travelers with disabilities. The main purpose of the hotline is to improve the quality of air transportation for people with disabilities by educating air travelers and airlines about the rights of passengers with disabilities, and to provide assistance in resolving disability-related air travel problems.

Hotline Duty Officers provide general information about the rights of air travelers with disabilities. They can also assist air travelers with disabilities in resolving real time or upcoming issues with air carriers. The purpose of "real time" assistance is to facilitate airline compliance with DOT rules by suggesting alternative customer-service solutions to the passenger and airline, although the airline remains responsible

for deciding what action to take to resolve the problem. Generally, if a caller has a real time problem or an upcoming issue with an air carrier, a Hotline Duty Officer will contact the air carrier and attempt to resolve the issue. For example, there have been a number of incidents in which Hotline Duty Officers have contacted air carriers and convinced them to accept service animals and electric wheelchairs on board flights, to stow folding wheelchairs in the cabin and to provide requested wheelchair assistance.

Hotline Officers can send printed consumer information about air travel rights of people with disabilities. For information about the rights of persons with disabilities in air travel, or for help in resolving disability-related air travel problems, call the Hotline at:

**1-800-778-4838 (Voice) or  
1-800-455-9880 (TTY)**

Hours of operation are 7 am to 11 pm Eastern Time, seven days a week.

The DOT will also investigate complaints about disability-related issues. The complaint must be submitted in writing via e-mail to: [airconsumer@ost.dot.gov](mailto:airconsumer@ost.dot.gov), or mailed to: Aviation Consumer Protection Division, U.S. Department of Transportation, 400 7th Street, S.W., Washington, D.C. 20590.

The DOT is asking all disability organizations to promote public awareness about the hotline. Call the Hotline to request business cards (also available in Braille) to distribute to individuals with disabilities.



PARENTS LEARNING ABOUT  
CHILDREN'S EDUCATION

## U.S. Department of Education Names Parents' PLACE a 2003 PIRC Grant Recipient

The Federation for Children with Special Needs in Boston is pleased to announce that it is a 2003 Parent Information and Resource Center (PIRC) grant recipient. With this funding, the Federation will continue to operate Parents' PLACE (Parents Learning About Children's Education). The PIRC program is an initiative of the U.S. Department of Education intended to increase the participation of parents in their children's education. This federal program is based on over thirty years of research that overwhelmingly demonstrates that parents' involvement in their children's learning is positively related to achievement.

Since 1999, Parents' PLACE has been working statewide with families and educators to help parents become more involved in their children's education and to help schools become more family-friendly. Over the next three years, Parents' PLACE will work statewide to help families and educators understand the

main objectives of the *No Child Left Behind Act*, to help families become educated consumers in their children's education, and to develop productive family-school partnerships aimed at raising student achievement. In addition, Parents' PLACE will work intensively with several urban school districts across the state.

Parents' PLACE is excited to be collaborating with the Massachusetts Department of Education, Massachusetts Advocates for Children, COMPASS, Inc. (a community-based organization that provides services to high-risk, inner city children who have behavioral, social and educational disabilities), Center for Resource Management, and six Parents as Teachers programs to implement the work of the project.

The Federation began in 1974 as a parent organization focused on educational rights for



children with disabilities. Since then, staff members have developed a rich body of resources and approaches to parent involvement in children's education. Through Parents' PLACE, the Federation is excited to be able to extend its expertise to support all families across the state, with special efforts devoted to at-risk children and families who are educationally disadvantaged.

Parents' PLACE services are available to families and schools throughout Massachusetts in English, Spanish, and Portuguese. For more information, please contact Parents' PLACE at 617-236-7210 or toll free in Massachusetts at 877-471-0980, or access the Parents' PLACE website at [www.pplace.org](http://www.pplace.org).

### MATCHING GIFTS Make Your Contributions Go Further!

1. Check with your company's personnel department to see if they have a matching gifts program.
2. Ask for matching gifts forms for all the members of your team.
3. Review the requirements of your matching gifts program carefully—each program has its own policies.

*You can contribute to The Federation for Children with Special Needs online!  
Go to [www.fcsn.org](http://www.fcsn.org) for details.*

### *Send Symbolic Sentiments™* Cards & gifts supporting children with challenges

*Many thanks!*



These simply delightful note cards, stationery and gifts are sure to bring a smile to parents, educators and therapists. Choose from many unique thank you, birthday and holiday designs — all featuring Picture Communication Symbols used by children with developmental disabilities.

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# UPCOMING FEDERATION TRAININGS AND WORKSHOPS

## Parent Consultant Training Program: Spring 2004

The Federation is pleased to announce Parent Consultant Training Programs

### BOSTON

**Dates:** April 28, May 4, May 11, May 18, May 25, June 1, June 8

**Time:** 9:00 am–3:00 pm

**Location:** FCSN, 1135 Tremont Street, Boston

**Contact:** Phyllis Sneirson  
800-331-0688 x115

### PITTSFIELD

**Dates:** April 29, May 1, May 13, May 15, May 27, June 3

**Time:** 10:00 am–2:30 pm

**Location:** UCP, 208 West Street, Pittsfield

**Contact:** Julie Sinclair 866-323-0681

### WORCESTER

**Dates:** April 16, April 30, May 7, May 14, May 28, June 4, June 11

**Time:** 9:30 am–3:30 pm

**Location:** FCSN-Central MA Office  
81 Hope Avenue, Worcester

**Contact:** Mary Loughlin 508-798-0531

The purpose of this training is to produce a knowledgeable and skilled group of parent consultants, able to make a sustained commitment to represent parents of children with special needs and persons with disabilities in matters relating to special education. The program consists of six or seven daylong sessions and an optional 50-hour internship. Topics covered include: special education laws, negotiation, mediation, inclusion, transition, communication skills and more. Class size is limited to 30.

**Prerequisites:** Completion of the Basic Rights and the IEP workshops. Check the Federation Workshop schedule at [www.fcsn.org](http://www.fcsn.org) or call the contact person for more information.

**Fee:** \$300.00 for tuition and materials. A small number of scholarships are available. For more information, please call the appropriate contact person, as noted above.

## Federation Workshops: April 2004–May 2004

\*Visit our web site for up-to-the-minute information ([www.fcsn.org](http://www.fcsn.org))

### APRIL 2004

- 4/5 Sherborn, *Basic Rights*, Pinehill School, Pinehill Drive off Rte. 16, 9–11pm
- 4/5 Northampton, *Basic Rights*, 56 Vernon Street, 6:30–8:30pm
- 4/6 North Reading, *Effective Communication*, N. Reading High School Library, Main Street, 7–9pm
- 4/6 Chelmsford, *Transition*, Murdock Middle School, 40 Brick Kiln Road, 6:30–9:00pm
- 4/8 Agawam, *Transition*, Agawam High School, 760 Cooper St, 7–9pm
- 4/12 Northampton, *IEP*, 56 Vernon Street, 6:30–8:30pm
- 4/12 Norwell, *IEP*, Norwell Middle School, 7–9pm
- 4/13 Granby, *IEP*, West Street School, Learning Center, 6:30–8:30pm
- 4/13 Beverly, *IEP*, Briscoe Middle School, 7–9pm
- 4/14 Bolton, *Basic Rights*, Sawyer Elementary School, 7–9pm
- 4/14 Wakefield, *Basic Rights*, Wakefield High School, Farm St., 7–9pm
- 4/14 Newburyport, *MCAS*, Nock Middle School, 7–9pm

### MAY 2004

- 5/13 Cambridge, *Basic Rights*, Cambridge Rindge and Latin Library, Broadway and Cambridge Street, 7–9pm

### WORKSHOP DESCRIPTIONS

**Access to the General Curriculum:** offers parent-friendly information on diverse learning styles and access to the general curriculum for all students. The workshop includes discussion and examples of modifications to content, delivery of instruction and performance that will allow students with disabilities fuller participation in the general curriculum.

**Basic Rights:** covers basic information about state and federal special education laws to assist parents in the planning, decision-making and monitoring of their child's IEP. (Materials available in Spanish and Portuguese.)

**Effective Inclusion of Students with Disabilities in the MCAS Testing System:** includes information on the IEP Team determination of the appropriate method for an individual student to participate in the MCAS testing system. The workshop covers accommodations available to students with disabilities taking the standard paper and pencil version of MCAS as well as information on the MCAS Alternate Assessment.

**An IEP for My Child:** includes a walk through of the Individual Education Program with emphasis on IDEA '97 and the latest Massachusetts special education regulations, access to the general curriculum and writing curriculum-based measurable annual goals. (Materials available in Spanish.)

**Effective Communication:** offers communication skill building and conflict resolution for parents as members of the IEP Team.

