



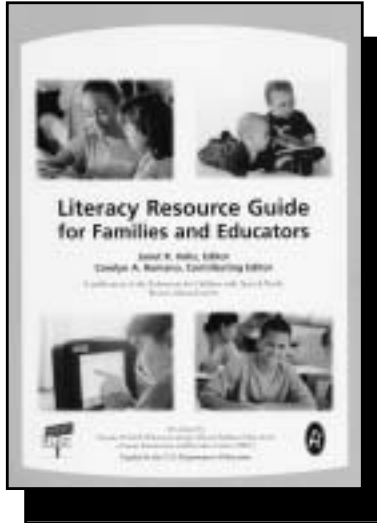
NewsLine

Volume 24, Number 2&3, Fall 2003

Double Issue!

The Federation for Children with Special Needs

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Introducing the Federation's Literacy Resource Guide

"A friend who is a teacher says, 'Reading is the new civil right.' A child who can read is a child who can dream about the future...and make that dream come true."

— First Lady Laura Bush at the Early Childhood Cognitive Summit, Little Rock, Arkansas, April 30, 2002

"...all excellence in education starts with making sure every single child, no matter where he or she lives, can read. And that's what's going to happen in the United States of America."

— President George W. Bush at the Read-Patho Elementary School, New Smyrna Beach, Florida, October 17, 2002

MassCare & Senator Kennedy at Voices 2003



Fernanda Gudiño-Valentin, MassCARE Coordinator of Family Support Initiatives, presented an award of appreciation to Senator Edward Kennedy at Voices 2003, the ninth annual conference of the AIDS Alliance for Children, Youth and Families in Washington, DC. MassCARE is a Federation project that is supported by the Massachusetts Department of Public Health. MassCARE provides support to families and children who are infected with and/or affected by HIV/AIDS.

It is with great pleasure that The Federation for Children with Special Needs publishes this *Literacy Resource Guide for Families and Educators*. The Federation, through its PEER (Parents Engaged in Education Reform) Project and through Parents' PLACE (Parents Learning About Children's Education)¹ has been involved in producing and disseminating research-based literacy materials over the past five years. The basic idea underlying all of our literacy efforts is well stated by Mrs. Bush in the above quotation. We firmly believe that *all* children have a right to quality reading instruction. This right belongs equally to all students, including those with disabilities and those who are English-language learners.² The right to the opportunity to learn to read also means that students, from the earliest years right through high school, deserve to be taught based on methods of instruction that have *proven to be effective*.

Recently, enormous attention and research have been devoted to finding out just what does work in teaching children to read. These intensive research efforts have produced groundbreaking results, so much more is now known about quality reading instruction. *The No Child Left Behind Act*,³ signed into law by President George W. Bush on January 8, 2002, codifies these research findings. The law establishes two national programs, Early Reading First and Reading First, to help states and districts set up scientific, research-based reading programs. The goal of the programs is to enable all students, including students with disabilities and those whose first language is not English, to become successful readers, beginning in the earliest years. The programs build on the findings of years of scientific research analyzed and compiled by the National Reading Panel.⁴

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IDEA Reauthorization Update

On November 4 the Senate HELP Committee filed a report on The Individuals with Disabilities Education Improvement Act of 2003 bill to reauthorize IDEA (S.1248). The substitute bill contains mostly technical changes that strengthen the bill somewhat. Lead sponsors of the Senate bill are still pushing hard to have it considered by the full Senate before recess. Pending approval by the full Senate, the bill would move to a conference committee of the US House and Senate before advancing to the President for his signature. It is unclear whether this will all take place during the current session or whether the bill will stall until Congress' next session in January. Ultimately, the bill could be signed as early as January or as late as May 2004 or beyond. Please stay tuned to fcsn.org for the latest developments in this important reauthorization.

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Bulletin

Parents Learning About Children's Education





Book Review

SIBLINGS OF CHILDREN WITH AUTISM: A GUIDE FOR FAMILIES

Paperback, \$16.95, ISBN: 1-890627-29-1, Woodbine House

A Book Review by Mary Loughlin

Dr. Sandra Harris and Dr. Beth Glasberg from Rutgers University have written their second edition of *Siblings of Children with Autism: A Guide for Families* from the Woodbine Special Needs Collection. The information provided is based upon research and clinical practice. Each chapter begins with a vignette from a family with a child who has autism, and ends with quotes from parents voicing their concerns for their children. The parents question, as I do, how having a child with autism will affect his or her siblings in the future. Other concerns raised include how to support the siblings emotionally, how much to allow the siblings to help, and how to balance the needs of everyone in the family. This is an extremely useful book for families with children with autism. Although the focus of the book is on a family with one child with autism, this book is also helpful for families like mine with multiple children with autism.

Chapter One explores the relationship between a child with autism and his or her sibling. The authors note that anger, competition, and resentment are normal in all sibling relationships. Siblings of children with autism, however, may have more emotional and behavioral problems than do children with siblings with other disabilities. Siblings experience less sibling intimacy, less positive social interaction, and less nurturing than children with siblings with other disabilities. Yet siblings of children with autism, as well as siblings of children with other disabilities, have greater admiration and less competition with their siblings than siblings of typically developing children.

In Chapter Two, the authors examine how siblings view autism. The authors raise the question, how much information about autism do you provide to your children? Children's understanding

of autism varies according to their developmental stage. Also, what parents share and what children grasp may be quite different. Children often have a lack of information or misinformation about autism. Children's most common questions are: what is autism and how do you get it?

My daughter, Cara, sister to two brothers, John and Brian, who have autism, often asks me about autism, what it is, how and why John and Brian have it, whether she has it or could develop it too, and why they can't speak and play the way she does.

The authors suggest that you ask your children questions such as these to gauge their understanding of autism:

- Have you ever heard the word "autism"? Tell me about it.
- How does someone get autism?
- How does autism make your brother's life different now from what it would be if he did not have autism?
- When your brother grows up, how will autism make his life different from what it would be if he did not have autism?

- How does having a brother with autism make your life different from what it would be if he did not have autism?
- When you grow up, will having a brother with autism make your life different from what it would be if he did not have autism?

Parents need to discuss autism with siblings at as young an age as possible on a level the child can understand, according to the authors. Encourage your child to turn to you with questions and feelings. Actively listen while remaining neutral. Offer praise to your child for sharing feelings. Be prepared for your child to have intense emotions ranging from sympathy to guilt to anger. Also, the authors remind us not to forget to explain autism to the child with autism himself.


Chapter Three discusses how to explain autism to children. The important concepts to tell young children are:

- You can't catch autism.
- It isn't anyone's fault.
- He needs to learn to talk or is still learning to talk.
- I will keep you safe.

For older children, you can explain:

- Autism happens before a child is born or when a child is a baby.
- Autism is a problem in the brain.
- Autism makes it difficult to talk, play, and understand others.
- Someone with autism can learn but not easily.

continues on page 17 ←



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From the Executive Director

“No Child Left Behind” — Except 1%

Recently, the US Department of Education issued a “Notice of Public Rule Making (NPRM)” in the *Federal Register*, requesting comment on the idea that 1% of students with disabilities be excluded from the accountability requirements under NCLB (No Child Left Behind), the national education reform law. Essentially what this means is that the most disabled students would be left behind.

It seems that suddenly, after nearly ten years of state and federal initiatives to reform the quality of education for all students, a dramatic turn around is occurring for those who are perceived as not benefiting from an education. For a long time the expression was “all means all”, even those students with significant disabilities. No child would be denied a high quality, standards-based education. As a result, access to the General Curriculum for all children on an IEP was an explicit new requirement of IDEA'97 and the subsequent

NCLB Act. While these components remain in the law, this new development of exclusion undermines the importance of those requirements.

Earlier this year, the Massachusetts House of Representatives overwhelmingly voted to exempt all (and only) special education students from the MCAS graduation requirement as an amendment to the FY'04 budget. The problem was that it was too late to help as over 80% of this year's graduates on IEP's had already passed the test. This act would have invalidated their successes and singled out special education students as a ‘lower’ class of students with low expectations. It did not hold schools and school districts accountable for doing everything possible to move every child ahead (i.e. No Child Left Behind); rather it implied that this group of students isn't even worth trying to educate.

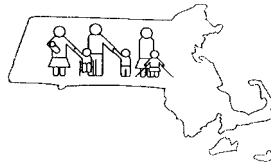
Students with special education needs have made some of the most dramatic progress among all groups of students since the advent of Education Reform across this country. In June 2003 we marked the 10-year anniversary of Education Reform in Massachusetts and soon the nation will celebrate 30 years of IDEA (Individuals with Disabilities Education Act). Professor Gunnar Dybwad used to say, “Never say Never!”. We've come too far and made too much progress to suddenly dismiss the neediest and most vulnerable. Let's be sure No Child is Left Behind.



Richard Robison

Richard J. Robison

Family TIES Update



*Together in
Enhancing Support*

It is a pleasure to announce that Family TIES, the statewide resource, referral, information and parent-to-parent support network, has three new staff members. As always, each staff member is a parent of a child or children with special needs.

Mary Castro Aten is the new Family TIES project director. For several years, Mary worked at the FIRST Project based out of UMass-Worcester. She provided information, referrals, and support to parents of children with special health needs. More recently, Mary has coordinated activities for NERGG, the New England Regional Genetics Group. This included providing administrator support to the leadership, developing budgets, writing grant proposals and other educational materials and activities as well as coordinating committee activities. Mary is based out of the Metrowest Regional Health Office and has been on the job since October 7.

The new Family TIES parent coordinator in the Boston Region is Roxanne Hoke-Chandler. Roxanne's previous experience includes doing trainings and portfolio reviews for the Early

Intervention Training Center (also based at the Federation), training at Franciscan Children's Hospital and work with the Harvard Down Syndrome Program. She has taken the Federation's Advocacy training, is very active in the Boston public school system and has worked on a literacy project with parents at the O'Hearn school. Roxanne has previous ties with the Family TIES project, as she has been trained as a Family TIES Support Parent. Roxanne has been at work since October 1 and is based out of the Boston Regional Health Office.

Kathy Morin is the new Northeast Regional parent coordinator for Family TIES. Kathy has worked with the Early Intervention Training Center where she gained substantial experience training early intervention providers, and also served as a portfolio reviewer. Prior to working with early intervention providers, Kathy worked for the Massachusetts Department of Public Health's Early Intervention Parent Leadership Project, sharing her experiences with other families who were enrolled in early intervention programs and participating as a

parent team member in the early intervention program recertification process.

We thank everyone for being so patient during the hiring process. We especially want to thank Joanne Spencer, the Family TIES Training and Outreach Coordinator, Barbara Donati, Parent Coordinator in the Central Region, and Mary Lee Gupta, our parent match-maker and parent-to-parent consultant, for their continued support throughout a busy summer and fall. Their efforts have been invaluable.

Family TIES is actively seeking candidates for parent coordinator positions in the Metrowest, Southeast, and Western Regions. Please share news of these opportunities with individuals whose life experiences and special skills make them uniquely qualified to help support other families of children with special health care needs, chronic illnesses and/or disabilities. For more information about this exciting job opportunity and the application process, call Mary Castro Aten 781-774-6609, or e-mail mcasten@fcsn.org. To contact the Family TIES parent coordinator nearest you, call 1-800-905-TIES (8437).

Federation Gala 2003 “Dare to Dream” — A Successful Event

We did not dare to think it was possible – but the Federation’s fourth annual fundraising gala broke all previous records! The event was held on May 9th at the Royal Sonesta Hotel in Cambridge. Generous support for this year’s Gala was provided by: Morgan Stanley, JP MorganChase, Fleet Specialists and The Holt Companies. Over 300 people enjoyed a festive evening with a splendid array of silent auction items to bid on and an elegant dinner with lively Brazilian music played by instrumentalist and composer Sergio Brandoa and his Manga-Rosa group.

The Federation was pleased to present The Martha Ziegler Founder’s Award to a long-time friend and advocate of the Federation, Deborah Klein Walker, Associate Commissioner for Programs and Prevention at the Massachusetts Department of Public Health. Debbie has been a tireless leader in her work, which has included advocating for children, youth and adults with disabilities, or in her words, “the pursuit of social justice”.

Under Debbie’s leadership, Massachusetts was one of the first states to employ parents of children with disabilities as consultants and staff to guide public health programs. Her leadership extends beyond Massachusetts as an elected Board member of the American Public Health Association and the immediate past-president of the Association of Maternal and Child Health Programs – to mention only a few of her positions.

Debbie called upon attendees “not to remain complacent in our work in the educational arena”. She reminded us of what advocacy and access to education, health and social opportunities can do for individuals with disabilities – “the challenge is to pro-

vide these as a right to all, regardless of income, gender, race, and geopolitical boundaries”. Debbie’s commitment—the full inclusion and participation of children and adults with disabilities and special health care needs in every facet of American life—is our mission as well. Thank you again, Debbie.

We were delighted to have Joe Sciacca, Deputy Managing Editor for Politics at the Boston Herald, return as our emcee for the evening. As a parent, his wit and humor set just the right tone for the evening.

Proceeds from the Gala provide the critically needed funds to support the work of the Federation. Over the past year, staff, volunteers, and board members worked together to ensure the financial success of this annual event. It is a collective effort and we are pleased to announce that this year’s fundraising goal of \$125,000 was not only achieved, but also surpassed. The annual silent auction yielded nearly \$14,000 alone! This figure represents contributions by over 150 restaurants and businesses that willingly donated their time, services, products, merchandise and food.

The Federation wishes to commend all the donors, volunteers, program participants, and supporters who made this the best Gala yet. We are honored by your commitment to the Federation’s mission and thank you for your support.

The 5th Annual Federation Gala will be at the Seaport Hotel in Boston on May 21, 2004.



Deborah Klein Walker, Associate Commissioner of Programs and Prevention at the Massachusetts Department of Public Health, was awarded the Martha Ziegler Founder's Award.



At left, Julius Richmond, Professor Emeritus at Harvard Medical School and the Former U.S. Surgeon General and Steve Gortmaker, public health and media researcher at Harvard School of Public Health.



At left, June Gross with Larry Kotin of Kotin, Crabtree and Strong, touched base with Betsy Anderson of the Federation.

Gala Thank You's

In addition to the generous sponsors and donors listed on the next page, the Federation for Children with Special Needs wishes to give special recognition to: Ed DeNoble and Jim Whalen for helping us to make this a truly successful fundraising event; Brooke Heraty, Miryam Wiley, Hope and Gary Colen, Ed and Allyson DeNoble, Jim Whalen, Mike Anderson, Micki Avery,

Lorna Jane and Linda Cohen for their outstanding work in soliciting silent auction donations; Mary and Brooks Thompson, Deyin Zang and Chong-Sheng Wang for their coordination of the silent auction tables; Anne Howard and Rosie Howard Carter for their creative Gala decorations; The Federation for Children with Special Needs wishes to thank all staff, volunteers and board members for their dedication and

commitment to quality education, healthcare, and for their tireless efforts working to protect the rights of all children.