**Taller Sobre Los Derechos Basicos De Educacion Especial:** este taller ofrece informacion sobre el Capitulo 766 y otras leyes estatales y federales de educacion especial. Esta informacion ayudara a los padres a planear, tomar decisiones y a asegurar que se este cumpliendo el plan educativo individualizado de su hijo/a.

**Transition 14–22:** provides basic information about the state and federal laws that require the IEP to address goals such as competitive employment and independent living to assist students 14 and older with planning transition to adult living.

**Turning Three:** an interactive workshop that helps parents and professionals understand parent's basic rights as their children approach the transition from Early Intervention into preschool at age three.

# A Special Education Journey Began at the Federation:

## A Parent's Perspective on the Federation's 30th Anniversary

When I found out my son, who has high functioning Autism, needed special education services, I was a little sad, but mostly I was scared. Someone at Mass General Hospital told me to call the Federation for Children with Special Needs. My journey into the world of special education began with a phone call to the Federation, where I spoke with Phyllis Sneirson. I told her the school system would not provide services to my son because the class was full. She explained my son's rights and instructed me to tell the school that it was not legal to exclude my child. Furthermore, if the school still wouldn't provide a placement for my son, Phyllis told me to call Program Quality Assurance Services (PQA) at the Department of Education. She also told me about Parent Advisory Councils (PACs). The PAC was meeting that night, and I attended. I became very educated about special education. My son got the services he needed. I felt empowered and wanted to 'give back' to the system. I became the PAC co-chair and held that position for many years, and also did volunteer parent consulting.

My daughter, who has Bi Polar disease, needed a residential school. I did not want to place her in a residential setting, but after 15 hospitalizations in one year, I realized it was necessary. After my experiences with my son, I thought I knew it all—special education regulations, laws, and my child's rights. However, after several serious "isolated incidents" in my daughter's residential school, some parents got together to discuss our concerns. Our children were all having serious "isolated incidents." We got more involved with the PAC, and spoke often to each other on the phone. Although we were all well educated about special education laws and regulations, we didn't realize our rights extended into the world of residential care. We even thought about starting our own residential program.

Eventually we learned about the regulations and licensing requirements for residential schools and group homes, which are overseen by the Office of Child Care Services (OCCS). We learned that OCCS and the Department of Education (DOE) cared very much that our children were being medicated incorrectly, restrained improperly, that required staff to student ratios were not being followed, that the girls were running away, that there was sexual misconduct, staff were not being trained properly, criminal background checks

were not being done, and IEPs (Individualized Education Programs) were not being followed. The school went so far as to tell parents that our "girls were not there for an education." Fortunately, the DOE didn't feel that way, as they were paying a huge amount of money so our children would receive an education in this type of placement.

**Sometimes I look back and am sad that my family had to go through what we did, and I wonder how we survived. But at the same time, I have used my family's experiences to make a difference in the lives of other child and their families.**

We realized we didn't need to start our own parent-run "Ultimate Residential School." What we needed was a venue where other parents could go to find important information about residential schools and group settings before placing their child's life in the hands of others. So began Parents for Residential Reform (PFRR) in January of 1999.

Sometimes I look back and am sad that my family had to go through what we did, and I wonder how we survived. But at the same time, I have used my family's experiences to make a difference in the lives of other child and their families. Parents are better educated and are treated as consumers no matter who is paying. PFRR helped raise the standards at the DOE. School Commissioner Driscoll led hearings for parents two years in a row with other state agencies attending. DOE now has a Private School Unit at their PQA and the most recent monitoring reports are online at the DOE website <http://www.doe.mass.edu/pqa>. PACs are required at all 766-Approved Schools and they must follow the curriculum frameworks and administer the MCAS. The OCCS now posts important licensing status information on their site at <http://www.quality-childcare.org>, and speak daily with parents regarding programs. The state legislature has taken us seriously with health, welfare, safety, and service delivery a priority. They also recog-

nize parents as leaders in the "residential world."

It's now 2004 and I sit at my desk at the Federation for Children with Special Needs. I never thought I would be doing this type of work, making it my life. I have learned a lot from my peers and colleagues and PFRR is part of the team. My daughter is now 21 and expecting her first child. She speaks eloquently about her residential school peers whose families weren't involved in their placements and ensuring their rights to an education. She stays involved through her work on the Children's Holiday Gift Fund Event. She also volunteers at the Federation's annual conference. I am so proud of her. My son, now 20, lives at home. He will begin taking 2 courses at a community college.

For 30 years, Federation staff has shared information and resources that has opened the door for so many parents. The Federation for Children with Special Needs was the first PTI (Parent Training & Information Center) in the country. Massachusetts enacted the first special education law. Thirty years ago, I was listening to Carole King, James Taylor, Carly Simon, the Carpenters, Johnny Rivers, and disco was just emerging. My friends and I went to Walter's Dairy for French fries and ice cream every weekend. I didn't have a worry in the world. Who would have thought that life would turn out this way? I never thought there would be a struggle, and there have been many. I now work to prevent others from having to experience those same struggles. I realize that while I was listening to music, and hanging out with my friends, other parents were struggling with many of the same issues I would face with my own children. Their actions helped pave the way for the Federation so that today information, support and training are just a phone call away and our children to have a chance to be educated and are treated with dignity.

Parents are consumers in the residential world; we now have choices, access to information, and hopefully are laying a stronger and better foundation for our children so when they are adults they can live in their communities, as self sufficient as possible. As the Federation enters into its 30th year, I reflect on how it could have been, had there never been a Federation for Children with Special Needs.

## Excertos do artigo: Práticas Efetivas para Envolver Famílias com Crianças Portadoras de Deficiência

(Leia o artigo integral online: [www.fcsn.org](http://www.fcsn.org))

Mais de trinta anos de pesquisas indicam que, quando as famílias estão envolvidas na educação de suas crianças, há um efeito significativo no rendimento das mesmas, com benefícios positivos para as escolas. Ainda que a maioria destas pesquisas não tenha sido direcionada especificamente quanto ao envolvimento dos pais na educação dos filhos portadores de necessidades especiais, há evidências que demonstram que as crianças portadoras de deficiência cujos pais se envolvem em sua educação, têm mais sucesso na escola do que os seus colegas cujos pais não estão envolvidos. Também, quanto mais cedo os pais se envolvem, maiores os benefícios para as crianças.

A Lei de Educação para Indivíduos Portadores de Deficiência, de 1997, garante procedimentos de salvaguardas para os pais, mas não facilita as parcerias entre as famílias e as escolas, sendo que muitas escolas falham em envolver as famílias com crianças portadoras de deficiência. Porém, o Congresso, através da Lei de Educação Primária e Secundária, exige que as escolas que recebem fundos do "Title 1" construam parcerias com as famílias. Esta lei, re-autorizada como a lei Nenhuma Criança Deixada Para Trás, de 2001, tem uma ênfase renovada nas parcerias com as famílias.

A Dra. Joyce Epstein, da Center on School, Family, and Community Partnerships at Johns Hopkins University, criou um modelo que amplia a discussão sobre a parceria com as famílias. Sua pesquisa mostra que o envolvimento familiar toma muitas formas, e que qualquer envolvimento por parte da família beneficia tanto os resultados educacionais quanto os relacionamentos com as escolas. O modelo inclui parcerias do tipo: vida em família, comunicação, voluntariado, aprendizagem em casa, tomada de decisão e colaboração com a comunidade.

A Dra. Mavis Sanders, outra pesquisadora da Johns Hopkins, apóia o modelo da Dra. Epstein e reconhece que há alguns desafios para criar as oportunidades para o envolvimento dos pais de crianças portadoras de necessidades especiais, contudo a criação de parcerias de sucesso seja, em geral, a mesma para todas as famílias, seja a criança portadora de deficiência ou não.

Usando o modelo da Dra. Epstein, os pais, os diretores, educadores especiais, diretores de educação especial, advogados de educação especial, assim como os pesquisadores, fornecem exemplos de práticas efetivas que facilitam e apóiam o engajamento de famílias com crianças portadoras de necessidades especiais na educação de seus filhos, através de uma variedade abrangente de atividades.

A Dra. Sanders descreve como a escola primária Lois T. Murray Elementary School, em Baltimore, Maryland, capacita as famílias e as comunidades a serem parceiras na educação das crianças portadoras de necessidades especiais: "A Equipe de Ação para Parcerias, que é responsável pelo planejamento e implementação do programa de parceria da escola era extremamente impressionante. Ela era composta de pais, avós, professores, paraprofissionais, do diretor e do vice diretor, e de uma assistente social. Também me

impressione com a variedade de atividades oferecidas e com o cuidado, o conhecimento, a sensibilidade com que estas atividades foram planejadas e implementadas. Além disso, a escola fez um grande trabalho nas avaliações das atividades, fazendo mudanças necessárias e aperfeiçoamentos. Esta experiência me ensinou muito sobre as possibilidades de parcerias para os alunos portadores de necessidades especiais."

O Dr. William Henderson é diretor da Patrick O'Hearn School, uma escola primária em Dorchester, Massachusetts. Sob a liderança do Dr. Henderson, a O'Hearn School se tornou uma escola inteiramente inclusiva, de alta performance e reconhecida nacionalmente. Os alunos do ensino regular, os alunos com necessidades especiais e os alunos considerados talentosos e com dons aprendem juntos e uns com os outros. Professores e o pessoal de apoio trabalham com as crianças em salas integradas.

O diretor Henderson concorda com as pesquisadoras de que o envolvimento dos pais para as famílias com crianças portadoras de necessidades especiais deve ser definido amplamente. Ele obteve sucesso no envolvimento de pais, em sua escola, em todas as categorias da Dra. Epstein. Um programa de sucesso, em particular, envolvia o ensino em casa através da leitura, onde os pais são os verdadeiros parceiros na educação dos



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filhos. Mais de 95% das crianças da O'Hearn School, incluindo as crianças excepcionais, lêem em casa por quatro noites cada semana. É o dobro do número que participou anos atrás quando se iniciou o programa. As notas aumentaram consideravelmente e a O'Hearn School deixou de ser de baixa performance para alta performance.

Em adição ao apoio para a aprendizagem em casa, o Dr. Henderson cria oportunidades para a tomada de decisão. Ele, ativamente, recruta e estimula as famílias a participarem das oportunidades, tais como os programas de alcance às famílias e de leitura em casa, ou facilitando os encontros dos comitês. Ele pergunta: "Como podem as famílias nas posições de liderança serem estimadas?" Ele escuta os pais, celebra o rendimento de suas crianças e a diversidade que estas famílias trazem para a comunidade escolar.

A pesquisadora e professora de educação especial Beverly Mattson concorda que o envolvimento dos pais deve ser diferenciado, de acordo com as necessidades da família. "Penso que é importante para cada escola identificar quando e como os pais querem ser envolvidos: por telefone, grupos de enfoque com [outros] pais, ou questionários. Percebi que havia uma escala no envolvimento dos pais." Como exemplo, a senhorita Mattson reconhece que a aprendizagem em casa pode ir além da lição de casa. As habilidades para a vida e o comportamento geralmente precisam ser lidadas no lar através das parcerias escola-casa. A srta. Mattson descreve uma middle-school onde os pais identificam os desafios ao envolvimento (e.g., tempo, distância, falta de transporte) e as estratégias para vencê-los. Como resultado deste processo, o plano de aperfeiçoamento da escola incorpora, especificamente, as recomendações dos pais de como elevar o envolvimento. Algumas das estratégias são: fazer a rotação dos jantares e dos encontros sociais noturnos em torno do distrito escolar e em lugares mais convenientes para os pais; identificar os recursos comunitários de acordo com as necessidades da família; agendar reuniões em um dia que não tem aula; oferecer aulas de computação para os alunos e as famílias. Ela aponta outra escola que contratou, em tempo integral, um pai (ou mãe) da vizinhança da escola para ser relações públicas. Este pai conhece todas as famílias. A escola tem 100% de comparecimento nas reuniões de pais, e tem eventos sociais/acadêmicos mensais, tais como a noite de Matemática, a Noite de Leitura, etc. Além disso, a escola envia informativos com foco em como os pais podem apoiar a aprendizagem de seus filhos.

Diana Autin, diretora executiva da Statewide Parent Advocacy Network (SPAN), de Nova

Jersey, e também mãe, comentou que o quadro de pessoal da escola deve ter cuidado para não ter uma visão muito estreita do envolvimento dos pais. Alguns pais vão se envolver na educação individual de sua criança. Outros podem desenvolver parcerias com as escolas participando dos treinamentos para pais/profissionais oferecidos para os membros das equipes de administração da escola, ou através do treinamento de liderança para os pais. Muitos pais obtêm conhecimentos por si próprios, comparecendo a seminários oferecidos através de organizações em sua comunidade.

Em ambas as experiências da Srta. Autin e do Dr. Henderson, eles entenderam que muitos pais de crianças com necessidades especiais iniciam-se aprendendo sobre leis de educação especial, procedimentos e processos, e terminam com um treinamento avançado. Estes pais líderes, então, tornam-se muito envolvidos em servir em vários conselhos escolares e equipes de administração. Estes pais líderes geralmente recrutam, treinam e apóiam outros pais.

A Srta. Autin descreve o sucesso da Parent Leadership Development Institute através da SPAN. Pais com ou sem filhos portadores de necessidades especiais trabalham juntos com o quadro de pessoal da educação especial e da educação regular. Este projeto forneceu um treinamento extensivo de oito sessões sobre a reforma escolar, leis educacionais, participação efetiva de pais, liderança, representação para oficiais do PTA, "Title 1", conselho de educação especial, pais nas equipes de administração com base na escola, e pais interessados em distritos urbanos. O foco estava nas coisas mais importantes que os pais precisam saber sobre educação especial. Os pais da educação geral, que previamente aceitavam os mitos de que a educação especial atrapalhava a educação regular, tornaram-se defensores da educação especial. Os administradores também participaram, e então mudaram suas práticas, uma vez que começaram a ver os pais diferentemente. Mil pais participaram em 30 distritos urbanos do estado de Nova Jersey, num período de 3 anos. Todos os membros do Parent Advisory Councils e um terço dos administradores escolares fizeram este treinamento. Como resultado desta participação, muitos pais continuaram seus estudos em ESL, GED e programas de faculdades comunitárias. Uma mãe diz que vai continuar com os estudos porque ela quer ser mais eficiente com sua criança, esforçando-se para aperfeiçoar a escola do filho.

Famílias com crianças portadoras de necessidades especiais encaram muitos desafios em sua tentativa de tornarem-se

envolvidas na educação e nas escolas de seus filhos. Para estas famílias, o envolvimento requer muito mais tempo e energia do que para famílias com filhos sem necessidades especiais. Mas todas as escolas devem lutar pelo envolvimento de pais de todas as famílias, pois a escola, a família e as parcerias comunitárias podem ajudar as crianças a obter sucesso na escola e na vida. Relacionamentos colaborativos entre os pais, escolas e as comunidades podem aprimorar o clima e os programas escolares, podem fornecer conexões e apoios às famílias, podem elevar as habilidades dos pais e podem ajudar no apoio aos professores. Os maiores benefícios da escola, da família e das parcerias comunitárias, entretanto, é que as parcerias podem ajudar as crianças a ter sucesso na escola e na vida.

Para mais informações e apoio em ter um papel mais ativo na educação de seu filho, bem como para aprender a criar parcerias de sucesso com sua escola, ligue para a Federação no tel. 1-800-331-0688.

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## Prácticas efectivas para la participación de las familias de niños con discapacidades en las escuelas

(Lea todo el artículo en la Web en [www.fcsn.org](http://www.fcsn.org))

Más de treinta y cinco años de investigaciones afirman que cuando las familias participan en la educación de los niños, hay resultados positivos en los logros de los niños y beneficios positivos en las escuelas. Aunque la mayoría de este estudio no se dirigió específicamente a la participación de los padres de familia en la educación de sus niños con discapacidades, hay evidencia que demuestra que los niños con discapacidades, que tienen padres de familias participando en su educación tienen más éxito en la escuela que sus compañeros que no tienen los padres de familias participando. Entre más pronto participen los padres de familia, mayor serán los beneficios para los niños.

La Ley de Educación para los Individuos con Discapacidades de 1997 provee garantías procesales para los padres de familia pero no facilita las asociaciones entre familias y escuelas y muchas escuelas fallan en darle participación en la educación a las familias de niños con discapacidades. De todas maneras, el Congreso, a través de la Ley de Educación Elemental y Secundaria requiere que las escuelas que reciban dineros del Título I construyan asociaciones con las familias y la Ley de Educación Elemental y Secundaria, ahora reautorizada como la Ley Que Ningún Niño se Quede Atrás del 2001, tiene un énfasis renovado en asociaciones con las familias.

La Dr. Joyce Epstein del Center on School, Family, y Community Partnerships en Johns Hopkins University, creó un modelo que amplía la discusión acerca de las asociaciones con la familia. Sus investigaciones muestran que la participación de las familias toma muchas formas y cualquier participación de la familia beneficia tanto los resultados educativos como las relaciones con las escuelas. El modelo incluye asociaciones como: siendo padres, comunicándose, voluntarios, aprendiendo en la casa, tomando decisiones, colaborando con la comunidad.