The Federation also wishes to thank the program participants: Deborah Klein Walker, Martha Ziegler, Sergio Brandão & Manga-Rosa and Joe Sciacca as well as all those in attendance at the 2003 Gala.

Gala 2003 Thank You's

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Reading Instruction: General Principles to Keep in Mind

The following general principles in reading instruction apply to all students, regardless of a student's age, ability level, or ability to speak English.

These principles have been excerpted and adapted from Teaching Students with Disabilities to Read (September 2000) by Carolyn A. Denton and Jan E. Hasbrouck, a publication of the PEER Project at The Federation for Children with Special Needs, Boston.

All students have the right to quality reading instruction, whether they are in preschool, elementary, middle, or high school. Parents have the right to insist that the school provide instruction designed to help their children improve their reading skills. Remember, too, that President Bush's mandate that no child be left behind includes children with disabilities and those whose first language is not English. Reading instruction should be an important part of the Individualized Education Program (IEP) for students with disabilities.

Parents should, first and always, communicate with their children's teacher(s). Parents can simply ask their children's teacher(s) what they can do to help their child at home. Parents are also important sources of information about their child's interests, abilities, and learning styles. Coordination of school and home efforts is one of the best ways to help a student suc-

ceed. Strategies to ensure communication and coordination between school and home can be addressed in a special *Compact for Reading*, and in a student's IEP.

Although different methods of teaching reading may work equally well with students having a variety of special needs, all students benefit from instruction that is systematic and structured. Reading skills should be introduced in careful order, and students must be given a great deal of practice and repetition in each skill, so that they master each skill before new ones are introduced.

The reading material used in reading instruction has to be "not too hard, not too easy," but at the right level for a student. Actual reading of real stories or other material should be part of a student's reading program.

Reading programs for struggling readers should be individually designed based on a student's strengths and needs. Parents and teachers should not make judgments about a student's ability to learn, or about the best way to teach him or her, based solely on a student's disability label, or ability to speak English.

Students with disabilities may need modifications (changes) in the way they receive instruction, and in the way they fulfill class requirements in order to succeed in areas such as science, social studies, and language arts. These modifications are important, but



they should not take the place of instruction designed to help students improve their reading skills.

In the past, some people believed that certain methods of teaching reading were best for students with certain disabilities: that some methods were best for students with brain injury, that others were better for students with learning disabilities, and that still other methods were best for students with mental retardation. This belief is not based on sound research. The success of a method of teaching reading depends on the content of the program, the way it is taught, the intensity of the instruction (how often and how actively it is taught), and the needs and strengths of the individual student.

Adapted from Denton, C.A. & Hasbrouck, J.E. (September 2000). Teaching Students with Disabilities to Read. Boston: Federation for Children with Special Needs. Reference: Snow, C.E., Burns, M.S., & Griffin, P. (Eds.) Preventing Reading Difficulties in Young Children. Washington, D.D.: National Academy Press.

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O Ensino de Leitura: Princípios Gerais para Ter em Mente

Os princípios gerais do ensino de leitura a seguir aplicam-se a todos os estudantes, independentemente da idade, nível de habilidade ou da habilidade de falar inglês.

Estes princípios foram retirados e adaptados do livro Ensinando Alunos Portadores de Deficiência a Ler (Setembro 2000), de Carolyn A. Denton e Jan E. Hasbrouck, uma publicação do PEER Project da Federação para Crianças com Necessidades Especiais, Boston.

Todos os estudantes têm direito a um ensino de qualidade, estejam eles na preschool, elementary, middle, ou high school.

Os pais têm o direito de exigir que a escola providencie a instrução designada para ajudar seus filhos a aprimorar o seu nível de leitura. Lembre-se, também, que a diretoria do presidente Bush para que nenhuma criança seja deixada para trás inclui as crianças portadoras de deficiências, assim como as que o inglês não seja a primeira língua. O ensino de leitura deve ser uma parte importante do Programa de Educação Individualizado (IEP – Individualized Education Program) para alunos com deficiência.

Os pais devem, primeiro e sempre, comunicar-se com o professor(es) de seus filhos. Os pais podem, simplesmente, perguntar ao professor dos filhos o que poderiam fazer para ajudá-los em casa. Os pais constituem uma fonte importante de informações sobre os interesses dos filhos, suas habilidades e estilos de aprendizagem. A cooperação da escola e da família do aluno é um dos melhores meios para auxiliá-lo a ter sucesso. Estratégias para garantir a comunicação e a cooperação entre a escola e o lar podem ser vistas no especial *Compact for Reading*, e no IEP do aluno.

Ainda que métodos diferentes de ensino de leitura possam funcionar igualmente bem com alunos com necessidades especiais diversos, todos eles se beneficiam de uma instrução que seja sistemática e estruturada. As técnicas de leitura devem ser apresentadas numa ordem cuidadosa, e deve ser dado aos alunos um bom tempo para prática e repetição em cada nível, de maneira quem possam desenvolver cada nível antes de que outros sejam introduzidos.

O material de leitura usado no ensino de leitura tem de ser “nem tão difícil e nem tão fácil”, mas no nível adequado para o aluno. A leitura de histórias reais e outros materiais devem fazer parte do programa de leitura do estudante.

Programas de leitura para alunos com dificuldades devem ser planejados individualmente com base nos pontos fortes e nas necessidades dos mesmos.

Os pais e os professores não devem fazer julgamentos sobre a habilidade de aprendizagem do aluno, ou sobre o melhor modo de ensiná-lo(a), com base apenas no nível de deficiência, ou na habilidade de falar inglês.

Os alunos portadores de deficiência podem precisar de adaptações (mudanças) no modo como recebem as instruções, assim como no modo como fazem os deveres da sala de aula, para que possam ter um bom desempenho em matérias como ciências, estudos sociais e linguagem. Estas adaptações são importantes, mas não devem tomar o lugar do ensino planejado para ajudar os alunos a aprimorar a habilidade de leitura.

No passado, algumas pessoas pensavam que certos métodos de ensino de leitura eram melhores para alunos com certas deficiências: que alguns métodos eram melhores para alunos com lesão cerebral,



que outros eram melhores para alunos com deficiência de aprendizagem, e que ainda outros métodos eram melhores para alunos com retardamento mental. Esta crença não é baseada numa pesquisa de qualidade.

O sucesso de um método de ensino de leitura depende do conteúdo do programa, do modo como é ensinado, da intensidade da instrução (com que frequência e quão ativamente é ensinado), assim como nos pontos fortes e nas necessidades de cada aluno individual.

Adaptado de: Denton, C.A. & Hasbrouck, J.E. (September 2000). Teaching Students with Disabilities to Read. Boston: Federação para Crianças com Necessidades Especiais Referência: Snow, C.E., Burns, M.S., & Griffin, P. (Eds.) Preventing Reading Difficulties in Young Children. Washington, D.D.: National Academy Press.

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***Providing representation to children and adults with disabilities,
their families, and non-profit service providers.***

KOTIN, CRABTREE & STRONG, LLP

Kotin, Crabtree & Strong is a general practice law firm one of whose specialties is in law relating to children, including education and child care issues. Other areas of practice include disability issues, civil and criminal litigation, personal injury law, estate planning and administration, intellectual property, corporations, including representation of private schools and programs, child care and other organizations, real estate, taxation and mediation.

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Aprendiendo a leer: Mantenga en cuenta los siguientes principios

Los siguientes principios para aprender a leer se aplican a todos los estudiantes sin importar su edad, su nivel educativo o su capacidad de hablar inglés.

Estos principios han sido tomados y adaptados de Teaching Students with Disabilities to Read (septiembre 2000) por Carolyn A. Denton y Jan E. Hasbrouck, una publicación de PEER Project en la Federación para Niños con Necesidades especiales, Boston.

Todos los estudiantes tienen el derecho a recibir una enseñanza de calidad para aprender a leer tanto a nivel pre-escolar, elemental, secundaria y bachillerato. Los padres de familia tienen el derecho de insistir que la escuela ofrezca enseñanza orientada a ayudar a los niños a mejorar sus habilidades en la lectura. Recuerde que el presidente Bush en la ley que ningún niño se quede atrás también incluye a los niños con discapacidades y a aquellos quienes su primer idioma no es el inglés. La enseñanza para aprender a leer debe de ser

una parte importante del Programa Educativo Individualizado (IEP por sus siglas en inglés) para los estudiantes con discapacidades.

Los padres siempre deben comunicarse primero con el (los) profesor (es) de sus niños. Los padres de familia pueden preguntarle al (los) profesor (es) como pueden ayudar a sus niños en la casa. Los padres de familia también son fuente importante de información acerca de los intereses, habilidades, e estilos de aprendizaje de sus hijos. La coordinación de esfuerzos entre la escuela y la casa es una de las mejores formas para ayudar al estudiante a triunfar. Las estrategias para asegurar la comunicación y coordinación entre la escuela y la casa puede ser encontradas en Compact for Reading y en el IEP (por sus siglas en inglés) del estudiante.

Aunque los diferentes métodos de enseñar a leer pueden dar los mismos resultados para los estudiantes con una variedad de necesi-

dades especiales, todos los estudiantes se benefician de una enseñanza sistemática y estructurada.

Las habilidades en la lectura deben ser presentadas en un orden cuidadoso y a los estudiantes se les tienen que haber dejado practicar y repetir cada habilidad, de manera que ellos la dominen antes de presentarles una nueva.

El material usado en la enseñanza de la lectura tiene que ser “no muy difícil ni muy fácil” pero si debe estar al nivel del estudiante. La lectura



de historias reales y otros materiales deben ser parte del programa de lectura del estudiante.

Los programas para estudiantes con dificultades en el aprendizaje de la lectura deben de estar basados en las fortalezas y necesidades del mismo estudiante. Los padres de familia y profesores no deben tomar una decisión sobre las habilidades de aprendizaje del estudiante o la mejor manera de enseñarle basándose solamente en su discapacidad o en su habilidad de hablar inglés.

Los estudiantes con discapacidades pueden necesitar modificaciones (cambios) en la manera que reciben la enseñanza y en la manera de completar los requisitos en la clase para tener éxito en áreas como ciencia, estudios sociales y artes del lenguaje. Estas modificaciones son importantes pero no deben tomar el lugar de las enseñanzas orientadas a ayudar a los estudiantes a mejorar sus habilidades en la lectura.

En el pasado, algunas personas creyeron que ciertos métodos de enseñanza de lectura eran los mejores para los estudiantes con ciertas discapacidades: que algunos métodos eran mejores para estudiantes con daños cerebrales, y otros eran mejores para estudiantes con problemas de aprendizaje y que otros métodos eran mejores para estudiantes con retardación mental. Esta creencia no esta basada en investigaciones. El éxito de un método de enseñanza de lectura depende del contenido del programa, de la manera en que se enseña, de la intensidad de la enseñanza (con que frecuencia y que tan activamente se enseña) y de las necesidades y las fortalezas de cada estudiante.

Adaptado de Denton, C.A. & Hasbrouck, J.E. (Septiembre 2000). Teaching Students with Disabilities to Read. Boston: Federation for Children with Special Needs. Referencia: Snow, C.E., Burns, M.S., & Griffin, P. (Eds.) Preventing Reading Difficulties in Young Children. Washington, D.D.: National Academy Press.

**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 or call (617) 556-4075 x18 to learn more about how you can get involved.**



Bulletin

Parents Learning About Children's Education

A service for all parents of kids in Massachusetts' public schools



Fun, Family Learning Activities!

Enjoy these activities with your children while developing their skills.

FOR GRADES K-3

Float or Sink—Encourage hypothesizing (guessing). Use several objects—soap, a dry sock, a bottle of shampoo, a wet sponge, an empty bottle. Ask your child which objects will float when dropped into water in a sink or bathtub. Then drop the objects in the water, one by one, to see what happens.

Telephonitis—Give your child practice in reading numbers left to right by dialing a telephone. Make a list of telephone numbers your child can read—for relatives, friends, the weather bureau—and have your child make a call or two.

Comic Strip Writing—Use comic strips to help with writing. Cut apart the segments of a comic strip and ask your child to arrange them in order.

FOR GRADES 4-5

TV and the World—Connect current events to TV viewing. Post a world map next to the TV set. Watch the TV news with your children and have them locate world news spots. Keep reference books such as dictionaries and the world almanac close by. Children can find answers to questions when their curiosity is high.

On the Move—Sharpen math skills while on trips. Use even short trips around town. For example, at the gas station, ask your child how much gas you need and the cost per gallon. On the highway, ask your child to read signs and check different speed limits.

History Time Line—Record history at home. Stretch a roll of paper along the floor. Use a ruler to make a line



about three feet long. (Use a separate sheet for each child.) Ask your children to fill in the important dates in their lives, starting with their birth.

FOR GRADES 6-8

Read All About It—Introduce your child to the many kinds of information in the daily newspaper. Ask your child to find the pages about government leaders, editor's opinions, weather reports, car sales, house and apartment rentals, and want ads. Discuss how to use this information.

Looking at Advertisements—Help your children improve their thinking and writing skills by looking carefully at newspaper, magazine, and TV advertisements. What is the main point of the ad? What details does it use to communicate its message?

Thank You!

To those who have responded to the Parents' PLACE *Bulletin* Survey we thank you! In this issue we've begun to incorporate a few of your suggestions:

- Larger font
- Separated columns
- Information that covers a range of age groups

Even more of your suggestions will appear in upcoming issues! If you have yet to submit a survey, please log on to our website www.pplace.org and submit online!

Expanding Horizons—Help your child learn about people from different countries. Suggest talking to neighbors from foreign countries, reading library books about other cultures, reading newspapers, and watching TV specials.

These home learning "recipes" have been tested and developed by Dr. Dorothy Rich, author of MEGASKILLS®, for the National Education Association. Reprinted with permission of the National Education Association and The Home and School Institute, 1994. Reproduction of this brochure is permitted.



Do you know... what supplemental services are available for your child?

Many services may be available in your area. For further information, please visit the Massachusetts Department of Education website at www.doe.mass.edu/ses/ or call us at 617-236-7210.

For future information on supplemental services as outlined in the new education act *No Child Left Behind*, check out their online brochure at www.nochildleftbehind.gov/parents/supplementalser-vices/services.pdf, or call for a copy, toll free at 1-877-4-ED-PUBS.