La Dra. Mavis Sanders, otra investigadora en Johns Hopkins, apoya el modelo de la Dra. Epstein's y reconoce que hay obstáculos que impiden la creación de oportunidades para la participación de las familias de niños con discapacidades, pero creando asociaciones

exitosas es generalmente lo mismo para todas las familias, aunque el niño tenga o no una discapacidad.

Usando el modelo de la Dra. Epstein los padres de familia, Directores de las escuelas, educadores especiales, Directores de educación especial, abogados de educación especial e investigadores ofrecieron ejemplos de prácticas efectivas para facilitar y apoyar el compromiso de las familias de niños con discapacidades en la educación de sus niños a través de una gran cantidad de actividades.

La Dra. Sanders describe como la escuela elemental Lois T. Murray Elementary en Baltimore, Maryland da poder a las familias y comunidades a formar asociaciones en la educación de los niños con discapacidades: "Me impresionó bastante que El Equipo Activo de las Asociaciones, es responsable por la planeación e implementación del programa de asociaciones. El equipo estaba formado de padres de familia, abuelos, profesores, padres y profesionales, el Director y el Vice-Director y la trabajadora social. También me impresionó la variedad de actividades ofrecidas y el cuidado, conocimiento y sensibilidad que se tomó en la planeación e implementación de estas actividades. La escuela también hizo un buen trabajo en la evaluación de las actividades y en hacer mejoras y los cambios necesarios. La experiencia me enseñó mucho sobre las posibilidades de las asociaciones

para los estudiantes con discapacidades." El Dr. William Henderson es el Director de la escuela elemental Patrick O'Hearn School, en Dorchester, Massachusetts. Bajo el liderazgo del Dr. Henderson la escuela O'Hearn ha llegado a ser totalmente inclusiva, reconocida en el ámbito nacional por su alto rendimiento académico. Los estudiantes en educación regular, estudiantes con necesidades especiales y estudiantes considerados genios y talentosos aprenden juntos y aprenden el uno del otro.

El Director Henderson está de acuerdo con los estudios que dicen que la participación de los padres de niños con discapacidades debe ser definida ampliamente. Él ha tenido éxito en su escuela con la participación de las familias en todas las categorías que describe la Dra. Epstein. Un programa en particular que ha tenido mucho éxito envuelve el aprendizaje de lectura en la casa donde los padres son verdaderos asociados en la educación de sus niños. Más del 95% de los niños de la escuela O'Hearn, incluyendo los niños con discapacidades leen en la casa cuatro veces en la noche cada semana. Ese número es el doble del número de los estudiantes que participaron hace muchos años cuando el programa empezó. Los resultados de los exámenes se han elevado y la escuela O'Hearn pasó de tener un bajo rendimiento a tener un alto rendimiento.

Además de apoyar el aprendizaje en la casa el Dr. Henderson crea oportunidades para la toma de decisiones. Él continuamente anima a las familias a participar en invitar más familias a la escuela, los programas de leer en la casa o en facilitar reuniones de comités. El pregunta: "Cómo se puede dar valor a las familias en posiciones de liderazgo? Él escucha a los padres, celebra los éxitos de los niños y

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celebra la diversidad que las familias traen a la comunidad de la escuela.

La investigadora y profesora de educación especial, Beverly Mattson, esta de acuerdo que la participación de los padres de familia tiene que ser diseñada para las necesidades de cada familia "Yo pienso que es importante que cada escuela identifique cuando y como los padres de familia desean participar: por teléfono, grupos con un enfoque con otros padres de familias o haciendo encuestas. Yo encontré que hay muchas cosas en las cuales los padres de familia pueden participar". Como por ejemplo, la Señora Mattson reconoce que el aprendizaje en la casa va mas allá de la tarea escolar. Las habilidades para el diario vivir y para el comportamiento frecuentemente necesitan ser orientadas en la casa a través de asociaciones entre la escuela y la casa. La Señora Mattson describe una escuela de secundaria donde los padres identifican los obstáculos para su participación (tiempo, distancia, falta de transportación) y las estrategias para vencer los obstáculos. Como resultado de este proceso, el plan de mejoramiento de la escuela incorpora específicamente recomendaciones de los padres de familia acerca de cómo incrementar la participación de estos. Algunas estrategias incluyen: tener las comidas en y las noches sociales en las diferentes escuelas del distrito y en lugares más convenientes para los padres de familia, identificar los recursos comunitarios para cubrir las necesidades de las familias, planear reuniones que no sean durante el las horas de escuela, ofrecer clases de computadoras para estudiantes y las familias. Ella describe otra escuela, la cual contrato por tiempo completo una madre de familia que vive en el mismo barrio donde esta la escuela. Esta madre de familia que es una mediadora conoce todas las familias. La escuela tiene un 100% de asistencia de padres de familia a las reuniones de la escuela y tiene evento sociales y académicos mensualmente, tales como la Noche de Matemáticas, la Noche de Lectura, etc. Además, la escuela envía a las cases boletines mensuales que se enfocan en como los padres de familia pueden apoyar el aprendizaje de sus niños.

Diana Autin, Directora Ejecutiva de Statewide Parent Advocacy Network (SPAN) de New Jersey, y madre dice que el personal de la escuela tiene que tener cuidado de no tener una visión limitada de la participación de los padres de familia. Algunos padres de familia participaron en la educación de su niño en particular. Otros pueden desarrollar asociaciones con las escuelas al participar en talleres para padres y profesionales ofrecidos a los miembros del equipo que administran la escuela o a través de talleres de liderazgo para padres de familia. Muchos padres se

educan ellos mismos al asistir a talleres ofrecidos a través de otras organizaciones en sus comunidades.

En ambas experiencias, la Señora Autin y del Dr. Henderson encontraron que muchos padres de niños con discapacidades empiezan al aprender acerca de la educación especial, los procedimientos y los procesos y terminan con un entrenamiento avanzado sobre el tema. Estos padres de familia con liderazgo, luego llegan a participar y a servir en varios comités de la escuela y de equipos de administración. Estos padres de familia líderes con frecuencia reclutan, entrenan y apoyan a otros padres de familias.

La Señora Autin describe el éxito de Parent Leadership Development Institute a través de SPAN. Los padres de familia de niños con y sin discapacidades trabajan juntos con el personal de educación especial y regular. Este proyecto ofreció un entrenamiento de ocho secciones en la reforma escolar, ley de educación, participación efectiva de los padres de familia, liderazgo y abogacías para oficiales de PTA, Título 1 y miembros consejeros del comité de educación especial, padres de familia de la escuela en los equipos administrativos y otros padres de familia interesados en distritos urbanos. El enfoque fue en las cosas mas importantes que los padres de familia necesitan saber acerca de la educación. Los padres de familia de educación regular, quienes anteriormente creyeron en los mitos de que la educación especial tomaba cosas de la educación regular, llegaron hacer defensores de la educación regular. Los administradores también participaron y cambiaron sus practicas porque empezaron a ver a los padres de familia de una manera diferente. Mil padres de familia en 30 distritos urbanos

en todo el estado de New Jersey han participado por un periodo de tres años. Todos los miembros de Parent Advisory Councils y un tercio de administradores de la escuela han participado en este entrenamiento. Como resultado de su participación en este entrenamiento, muchos padres de familia han continuado su educación a través de ESL, GED y programas en Universidades de la comunidad. Una madre de familia dijo, que ella continua su educación porque desea ser más efectiva con su niño y con sus esfuerzos de mejorar la escuela de su hijo.

Las familias de los niños con discapacidades enfrentan muchos obstáculos a medida que ellos intentan participar en la educación de sus niños y en sus escuelas. La participación para estas familias requiere mas tiempo y energía que para las familias que tienen niños sin discapacidades. Pero todas las escuelas deben esforzarse por obtener la participación de todas las familias, porque las asociaciones entre la escuela, la familia y la comunidad puede ayudar a los niños a tener éxito en la escuela y e la vida. Las relaciones de colaboración entre padres, escuelas y comunidades pueden mejorar los programas y el ambiente escolar y puede proveer una conexión y un apoyo para las familias, puede incrementar las habilidades de los padres de familia, y puede ayudar a apoyar a los maestros. El mayor beneficio de las asociaciones entre la escuela, familia y comunidad es que estas asociaciones puedan ayudar a sus niños a tener éxito en la escuela y en la vida.

Para mas información y apoyo en como tener un papel más activo en la educación de su niño y en aprender como crear asociaciones exitosas con su escuela llame a la Federación al 1-800-331-0688.

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## Effective Practices for Involving Families

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support staff work with all children in integrated classrooms.