Keeping Children Drug Free



- Make sure they are well-versed in the reasons to avoid alcohol, tobacco, and drugs.
- Get to know their friends by taking them to and from activities, whenever possible.
- Get acquainted with the parents of your children's friends and learn about their children's interests and habits.

To make sure that your child's life is structured in such a way that drugs have no place in it, you should:

- If possible, arrange to have your children looked after and engaged in the after-school hours if you cannot be with them. Encourage them to get involved with reputable youth groups, arts, music, sports, community service, and academic clubs.
- Make sure children who are unattended for periods during the day feel your presence. Give them a schedule and set limits on their behavior. Give them household chores to accomplish. Enforce a strict phone-in-to-you policy.
- Call parents whose home is to be used for a party. Make sure they can assure you that no alcoholic beverages or illegal substances will be dispensed. Do not be afraid to check out the party yourself to see that adult supervision is in place.

- Make it easy for your child to leave a place where illegal substances are being used. Discuss with your child in advance how to contact you or other designated adults to get a ride home.
- Set curfews and enforce them. Weekend curfews might range from 9 p.m. for a fifth-grader to 12:30 a.m. for a senior in high school.
- Encourage open dialogue with your children about their experiences. Tell your child, "I love you and trust you, but I don't trust the world around you, and I need to know what is going on in your life so I can be a good parent to you."

From Tips for Parents on Keeping Children Drug Free by the U.S. Department of Education, Office of Intergovernmental and Interagency Affairs, Educational Partnerships and Family Involvement Units, Washington, D.C., 2003.

NEW! FCSN Holiday Cards ❄️



This year, send holiday cards that make a difference in the quality of life for a child with special needs.

Choose from many unique holiday and note card designs. Great gift ideas too!



A portion of the proceeds is donated to support programs at The Federation for Children with Special Needs.

Easy online ordering at

www.GivingGreetings.com

Email: info@GivingGreetings.com

Call: 978-440-9540 ❄️



Parents' PLACE *Bulletin* is available in English, Spanish, & Portuguese and online at www.pplace.org. Parents' PLACE is a Parent Information and Resource

Center (PIRC) funded by the U.S. Department of Education to help parents and educators advance children's success in school. For more information, call toll-free 877-471-0980.

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A Successful Year for Parents For Residential Reform

Parents for Residential Reform (PFRR) had a successful year. We worked with the Department of Education (DOE) and the Office for Childcare Services (OCCS) to have them post the most recent monitoring reports from both public and private 766 approved schools (www.doe.mass.edu/pqa) and were able to get OCCS to post regulations as well as information about licensing status, staff to student ratio, and much more (www.qualitychildcare.org). The list serve is growing, and we are beginning to partner with others to help disperse much needed information to parents and others.

Our workshops have been very successful, and we are already scheduling workshops for the fall. Visit our website at www.pfrr.org to register for a workshop or contact us if you would like us to present a workshop to your Parent Advisory Council or other group.

Our motto is: Better Educated Consumers Bring Better End Results! Did you know all 766 approved schools must have a Parent Advisory Council (PAC)? It's the law. Does your child's 766-approved school have a PAC? If so, we would love to come out and do one of our information-packed workshops. All the changes in IDEA and at EOHHS may be confusing for parents as well as providers and school systems. PFRR is happy to help you navigate through these changes. You can see our workshop schedule on our website at www.pfrr.org, or e-mail (pfrr@fcsn.org) or phone 617-236-7210, ext. 145 or 1-800-672-7084 to schedule a workshop.

5th Annual Silent Auction and Dinner Dance a Huge Success

Last June, PFRR, along with the Federation for Children with Special Needs, hosted our 5th Annual Silent Auction and Dinner Dance at Anthony's Pier 4 in Boston. This benefit supports the Children's Holiday Gift Fund, which provides holiday gifts for children with disabilities in state custody that have little or no family involvement.

Richard Sheola, a past Powerful Friend Award Recipient, was our Master of Ceremonies. This year our Powerful Friend Award Recipients were Jack Williams, Robin Dawson, and the Marsels. Jack was recognized for his work with



Richard Robison, Ellen Pompeo, Andrea Watson, and Jack Williams at the 5th Annual Silent Auction and Dinner Dance.

Wednesday's Child by helping to find homes for hard-to-adopt children with special needs; Robin, from the Mass Film Bureau, was honored for her long-term commitment to Parents for Residential Reform and the Children's Holiday Gift Fund. She has used her contacts with actors and actresses to help raise awareness about PFRR and the Gift Fund. We also honored the Marsels, who have been with us since the inception of the Children's Holiday Gift Fund; they have provided the music that's kept us dancing all night at our many events throughout the years.

The highlight of the evening was our special guest Ellen Pompeo, a native of Everett, Massachusetts, and Hollywood actress who jetted in especially to attend this event. Ellen is best known for *Moonlight Mile*, *Old School*, and *Catch Me if You Can*. She dazzled the crowd with her beauty and her kind and wonderful words about PFRR and the Gift Fund.

Many thanks to Bill Lyttle and Kathy Betts the wonderful co-chairs of this year's benefit. We also extend our thanks to Cheryl Leathom for her hard work gathering items for the silent auction, and to Kenny Larkin who helped with the set up. Thanks also to the PFRR Advisory Board and our colleagues at the Federation for Children with Special Needs who never fail to roll up their sleeves and help with all of our events. Thanks especially to all who attended and helped make this year's holiday for our young people a better one.

We are still taking donations to help purchase age appropriate holiday gifts for young people living with disabilities who are in state custody with little or no family involvement due to abuse/abandonment/and or neglect. To donate to the Gift Fund, make your checks payable to CHGF – FCSN, and send them to PFRR c/o FCSN, 1135 Tremont Street, Suite 420, Boston, MA 02120.

We look forward to seeing you at our next gift fund event on June 25th, 2004.

NewsLine

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

The Federation for Children with Special Needs, Inc.

Our Mission:

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

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Federation Workshops

November 2003–April 2004

NOVEMBER 2003

11/25, Springfield, *Two Nights to Transition, Planning for Turning 3 in Early Intervention—Turning Three*, 6–8pm *Save the date*

DECEMBER 2003

12/3 Hudson, *Basic Rights*, 7–9pm

12/3 Wilbraham, *IEP*, 7–9pm

12/9 Wayland, *Basic Rights*, 7–9pm

12/9 Lowell, *Basic Rights*, 6:30–8:30pm

12/9 Granby, *Basic Rights*, 6:30–8:30pm

12/15 Chelmsford, *Access to the General Curriculum*, 7–9pm

12/18 Chicopee, *Effective Communication*, 6:30–8:30pm

JANUARY 2004

1/6 North Reading, *Basic Rights* (snow 1/20)

1/8 Great Barrington, *IEP*, 7–9pm

1/12 Barre, *Effective Communication*, 7–9pm (snow 1/26)

1/13 Waltham, *Basic Rights*, 7–9pm

1/13 Lowell, *IEP*, 6:30–8:30pm (snow 1/20)

1/14 Belmont, *IEP*, 7:30–9:30pm (snow 1/21)

1/14 Newburyport, *Basic Rights*, 7–9pm (snow 1/21)

1/15 Melrose, *Access to the General Curriculum*, 7–9pm (snow 1/15)

1/27 Braintree, *MCAS*, 7–9pm

1/28 West Concord, *IEP*, 7–9pm (snow 2/4)

FEBRUARY 2004

2/5 Arlington, *Basic Rights*, 7–9pm (2/12 snow)

2/9 Milton, *IEP*, 7–9pm (2/23 snow)

2/10 Hopkinton, *MCAS*, 7–9pm (2/11 snow)

2/10 West Warren, *Basic Rights*, 6:30–8:30pm (2/24 snow)

2/11 Canton, *Access to the General Curriculum*, 7–9pm (2/18 snow)

2/26 Groton, *IEP*, 7–9pm

MARCH 2004

3/4 Billerica, *Basic Rights*, 7–9pm

3/9 Lowell, *Effective Communication*, 6:30–8:30pm

3/10 Belchertown, *NCLB & IDEA*, 7–9pm

3/10 Newburyport, *Effective Communication* (snow 3/17)

3/15 South Hadley, *IEP*, 7–9pm

3/18 Arlington, *IEP*, 7–9pm

APRIL 2004

4/6 North Reading, *Effective Communication*, 7–9pm

4/6 Chelmsford, *Transition*, 6:30–9:00pm

4/14 Bolton, *Basic Rights*, 7–9pm

4/14 Wakefield, *Basic Rights*, 7–9pm

4/14 Newburyport, *MCAS*, 7–9pm

*Visit our web site for up-to-the-minute information (www.fcsn.org)

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 to more fully participate 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 Communication offers communication skill building and conflict resolution for parents as members of the IEP Team.

Effective Inclusion of Students with Disabilities in the MCAS Testing System includes information on the IEP Team's 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 who take the standard paper-and-pencil version of MCAS as well as information on the MCAS Alternate Assessment.

IEP includes a walk-through of the new IEP with emphasis on IDEA '97 and the latest Massachusetts special education regulations, access to the general curriculum and writing curriculum-based, measurable annual goals.

Transition provides basic information on 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 is an interactive workshop that helps professionals and parents understand parents' basic rights as their children approach the transition from Early Intervention into preschool at age three.

Stephen Schneider, Esquire

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Affordable Fees

Literacy Guide

continued from page 1

Bridging the Gap Between What is Now Known and What is Practiced

The U.S. Department of Education, along with other federal departments, has led and supported groundbreaking research studies. Yet, for children to benefit from the knowledge gained by research, parents, grandparents, other caregivers, and educators need understandable information based on research readily at hand. With funding from the U.S. Department of Education, this *Guide* helps close the gap between research and practice by informing important people in a child's life about available resources that are based on current research findings.

This *Guide* is primarily devoted to highlighting literacy resources available through the U.S. Department of Education. It includes information on major national scientific research studies. It also lists easy-to-understand publications with practical tips based on these research studies. The volume of high quality, research-based resources available through the Department of Education is staggering.⁵ Its many clearinghouses, networks, projects, and partnerships are actively engaged in developing new knowledge through ongoing research. New resources are constantly being generated. This *Resource Guide* supports the Department's commitment to getting this knowledge into the hands of the people who need it most: families, educators, caregivers, policymakers, and others across the country who are helping children learn to read.

Bridging the Digital Divide

Another important gap taken into consideration in developing this *Guide* is the "digital divide." While an abundance of free and low-cost

resources exist, knowledge about them and access to them is often available only to those who have access to a computer and the Internet and who have computer literacy skills. According to "Kids Count Snapshot," a June 2002 Annie E. Casey Foundation study, "Generally, children who are already disadvantaged are the least likely to have access to the new technology. Minority children, children living in poor families, and particularly those living in high-poverty neighborhoods are the least likely to have a computer at home or access to the Internet."⁶ These disparities remain even after access at school is taken into account. This study found that 95 percent of children in the richest bracket of American society have access to a computer, while only 33 percent of the poorest enjoy the same benefit. Similarly, there is a 49 percent difference between the same income groups for Internet access.⁷ Another study, "Bringing a Nation Online," released by Leslie Harris and Associates in July 2002 found that, despite gains in access to computers and the Internet for all Americans, a significant divide remains based on income, race and ethnicity, geography, and disability.⁸ As a result, many Americans have yet to benefit from the tremendous advances in technology and information.

In developing this *Guide*, we found many excellent free and low-cost materials through research over the Internet. However, many organizations and agencies only provide web-based listings of their literacy materials and are not prepared to provide information on available resources over the telephone. Often, to request materials, the person calling has to already know specific titles or other identifying information. To meet the needs of families and educators without computer and Internet access, we have made a special effort to list relevant titles and to provide the necessary information to request print copies of most of the materials listed here. This identify-

ing information, along with the mailing addresses and, wherever possible, toll free telephone numbers, make it possible for those without computer/Internet access to request materials.

Summary

The networks of regional education laboratories, research and development centers, and other education and research organizations listed here produce a variety of publications, videos, and other products that can help improve the teaching of reading and literacy education in schools and communities. They can be invaluable resources for identifying solutions for every learner. Of course, this list is not exhaustive. New information appears almost daily. Many other organizations, journals, books, and websites could have been included. In this *Guide*, we have attempted to include the most up-to-date research-based resources and information that is appealing to parents, educators, and caregivers.

The listings here can also serve as a beginning point for more thorough research in particular areas. Our aim is to provide information on resources that will help parents and educators make sure that the children they care about really do benefit from the recent explosion of knowledge about how to teach reading. Our goal is to help bridge the gaps between what is known from research and what is practiced in everyday life, and between what is available to those with and without computer access. With information on resources readily at hand, parents, educators and others will be able to use the findings to select the most appropriate learning activities to support children's literacy education at home and at school.

See pg. 18 for information on ordering A Literacy Resource Guide for Families & Educators

FOOTNOTES:

1. The **PEER Project** was funded by the U.S. Department of Education's Office of Special Education Programs (OSEP) as a national technical assistance project to increase the participation of students with disabilities in education reform efforts in schools across the country. **Parents' PLACE** is a Massachusetts statewide Parent Information and Resource Center (PIRC), one of a national network of PIRCs funded by the U.S. Department of Education's Office of Innovation and Improvement to increase family involvement in children's education and to foster parent-professional partnerships.

2. English language learners (ELLs) are students from non-English language backgrounds whose first language is not English. These students represent one of the fastest growing segments of the K-12 student population in the U.S.

3. The *No Child Left Behind* website (www.nclb.gov/) features news on reading reform efforts across the country. Visit the website to subscribe to its free monthly electronic newsletter and for many free downloads. Also, *No Child Left Behind: A Desktop Reference* (2002) is available free through ED Pubs. Please see page 11 for information on how to order materials from ED Pubs.

4. For more information on the National Reading Panel's work, please see page 9.

5. Please note: Developing a comprehensive listing of all the literacy resources, even from only one of the many Federal Departments involved in literacy, would be far beyond the scope of this project. U.S. Department of Education-funded projects undertake many more literacy initiatives than could be included here. We have attempted to select resources that would have broad appeal that are based on the most current research.

These resources provide solid information as well as a beginning point for further study.

6. Wilhelm, Tony; Carmen, Delia; Reynolds, Megan. (June 2002). "Kids Count Snapshot: Connecting Kids to Technology." Baltimore: Annie E. Casey Foundation. (p. 1). Available online at www.aecf.org/publications/data/snapshot_june_2002.pdf. (Adobe Acrobat PDF reader required.)