Principal Henderson agrees with researchers that parent involvement for families of children with disabilities should be defined broadly. He has had success at his school with parent involvement in all of Dr. Epstein's categories. One particularly successful program involved learning at home through reading where parents are true partners in their children's education. More than 95% of the children, including children with disabilities, at the O'Hearn School read at home four nights each week. That number is double the number who participated several years ago when the program started. Test scores have soared, and the O'Hearn School has gone from low performing to high performing.

In addition to supporting learning at home, Dr. Henderson creates opportunities for decision-making. He actively recruits and encourages families to participate in opportunities such as the family outreach and the home reading programs or chairing and facilitating committee meetings. He asks, "How can families in leadership positions be valued?" He listens to parents, celebrates their children's successes, and celebrates the diversity that these families bring to the school community.

Researcher and special education teacher, Beverly Mattson, agrees that parent involvement must be customized to meet the needs of any given family. "I think that it is important for each school to identify when and how parents want to be involved: by phone, focus groups with [other] parents, or questionnaires. I found that there was

a continuum of involvement for parents." As an example, Ms. Mattson recognizes that learning at home may go beyond homework. Living skills and behavior often need to be addressed at home through school-home partnerships. Ms. Mattson describes a middle-high school where parents identify challenges to involvement (e.g., time, distance, lack of transportation) and strategies to overcome challenges. As a result of this process, the school's improvement plan specifically incorporates recommendations from parents on how to increase involvement. Some of the strategies include: rotating school dinners and social nights around the school district and in more convenient locations for parents; identifying community resources to meet family needs; scheduling meetings other than during the school day; offering evening computer classes for students and families." She describes another school, which hired a full-time parent liaison from the school's neighborhood. The liaison knows every family. The school has 100% attendance for parent conferences and has monthly academic/social events, such as a Math Night, Reading Night, etc. In addition, the school sends home monthly newsletters that focus on how parents can support their children's learning.

Diana Autin, Executive Director of the Statewide Parent Advocacy Network (SPAN) of New Jersey, and a parent, commented that school staff must be careful not to have too narrow a vision of parent involvement. Some parents will be involved in their individual child's education. Others may develop partnerships with schools by participating in parent/professional training offered to members of school management teams or through parent leadership training. Many parents educate themselves by attending workshops offered through organizations in their community.

In both Ms. Autin and Dr. Henderson's experiences, they found that many parents of children with disabilities begin by learning about

the special education law, procedures, and processes and end up with advanced training. These parent leaders then become very involved in serving on various school councils and management teams. These parent leaders often recruit, train and support other parents.

Ms. Autin described the success of the Parent Leadership Development Institute through SPAN. Parents with and without children with disabilities worked together with special education and regular education staff. This project provided a comprehensive eight-session training in school reform, education law, and effective parent participation, leadership, and advocacy for PTA officers, Title 1 and special education advisory council members, parents on school-based management teams, and other interested parents, in urban districts. The focus was on the most important things parents need to know about education. General education parents, who previously bought into myths that special education took away from regular education, became special education advocates. Administrators also participated and then changed their practices because they began to view parents differently. One thousand parents in 30 urban districts across the state of New Jersey have participated over a three-year time frame. All members of the Parent Advisory Councils and one-third of school administrators have taken this training. As a result of their participation in this training, many individual parents have continued their education through ESL, GED, and community college programs. One parent says that she is continuing her education because she wants to be more effective with her child and with her efforts to improve her child's school.

Families of children with disabilities face many challenges as they attempt to become involved in their children's education and schools. Involvement for these families requires greater time and energy than for families of children without disabilities. But all schools should strive for parent involvement from all families, because school, family, and community partnerships can help children succeed in school and in life. Collaborative relationships between parents, schools and communities can improve school programs and climate, can provide connection and supports to families, can increase parents' skills, and can help support teachers. The greatest benefit of school, family, and community partnerships, however, is that partnerships can help children succeed in school and in life.

For information and support in taking an active role in your child's education, and to learn how to create successful partnerships with your school, call the Federation at 1-800-331-0688.

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# Needs Assessment Survey

**Parents: Your input is important! • Pais: Sua Participação é importante • Padres: Su opinión es importante**

## Help us to help you!

The Parent Training and Information Center at the Federation is interested in learning about your experiences with special education in Massachusetts. We are conducting an assessment of the training and information needs of parents and families to assist us in planning and creating activities that will more effectively serve families. Please send your responses to: **The Federation for Children with Special Needs, 1135 Tremont St., Suite 420, Boston, MA 02120** or participate on-line at [www.fcsn.org](http://www.fcsn.org). The deadline is April 30, 2004. Thank you for your time and responses.

## Ajudem-nos a ajudá-los!

O Centro de Treinamento e Informações dos Pais da Federação está interessado em aprender sobre a sua experiência com educação especial em Massachusetts. Estamos conduzindo uma enquete sobre as necessidades de treinamento e informação de pais e famílias para auxiliar-nos no planejamento e criação de atividades que servirão mais efetivamente às famílias. Por favor, envie suas respostas para: **The Federation for Children with Special Needs, 1135 Tremont St., Suite 420, Boston, MA 02120** ou participe on-line no [www.fcsn.org](http://www.fcsn.org). Até 30 de abril de 2004. Obrigado pelo seu tempo e por suas respostas.

## ¡Ayúdenos a ayudarle!

El Centro de Entrenamiento e Información para Padres de Familia en la Federación esta interesado en conocer las experiencias que ustedes han tenido con la educación especial en Massachusetts. Estamos haciendo, evaluaciones sobre las necesidades de entrenamiento e información de las familias, para que nos ayuden en la planeación y creación de actividades que le servirán mas efectivamente a las familias. Por favor envíe sus respuestas a: **The Federation for Children with Special Needs, 1135 Tremont St. Suite 420, Boston, MA 02120** o participe en la Web [www.fcsn.org](http://www.fcsn.org). Envíe sus respuestas antes del 30 de abril del 2004. Gracias por su tiempo y sus respuestas.

## Background Information / Informações Básicas / Información sobre usted:

- Are you a: (check all that apply)
  - Você é: (assinale tudo o que aplicar)
  - Es usted un: (Marque todas las que se refieran a usted)
    - Parent/Pai/Padre
    - Professional/Profissional/Profesional
    - Student with special needs/Aluno com necessidades especiais/Estudiante con necesidades especiales
- How do you identify your ethnicity?
  - Como você identifica a sua etnicidade?
  - ¿Cómo identifica su raza?
    - African American/Afro-americano/Afro-Americano
    - Asian/Asiático/Asiático
    - Hispanic/Hispanico/Hispano
    - Native American/Nativo-americano/Índigena
    - White/Branco/Blanco
    - Portuguese speaking/Falante de Português/Português
    - Other/Outro/Otro: \_\_\_\_\_
- Where in Massachusetts do you live?
  - Onde você mora em Massachusetts?
  - ¿En que parte de Massachussets vive?
    - Metrowest/Oeste Central  Boston  Central/Centro
    - West/Oetse  Southeast/Sureste  Northeast/Noreste
- If you are a parent, how old is your child with a disability?
  - Se você é mãe (ou pai), quantos anos tem seu filho com deficiência?
  - Si usted es un padre de familia, ¿Cuántos años tiene su niño con discapacidades?
    - 0-2  3-5  6-11  12-14  15-18  19-22+
- Which disability best describes your child's?
  - Qual é a melhor descrição da debilidade de seu filho(a)?
  - ¿Qué discapacidad tiene su niño?:

- Does your child qualify for the free or reduced school lunch program?
  - O seu filho se qualifica para o programa de lanche gratuito ou de custo reduzido na escola?
    - ¿Califica su niño para el programa de almuerzo gratis o con un costo menor?
      - No/Não/No  Yes/Sim/Si

**IDEA (the federal special education law) requires that Individualized Education Program goals should be measurable (in other words, you should be able to document student progress at agreed upon points in time).**

**IDEA (a lei federal de educação especial) demanda que os objetivos do Programa Educacional Individualizado deve ser mensurável (em outras palavras, você deve estar apto a registrar o rendimento do aluno, conforme o acordo, com o passar do tempo).**

**IDEA (la ley de educación especial) requiere que las metas del Programa Educativo Individualizadas sean medibles (en otras palabras, usted puede documentar el progreso del estudiante y estar de acuerdo sobre cuando se le deben enviar los informes sobre el progreso).**

- To what degree do you think the goals in your child's IEP measureable?
  - Em que grau você entende que os objetivos do IEP de seu filho são mensuráveis?
    - ¿Cree usted que las metas del IEP de su niño son medibles?
      - Not at all/Nenhum/No  Somewhat/Um pouco/En parte
      - Almost all/Quase tudo/Casi todas  Don't know/Não sei/No sé
- To what extent do you think your child's IEP goals are being implemented?
  - Em que extensão você acha que os objetivos do IEP de seu filho estão sendo implementados?
    - ¿Cree usted que las metas del IEP de su niño se están implementando?
      - Not at all/Nenhum/No  Somewhat/Um pouco/En parte
      - Almost all/Quase tudo/Casi todas