7. Wilhelm, *et al.* p. 3.

8. "Bringing a Nation Online: The Importance of Federal Leadership." (July 7, 2002). Leslie Harris and Associates. Washington, DC: Leadership Conference on Civil Rights Education Fund and Benton Foundation. Available online at www.civil-rights.org/publications/bringinganationonline/nation1.html

The Federation Annual Appeal 2003

Dear *NewsLine* Readers,

We are writing to you because you are currently receiving our newsletter, *NewsLine*. We are very pleased that we are able to offer this valuable publication and hope that you find the information helpful as well as educational. *NewsLine* is distributed **free of charge** to more than 30,000 families and professionals. Feedback from readers is very positive.

The reality remains that state and federal budgets will continue to shrink, and foundations cannot possibly meet the demands of so many organizations seeking their support. Furthermore, many of our sources of funds have simply disappeared. Therefore, we need your help to ensure that *NewsLine* remains easily available and accessible for families. Our goal is to continue to provide timely information regarding critical education and healthcare issues.

This year, our annual campaign aims to increase our funds raised by 20 percent over last year's total. Your contribution will help immensely toward this goal. Please consider a \$10, \$20, \$30 or more contribution today. Help the Federation keep helping families in these difficult days.

Please support *NewsLine* and the Federation. We need your support NOW!

Thanks,



Richard J. Robison
Executive Director



The reality remains that state and federal budgets will continue to shrink, and foundations cannot possibly meet the demands of so many organizations seeking their support.

***** Please make a contribution to the Federation today *****

YES! I will help the Federation continue its Mission! I want to support the Federation for Children with Special Needs. Enclosed is my gift.

\$30 \$50 \$100 \$250 \$500 Other \$ _____

Name: _____

Address: _____

City: _____ State: _____ ZIP: _____

Home Telephone: _____ Business Telephone: _____ E-mail: _____

I would like to make my gift by VISA Mastercard

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My company has a matching gift program.

Company name: _____

Address: _____

I would like to make my contribution in honor of: _____

I would like to make my contribution in memory of: _____

Please include this form with your check made payable to:
Federation for Children with Special Needs, 1135 Tremont Street, Suite 420, Boston, MA 02120
The Federation for Children with Special Needs, Inc. is a 501(c)3 organization.

Now you can donate on line! Visit us on the web at www.fcsn.org.

Making Connections

Twenty-eight years ago, I sat at my kitchen table with a cup of tea and a parent sent to me by the March of Dimes. My son had been born with Cerebral Palsy, and the doctors told me to place him in a nursing home and forget him because he would be “a vegetable”. Yes, that’s a direct quote. I was a young mom and this was such a traumatic time. My beautiful baby was not “vegetable”-like to me. He was a beautiful, loved baby boy with the cutest cheeks and the brightest eyes. I called the March of Dimes to find out more about cerebral palsy, and they asked me if I would like to speak to another parent of a child with a disability. “You mean there are others out there like me?” A wonderful mom came out to see me. Six hours and two boxes of tissues later I knew the true meaning of parent-to-parent.

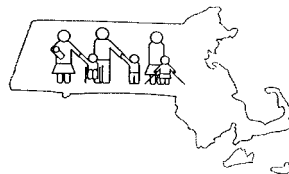
Since that day, I have never had to face the bad or the good days alone. A voice of support is always a phone call away. There is no one else that truly understands the joys, the frustrations, the losses and the successes we, as parents of children with special needs, face every day, the way another parent can. The feeling of support and camaraderie is amazing and brings a source of strength to your life that carries you through all the ups and down.

Family TIES offers families this same opportunity—to be matched with a support parent, or to become a support parent. Maybe you’ve had great success at getting services for your child and you’d like to help another parent find their way. Perhaps you would like to help support a parent whose child was just diagnosed with the same disability as your child. This is an opportunity that you will never be sorry you took.



Want to talk to a parent whose child has already transitioned out of EI? Or maybe you have a child who is going to turn 22 and you are concerned about going through the “medical transition”. Family TIES offers parents the opportunity to take our support parent training or to speak with a trained support parent. If you would like more information, please call one of our Family TIES Regional Coordinators at 1-800-905-TIES. And welcome to the world of support!

Family TIES of Massachusetts



*Together in
Enhancing Support*

SHARE YOUR VOICE!

Family TIES invites you to make your voice heard by becoming a parent leader in Massachusetts. Parents of children with special needs advocate daily for our children’s educational, medical and social needs. Each of us has the potential to be an advisor to the “powers that be”. Family TIES is offering you the opportunity to take the next step in your advocacy roles—become a Family TIES Advisor.

As a Family TIES Advisor you will be invited to share your unique expertise and given the option to participate in whatever way fits into your life. Some examples:

- Attend focus groups
- Participate in phone or written surveys
- Become part of an advisory board
- Review materials
- Participate on a committee
- Become part of a phone tree

For more information, call Joanne Spencer at 617-727-1440 or 508-947-1231

Would you like to help us make a difference? Please fill out the information to the right on this form and return it to:

Joanne Spencer,
Family TIES Training & Outreach Coordinator
Department of Public Health
109 Rhode Island Road
Lakeville, MA 02347

Name _____

Phone _____

Address _____

E-mail _____

I’m interested in working on:

- Transition issues
- Medical transitions
- Nutrition issues for children with special needs
- Medical home
- Insurance Issues
- Other issue – (Please specify)

- Please notify me if a Leadership workshop becomes available

Thank you, a Family TIES coordinator will be in touch with you! Family TIES is a project at the Federation for Children with Special Needs, funded by the Department of Public Health, Bureau of Family and Community Health, Division for Special Health Needs.

2003 Martha Zielger Award Winner Deborah Klein Walker

The following are excerpts from Deborah Klein Walker's acceptance speech for this year's Martha Ziegler Founder's Award.

Thank you very much. I am very honored and pleased to receive this special recognition.

Advocating for children, youth and adults with disabilities is an extension of my basic passion—the pursuit of social justice. Public health, as a field and career path, has given me opportunities to be a leader and advocate, a scholar and policy maker for achieving better health outcomes and quality of life for those who have chronic conditions and disabilities of all types. I have conducted research concerning the psychosocial outcomes and overall functioning of individuals with chronic conditions in various settings. Through this work I am convinced that individuals with disabilities can reach their full potential if physical, social and other barriers in their environments are removed. That is why the special education laws in the state and

nation have been so important in opening up access and opportunity for so many children and youth. This is truly the landmark work of the Federation's origins as well. For this work we all walk in the path of Martha Ziegler, the founder of the Federation. Consumer voices are the key to policy change and advocacy. As Margaret Mead once said, "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed it's the only thing that ever has."

Although we cannot remain complacent in our work in the educational arena (especially with recent proposals . . . at the federal and state levels), I . . . have more concerns about the establishment of a parallel right to health insurance and social services for all children, youth and adults with disabilities. Because of the passage of a variety of health programs, including Commonhealth, we in Massachusetts had made more progress towards health care for all than other states. I want to acknowledge the leader-

ship role of the Federation in this area as well.

We know what advocacy and access to education, health and social opportunities can do for individuals with disabilities; the challenge is to provide these as a right to all, regardless of income, gender, race, and geopolitical boundaries. I accept this award and commit to continue with all of you to fight for this shared vision of social justice and social democracy . . .

This recognition is a thank you for this work to date and support for continuing with this work in the decades to come.