**IDEA requires that all students have meaningful access to the general education curriculum.**

**A lei IDEA exige que todos os alunos tenham acesso significativo ao currículo geral de educação.**

**IDEA requiere que todos los estudiantes tengan un acceso significativo al currículo de educación general.**

**Parents: Your input is important! • Pais: Sua Participação é importante • Padres: Su opinión es importante**

9. How often is your child given the opportunity to participate in the general education curriculum?
- Com que frequência o seu filho tem a oportunidade de participar do currículo geral de educação?
  - ¿Cada cuanto tiene la oportunidad su niño de participar en el currículo general?
    - Never/Nunca/Nunca
    - Sometimes/Algumas vezes/Algumas veces
    - Frequently/Freqüentemente/Frecuentemente

**IDEA requires schools to provide Parents with information about the support services and accommodations your child may need to participate in the MCAS testing system.**

**A lei IDEA exige que as escolas forneçam informações aos Pais sobre os serviços de apoio e adaptações que sua criança possa precisar para participar do sistema de testes do MCAS.**

**IDEA requiere que las escuelas ofrezcan a los padres de familia información acerca de los servicios de apoyo y las acomodaciones que sus niños pueden necesitar para participar en el sistema de evaluación del MCAS.**

10. Overall, how satisfied were you with the information your school provided on these topics?
- Em geral, você ficou satisfeito com as informações que a escola lhe forneceu sobre estes tópicos?
  - ¿En general, esta usted satisfecho con la información que le dio la escuela sobre estos temas?
    - Not at all/Nada/No     Somewhat/Um pouco/En parte
    - Very/Muito/Mucho     Information was not provided/ Nenhuma informação foi fornecida/No me dieron información

**IDEA requires that schools make every effort to include parents in Team meetings.**

**A lei IDEA requer que as escolas façam todos os esforços para incluir os pais nos Team meetings (Reuniões da Junta).**

**IDEA requiere que las escuelas hagan el esfuerzo de incluir a los padres de familia en las reuniones de Equipo.**

11. Did you attend your child's last IEP meeting?
- Você compareceu na última reunião do IEP de seu filho?
  - ¿Asistió usted a la última reunión del IEP de su niño?
    - Yes/Sim/Sí     No/Não/No
    - If not, why not?/Se não, por que não?/Si es no, ¿porque?

**IDEA requires effective transitions out of Early Intervention services by age 3.**

**A lei IDEA exige transições efetivas a partir dos serviços de Intervenção Infantil (Early Intervention) aos 3 anos de idade.**

**IDEA requiere servicios efectivos de transición fuera de la Intervención Temprana a la edad de 3 años.**

12. If your child (within the last 18 months) transitioned from Early Intervention services, how would you describe the experience?
- Se sua criança (dentro dos últimos 18 meses) fez a transição dos serviços de Early Intervention, como você descreveria esta experiência?
  - ¿Si su niño (durante los últimos 18 meses) ha pasado por la transición de los Servicios de Intervención Temprana, como describiría esta experiencia?

Not smooth/Não suave/Difícil    1   2   3   4   5   Smooth/Suave/Fácil

Please describe/Descreva, por favor/Por favor describa:

**IDEA requires that students, 14 years and older, must be involved in transition planning for appropriate post-school experiences.**

**A lei IDEA exige que os alunos com 14 anos ou mais devem se envolver no plano de transição para as experiências apropriadas pós-escola.**

**IDEA requiere que los estudiantes de 14 años y más, tienen que estar participando en la planeación de una transición apropiada para después de la escuela.**

13. If age 14 or older, did your child attend his/her last IEP/transition meeting?
- Sua criança, com 14 ou mais, compareceu na última junta de transição do IEP?
  - ¿Si su hijo/a tiene 14 años o más, asistió
    - No/Não/No     Yes/Sim/Sí     Don't know/Não sei/No sé
    - Not yet 14/Não tem 14/Todavía no tiene los 14

**The law also requires that transition planning include instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and a functional vocational evaluation.**

**A lei também exige que o plano de transição inclua a instrução, os serviços relacionados, experiências comunitárias, o desenvolvimento do emprego e outros objetivos pós-escola e da vida adulta, e, quando apropriado, a aquisição das habilidades diárias do viver, assim como uma avaliação vocacional funcional.**

**La ley también requiere un plan de transición que incluya instrucción, servicios relacionados, experiencias en la comunidad, el desarrollo de empleo y otros objetivos para la vida adulta después de la escuela y cuando sea apropiada la adquisición de las habilidades para la vida diaria y una evaluación vocacional.**

14. If your child is 14 or older, does his/her IEP include goals that address needed transition services in order to prepare for success after school (i.e. community awareness, on the job training, college classes, employment supports)?
- Se seu filho tem 14 ou mais, o seu IEP inclui os objetivos que endereçam os serviços de transição necessários para prepará-lo para o sucesso depois da escola (i.e. consciência comunitária, treinamento no trabalho, aulas na faculdade, apoios no emprego)?
  - ¿Si su niño tiene 14 años o más, incluye su IEP metas que respondan a sus necesidades de servicios de transición para prepararlo para el éxito después de la escuela? (Por ejemplo concientización comunitaria, entrenamiento en el trabajo, clases en la Universidad, apoyos para empleo?
    - No/Não/No     Yes/Sim/Sí     Don't know/Não sei/No sé
    - Not yet 14/Não tem 14/Todavía no tiene los 14

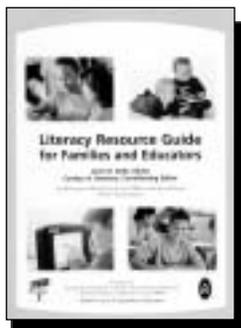
15. What information could the Federation provide that would help you support your child's success in school?

- Quais as informações que a Federação poderia fornecer que o ajudaria a dar apoio para o sucesso de seu filho na escola?
- Que información le puede ofrecer la Federación que le ayude a apoyar el éxito escolar de su niño?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

**Thank You! • Obrigado! • ¡Gracias!**

# Federation Publications Catalog

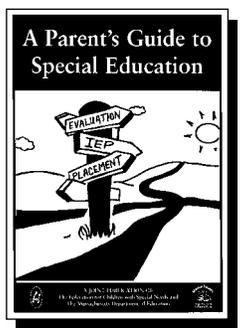


## Literacy Guide for Families & Educators

The Literacy Resource Guide for Families and Educators highlights current research-based literacy resources available through the U.S. Department of Education and its funded projects with an eye toward appealing to parents, educators, and caregivers.

The Guide lists whether the resources are available in print, online, CD-rom, and videotape. The description of each item also includes information about cost (many are free!), ordering (including bulk copies), and the relevance for specific audiences (e.g., older students, students with disabilities, and English-language learners). Bold symbols denote resources that address one or more of the five key early reading skills: phonemic awareness, phonics, vocabulary, reading comprehension, and fluency.

52 pages. 2003. Special! \$10 includes shipping & handling.



## A Parents' Guide to Special Education

The Guide contains the most current and accurate information available regarding the special education system in Massachusetts.

The Federation hopes that this publication will assist families in obtaining the supports and services that their children with disabilities need to succeed in school. The Guide is

also an excellent resource for schools and service providers seeking concise, easy-to-read guidance on the implementation of the state's new special education laws, regulations, and policies.

36 pages. 2001. First copy free; each additional copy \$10.00. Bulk discounts available.

**NOW AVAILABLE**



## Guia dos Pais Sobre Educaçao Especial

Esta Guia contém a informação mais atual e correcto disponível sobre a sistema de educação especial em Massachusetts.

A Federação espera que esta publicação ajudará famílias obter apoios e serviços que seus filhos com deficiências precisam de ser sucedidos na escola. Est Guia também é um recurso excelente para escolas, e provedores de serviços procurando conselho preciso e facil de

compreender sobre a implementação das novas leis do estado de educação especial, regulações, e política.

40 páginas. 2001. Primeira cópia gratis; cada cópia adicional \$10.00. Descontos disponíveis.



## Guía para los Padres de Familia sobre los Servicios de Educación Especial

Esta Guía contiene la información más reciente y actualizada sobre el sistema de educación especial en Massachusetts.

La Federación espera que esta publicación ayude a las familias a obtener los apoyos y servicios que sus niños con discapacidades necesitan para tener éxito

en la escuela. La Guía también es un excelente recurso para las escuelas y los proveedores de servicios que buscan una guía concisa y fácil de leer para la implementación de las nuevas leyes, reglamentos, y pólizas del estado sobre educación especial.

40 páginas. 2002. La primera copia es gratis, cada copia adicional cuesta \$10.00. Se hará un descuento a los pedidos de cantidades grandes.

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# Bulletin

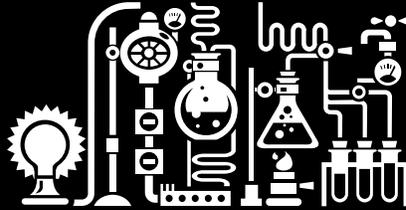
Parents Learning About Children's Education

The Massachusetts Statewide Parent Information & Resource Center (PIRC)

Available online in English, Spanish, and Portuguese at [www.pplace.org](http://www.pplace.org)



## Parents, your involvement matters... IN SCIENCE, TOO!



*As a parent, you are your children's first and most influential teacher. Your support can enhance their success in science, as well as other areas. How to begin? Here are some tips to guide your involvement:*

**1. Set the example.** One of the most important ways parents can help is by expressing how much they value learning. Share your science-related interests with your children.

**2. Become interested in your children's science interests.** Find out what your children enjoy about science. Fuel these fires. If they like dinosaurs, read dinosaur books, discuss dinosaurs, construct dinosaur models, and visit museums to see dinosaur fossils and models. Being excited about your children's science interests and school work can spark their further quests for knowledge.

**3. Help children see the science around them.** Help children recognize the science in everyday life. Play games and choose activities that help them become familiar with science concepts and scientific thinking.

**4. Help children observe objects carefully.** Learning to look carefully is an important first step toward forming scientific explanations. Noticing and identifying the characteristics of objects and living things can help children learn how to classify or group things based on their characteristics.

**5. Encourage children to ask questions.** No one knows all the answers. Learning to ask questions, propose answers, and test them out are keys to learning in all academic disciplines.

**6. Listen to children's ideas and explanations.** Being listened to gives children confidence. Expressing their ideas helps them sort out what they know and don't know.

**7. Introduce your children to stimulating environments.** Oceans, swamps, parks, airports, and even kitchens, bathrooms, and backyards are good places to observe and discuss science. Look for situations that encourage playful exploration, a natural way to learn. Toys can also spark discovery and learning. It's not the number of toys that is important, but the kind of toys. Children develop better skills if their toys are varied and educational. The more things a child can do with a toy, the more likely it is to be educational.

**8. Seize the teachable moments.** Your child sees a beautiful tulip flower in the spring and asks about it. Use that question as a chance to discuss flowers and bulbs. You can follow up by planting bulbs or flower seeds in the garden or in the house and watching them grow. Life at home is full of teachable moments that classroom teachers can only dream about. You can use these moments to help your children become fascinated with science.

*Parents' PLACE is pleased to welcome Evelyn Nellum as our new Co-director!*



Evelyn brings a wealth of knowledge and experience in program administration as well as early childhood development and learning. Her commitment to children and families has energized all her work, from volunteer efforts to directing early childhood programs for homeless families. Evelyn has her B.A. from the Boston College School of Education and has attended Wheelock College's Master's Program in Early Intervention.

We are excited to be working with Evelyn as we move forward in year one of our new Parents' PLACE PIRC grant.

**9. Provide hands-on experiences.** Give children the chance to do science. The best way to develop children's understanding of how science works is through hands-on science experiences while having conversations about what is happening. Not only are hands-on experiences a great way to learn, but they are also a great way to get children

continues on page 17

**Parents' PLACE** is a project of the  
 Federation for Children with  
 Special Needs  
 1135 Tremont St., Ste. 420  
 Boston, MA 02120  
 (877) 471-0980 • [www.pplace.org](http://www.pplace.org)



## Myths about Science

*Parental involvement is important in all subjects. But many parents may feel particularly intimidated about helping their children with science. Clearing up some popular myths about this subject should show that all parents have the skills to help their children learn science.*

### Myth #1: Science is Difficult.

Really, science is not just about knowing a lot of facts and figures, but is a way of seeing the world and solving problems.

### Myth #2: You need to know a lot about science to teach it to your children.

Not true! Saying 'I don't know; let's find out together' is actually better than giving answers.

### Myth #3: Science Requires Equipment.

Actually, science is everywhere, and the best way to begin is through conversation and asking open-ended questions.

### Myth #4: Science skills should wait for reading skills.

The developmental skills of preschool children are actually more suited to doing science than reading. Learning about science also can motivate children to read.

*Adapted from "Helping Your Child With Science," by David L. Haury & Linda A. Milbourne, ERIC Clearinghouse for Science, Mathematics, and Environmental Education, March, 1999 (Updated June 2003). For more information, call Parents' PLACE and ask for a complete copy of this publication.*

## Getting Familiar with the Standards

In Massachusetts, the education standards are known as "Curriculum Frameworks." These standards describe what all students should know and be able to do as a result of their education. Schools and districts use them as the "framework" for what they will teach each year—the curriculum. Then, the statewide tests known as

MCAS (Massachusetts Comprehensive Assessment System) are set up to test how well students have learned the standards. Below is an example of a standard for grades pre-k to 2 taken from the Massachusetts "Science and Technology/ Engineering Curriculum Framework," May 2001.

**Strand 1:** Earth & Space Science, Grades PreK–2

**Learning Standard #1.** Recognize that water, rocks, soil, and living organisms are found on the earth's surface.

**Ideas for Developing Investigations and Learning Experiences:**

Walk around the playground observing and discussing where water, rocks, soil, and living organisms are found.

**Additional Activity:** Use a hand lens to observe and describe the components and properties of a sample of soil, e.g., color, texture, presence or absence of clumps, etc. Extend the examination to moist topsoil.

## Parents, your involvement...

continued from page 16

excited about science. Science begins for children when they discover that they can learn about the world through their own actions, such as blowing soap bubbles, or adding a block that causes a structure to collapse.

The best way to tell if an activity is appropriate for a child is to see if the child is interested while doing it. Activities should challenge, but not overly frustrate. Concrete experiences that require children to use their senses, such as planting and watching a seed germinate, give a strong framework for abstract thinking later in life.

**10. Bridge from the media.** Movies, television specials, magazines, newspapers, books, and computer

programs frequently present science-related topics. Talk with your children about the science they encounter: What interested them? What did they learn?

By encouraging your children to think about and interact with the world around them, by providing opportunities for hands-on experiences, and by talking with them about science, your children will develop a firm foundation in science.

*Adapted from "Helping Your Child With Science," by David L. Haury & Linda A. Milbourne, ERIC Clearinghouse for Science, Mathematics, and Environmental Education, March, 1999 (Updated June 2003), and "Doing Science With Your Children," by Peter Rillero, ERIC Clearinghouse for Science, Mathematics, and Environmental Education, EDO-SE-94-1, June 1994. For more information, call Parents' PLACE and ask for a complete copy of these publications.*



## 2004 Summer Camp Guide—A Listing of Day and Residential Summer Camp Programs

The Federation's annual *Summer Camp Guide* is now available! The *Guide* provides information on more than 80 day and residential summer camps, plus a listing of local community resources.

It provides guidelines for selecting a camp, and suggestions for including children with special needs in regular camps.

56 pages. \$7.00.

Use the form on page 15 to order The *Guide*.

*Parents' PLACE Bulletin* is funded by the U.S. Department of Education, Office of Innovation and Improvement, Grant #U310A030443. The views and opinions herein do not necessarily reflect the views or policies of the U.S. Department of Education or of the Federation for Children with Special Needs.

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## Health News

at the Federation for Children  
with Special Needs

### From Mass Family Voices

For the past year, Massachusetts Family Voices activities have been funded by the Center for Health Care Strategies in Lawrenceville, NJ through a grant to the Federation for Children with Special Needs. Massachusetts Family Voices worked in partnership with Massachusetts Medicaid Managed Care Organizations to build capacity for family partnerships with these types of health care insurance plans. The result of this collaboration was the creation of family-friendly informational articles and brochures specifically designed to address the unique needs of families of children and youth with special health care needs. Our four Medical Managed Care Organization partners distributed these materials in their consumer newsletters, on their websites, and case managers gave the publications directly to families.

### From MassCARE

MassCARE is a statewide program for women, children, youth, and families living with HIV. If you, your child, or someone else you care for is HIV positive, MassCARE can help. We offer supportive services, access to medical care, case management, and participation in the Family Advisory Network (FAN).

We have some exciting news about MassCARE activities, aimed to support the families we serve:

**MassCARE Conference:** This conference is a consumer-led event that features educational workshops and a support system for adults and teenagers. This event will be held at the Holiday Inn in Worcester on June 25, 2004.

**Family Networking Day:** This is an opportunity for infected/affected families to meet, interact, and gain support from each other. The date for this activity will be announced.

**Family Advisory Network Meetings:** The FAN meets on the fourth Friday of each month. Agendas for these meetings range from planning of consumer activities to educational workshops and family-to-family support.

For more information about any MassCARE activity, please contact Debbie Gilbert at 508-992-6553 or Sara Miranda at 1-800-331-0688, x 186.

**1. Does Your Child Have Special Health Care Needs?** Children don't have to have a medical diagnosis to have special health care needs. This article provides questions for families to consider and emphasizes the relationship between the family and the child's primary care physician.

**2. There's No Place Like [A Medical] Home.** This article introduces the Medical Home concept—a way for families to work in partnership with health care and community providers.

**3. Medical Testing & Children with Special Health Care Needs: A Guide for Families.** Helps families understand why doctors recommend medical tests, and provides a brief explanation of the types of medical tests. Includes questions families may want to ask about the tests, and tips for preparing a child for medical testing.

**4. Prescription for Success: Managing Prescription Medications for Children & Youth with Special Health Care Needs.** Lists questions to ask about prescription medications, provides suggestions about managing multiple medications, and tips for teaching a child to manage his/her own medications.

**5. Massachusetts Resources for Families of Children with Special Health Needs.** Families of children with special health care needs have lots of questions. This guide, presented in question and answer format, helps families identify services and supports.

**6. The Individualized Health Care Plan:** Keeping Children with Special Health Care Needs Safe at School (see box).

These materials are available to families and to professionals to use with families. Each brochure includes links and/or toll-free numbers families can visit or call for more information. Many of these articles may be downloaded from the Mass Family Voices website at [www.massfamilyvoices.org/MFVIR/articles.html](http://www.massfamilyvoices.org/MFVIR/articles.html). You may also request copies by e-mailing [massfv@fcsn.org](mailto:massfv@fcsn.org) or calling 1-800-331-0688, ext. 210. Leave a message; your call will be returned.

Additional information about resources and supports for families of children and youth with special health care needs can be found in a series of "Tip Sheets" created by the Massachusetts Department of Public Health Care Coordination Program. These are posted at [www.massfamilyvoices.org/resources/dph.html](http://www.massfamilyvoices.org/resources/dph.html).

### The Importance of an Individualized Health Care Plan

Due to advances in medical knowledge and technology, more and more children with special health care needs are able to attend school. An Individualized Health Care Plan, or IHCP, helps ensure your child's medical needs will be met during the school day. Even if a child has an Individualized Education Program (IEP) and/or 504 Accommodation Plan, if the child has special health care needs, he or she should also have an IHCP.

The most important part of developing an IHCP is good communication between parents and the school. The school nurse is usually the liaison between the school and the family. Work with the nurse to devise a communication method that best meets both your needs. This may include phone calls, written notes, e-mails or face-to-face meetings. Be prepared to sign waivers, as the nurse may want to consult your child's physicians to: ask questions, obtain medical orders, and get documentation about your child's health care needs.

The nurse will also meet with the child's teachers. Parents are welcome at these meetings. Depending on the child's age and condition, he or she may also want to

attend. It can be reassuring for teachers to meet your child in person instead of just learning about their medical diagnosis. If your child cannot attend the meeting, bring a photograph or tell a story that illustrates your child's personality and strengths.

The IHCP should include:

- Information about your child's health, including baseline vitals.
- Medications.
- The person who will be responsible for monitoring any issues related to your child's special health needs during the school day, on field trips and while being transported to and from school.
- Regular medical care/monitoring/procedures your child needs during the school day and the person who will deliver this care.
- Interventions and procedures to follow in the event of an emergency.
- Special procedures or accommodations to follow in the event of fire drills, fires or other building emergencies.
- Contact information for your child's physicians.
- Consents for treatment.
- Any special transportation needs.

## News from Family TIES

Family TIES of Massachusetts is a parent-run, statewide information and support network for families of children with special needs. We provide information, resources and referrals as well as parent-to-parent support, and trainings to support families. Family TIES is a project of the Federation for Children with Special Needs, supported by the Massachusetts Department of Public Health (DPH), Division for Special Health Needs.

**STAFFING UPDATE:** On January 5th, Family TIES welcomed Lisa Mayer as the new Metrowest Coordinator. Many people may recall that Lisa was the Metrowest Coordinator for the Early Intervention Parent Leadership Project, and she was a parent presenter for the Early Intervention Training Center. You may reach Lisa at the DPH office in Canton at 1-781-774-6609.

### **PROGRAM UPDATE: Family TIES Parent-to-Parent Program**

Joanne Spencer is now overseeing the Family TIES Parent-to-Parent Program. With this change, we offer much-deserved words of appreciation to Mary Lee Gupta, who has managed these activities since June 2003. In her new role, Joanne will coordinate requests for Parent-to-Parent matches and support. You may reach Joanne at the DPH office in Canton at 1-781-774-6740.

### **WHAT IS PARENT-TO-PARENT SUPPORT?**

When you have a child with a disability or chronic illness, you often feel very much alone. The mission of the Parent-to-Parent program is to match you with a more experienced parent who has a child with the same or similar disability or the same issue that you are facing with your child. It is a chance to connect with someone who will listen, share some of his or her own story, provide information from personal experience, and offer emotional support while respecting confidentiality, culture and individual differences. It is a chance to talk to someone else that has "been there" and to realize that you are not alone in your experiences with your child.

Family TIES coordinators are all parents of children with special needs and have come to this job because we have experienced the power of parent-to-parent support in our own lives. We appreciated parent-to-parent support, especially when we were first facing the news of our child's diagnosis and along the way also, as we faced obstacles and crises with our children. We have developed a database of volunteer Family TIES Support Parents. These parents have either been trained by Family TIES, or have had previous experience and training to provide this unique type of support.

You can request a Parent-to-Parent match by calling Joanne Spencer, the Family TIES Parent-to-Parent and Outreach Coordinator at 1-781-774-6740, through the link on our website at [www.massfamilies.org](http://www.massfamilies.org), or by e-mailing [famtiesp2p@fcsn.org](mailto:famtiesp2p@fcsn.org). You may also request a match by leaving a message on the Family TIES toll free line at 1-800-905-TIES (8437). We will contact you and discuss what would be most helpful in a match, and get your written permission to make a match. Once we have your permission, we will search for a parent match and then contact you to let you know the name of the Support Parent who will be calling you. In our Family TIES Parent-to-Parent program, you will receive two phone calls from a Family TIES Support Parent within two weeks of our making the match. If for any reason the match does not suit you, let us know and we will try again.

### **Consider becoming a Family TIES Support Parent!**

If you feel that you are at a point in your life where you might enjoy volunteering to provide this kind of support to other parents, please contact Joanne Spencer at 1-781-774-6740 or e-mail [famtiesp2p@fcsn.org](mailto:famtiesp2p@fcsn.org). Being a Support Parent is a very rewarding experience. Typically we will call you a few times a year to be a match, and you can let us know if it is not a good time for you. If providing this kind of support is new to you, we can offer a two-hour training, at your convenience. If you already have some training and experience in this area, we can simply do a brief orientation on the phone.

## New Family Voices Project

Family Voices staff at the Federation for Children with Special Needs is leading a new project focused on healthy lifestyles for families of children with special health care needs. Family Voices was awarded a three-year grant from the Centers for Disease Control and Prevention. The project, "**Family Matters: Using Bright Futures to Promote Health and Wellness for Children with Disabilities,**" will be conducted with research partners at the Department of Family Medicine & Community Health at Tufts University School of Medicine in Boston.

Barbara Popper is the Project Director; Betsy Anderson and Lindsey Pope are Project Coordinators. The Advisory Committee for the

grant recently met in Boston and discussed ways of increasing the ability of families to receive and utilize health promotion messages and to implement health and wellness activities for their children with disabilities. We will be using the Bright Futures guidelines and the Family Voices Bright Futures for Families materials ([www.brightfuturesforfamilies.org](http://www.brightfuturesforfamilies.org)) as the basis of our study to help address some of the challenges and issues that families face in implementing health and wellness activities for their children. Massachusetts is one of five states that will participate in the research activities along with Vermont, New Jersey, Louisiana and Washington. For further information contact Barbara at the Federation at [bpopper@fcsn.org](mailto:bpopper@fcsn.org).

## NewsLine

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*NewsLine* is a quarterly publication of the Federation for Children with Special Needs, 1135 Tremont St., Ste. 420 Boston, MA 02120.

*NewsLine* is supported in part by grants from the U.S. Department of Education. The views and opinions herein do not necessarily reflect views or policies of the U.S. Department of Education, or of the Federation for Children with Special Needs. Ads herein do not constitute endorsement by the Federation for products, services, or organizations.

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## 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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