I will end with a quote from Ivan Illich, "The celebration of man's humanity through joining together in the healing expression of one's relationships with others, and one's growing acceptance of one's own nature and needs will clearly create major confrontations with existing values and systems. The expanding dignity of each man and each human relationship necessarily challenge existing systems. The call is to live the future. Let us join together joyfully to celebrate our awareness that we can make our life today the shape of tomorrow's future."

Shishmanian Fellowship Awards, 2003

At this year's Massachusetts Early Intervention Consortium Conference, two recipients of the 2003 Shishmanian Fellowship offered participants a glimpse at the respective projects the award will help fund. While each project is tailored to unique needs—one will expand the Montessori method into a classroom which includes children served in early intervention, while the other will support a family-focused early language intervention program for parents and professionals at the Pentucket Early Intervention Program—both manifest the value of lifelong learning, which is essential to professionals and students entering their careers in early intervention.

Funded by the Massachusetts Department of Public Health and administered through the Early Intervention Training Center at the Federation for Children with Special Needs, the Shishmanian Fellowships provide a unique opportunity to obtain assistance for professional development for early interventionists. In this way, they enrich their own knowledge and skills to support the dreams and aspirations of families as they enhance and celebrate the development of their babies and toddlers. Within a dynamic and complex system, early interventionists need to fill and refill their cup

of inquiry, new knowledge and skills.

Senior practitioner and student fellowships are awarded each year to honor Eunice Shishmanian, whose vision and dedication to the needs of very young children and their families internationally serves as a model for the early intervention community. As a nurse, Eunice has devoted her career to Maternal Child Health initiatives and has been a leader in supporting families who have children experiencing developmental challenges. As the first chair of the Massachusetts Early Intervention Interagency Coordinating Council, Eunice helped shape the foundation for a system which continues to individualize supports and services to young children and their families. Currently, Eunice is a member of the interdisciplinary faculty team at Northeastern University, preparing students in five disciplines to be Early Intervention Specialists.

Congratulations to this year's Shishmanian awardees. For more information about the Fellowship program, please contact the Early Intervention Training Center at (617) 236-7210, e-mail rmasbold@fcsn.org, or check out the Training Center's website at www.eitrainingcenter.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 for details.

The CJP Disabilities Trust

All parents worry about their children's futures. For parents of children with disabilities, concern about the future is even more complicated because in some cases, a person's disability affects his or her ability to be independent and financially secure as an adult. Questions such as "What happens after I'm gone?" take on new importance and a sense of immediacy. Therefore, planning for a child's future is not something that can be postponed. And today's fiscal climate of shrinking entitlements and an uncertain economy only adds to this sense of urgency.

The CJP (Combined Jewish Philanthropies) Disabilities Trust is one way to address these important concerns. The Trust offers families a way to pay for expenses not covered by government benefits for their loved ones, without affecting government or other entitlements. This trust is specially designed for individuals with disabilities and meets needs that other trusts overlook, such as providing the beneficiaries with a lifetime of personal advocacy. It can also provide peace of mind for siblings who may feel burdened by the responsibilities of care giving when parents are no longer able to provide it.

By combining the financial expertise of CJP with the resources and experience of Jewish Family & Children's Service's Services for People with Disabilities, the CJP Disabilities Trust ensures that loved ones will have the supports they need throughout their lives.

The CJP Disabilities Trust is non-sectarian and serves all members of the community with physical disabilities, developmental disabilities, mental illness, and significant learning disabilities. If you would like to learn more about the CJP Disabilities Trust, please contact Ilana Gordon-Brown at JF&CS 617-558-1278.

Book Review

continued from page 2

- You can help him play and show him how to do things.
- I can help you with what to say to your friends.

Chapter Four discusses in detail how to help your children share their thoughts and feelings. Skills for communicating openly with your family are highlighted. The authors suggest:

- Communicating in the right place and at the right time
- Checking to be sure that you understand what your child is saying
- Letting your child know that you understand
- Being open about your own thoughts and feelings
- Accepting your child's feelings

Chapter Five addresses how to balance time for your family, your work, and yourself. Research supports that mothers spend more time with a child with a disability than with a typical child. Parents need to communicate with the sibling why they spend more time with the child with autism, so the sibling does not view the extra attention paid to the child with autism as evidence of greater love for the child with autism than for the sibling. The sibling often feels the unfairness of the greater demand on the parent's time and resources by the child with autism than by the sibling. So many times my daughter has said, "Mommy, it's not fair!"

The authors suggest that we should think flexibly about which children are included in various family events. We need to strike a balance between everyone sharing family events and separate time with each child. To do this, we need to turn to family, friends, and respite providers. Also, realize

that preadolescents and adolescents may be embarrassed in public by a sibling with autism, and these feelings need to be accepted. Family life must then be balanced in such a way as to enjoy shared, but possibly more private, events while the sibling works through these feelings. Tips for successful family activities are provided.

The authors suggest that we should think flexibly about which children are included in various family events. We need to strike a balance between everyone sharing family events and separate time with each child. To do this, we need to turn to family, friends, and respite providers.

Other ways to prevent resentment by the sibling are discussed. Everyone in the family should contribute to the family in some way, for example, chores. Private space and respect for belongings for all family members should be emphasized. Suggestions are given for what to do when the child with autism damages the sibling's belongings (a frequent occurrence at my house, unfortunately.) I'll always remember when my daughter received a special tea set only to have her brother break the spoons in half. Cara scotch-taped them together and said, sounding like me, "See, I fixed them!"

This chapter also addresses the importance of using resources to help your family, whenever

possible, whether it be family, friends, or respite care. Parent and sibling support groups are also recommended.

Chapter Six discusses how to help your children learn to play together to develop the sibling bond, which is so crucial throughout their lives. The child with autism has difficulty with play due to the presence of autistic behaviors and a lack of social interaction skills. Siblings, with help, can learn skills to enhance the play skills of the child with autism.

Chapter Seven presents the possible relationships between adults with autism and adult siblings. Suggestions for parents in this section are to help siblings understand advocacy skills from an early age. Also, long before necessary, discuss financial plans, guardianship, and various public benefits.

There is also a section of special considerations regarding marriage and family for siblings that is discussed in a sensitive manner. Sibling career choices are also discussed. It is interesting that many adult siblings choose helping professions. Resources for adult siblings are discussed as well.

The authors conclude that there are challenges growing up in a family with a child with autism and the relationship does differ from the relationship between typical children. Most children, however, are resilient in the way they respond to life as a sibling. One final note from the authors is that we as parents will make mistakes along the way in the way that we parent siblings. Although I talk frequently with my daughter about autism, I rarely talk with my sons. After reading this book, I feel better prepared to talk with all of my children about autism, since all of them are siblings of a child with autism.

News Update

from FAMILY VOICES

at the Federation for Children with Special Needs

Massachusetts Family Voices activities can be summed up by the three C's: Creating partnerships, Collaboration and building Capacity. Our primary focus has been on partnership activities with Medicaid Managed Care Organizations (MCOs). With input from our diverse membership, and in collaboration with staff from four Medicaid MCOs, we've created family-friendly informational materials specifically designed for families of children with special health care needs. The MCOs are distributing these materials through their member and provider newsletters, through links on their websites, and in brochure format to families with children and youth with special health care needs. These materials are also available on our website, or by request (see contact information below). To date, these materials include: Resources for Families of Children with Special Health Care Needs, Prescription for Success: Managing Prescription Medication for Children & Youth with Special Health Care Needs, The Individualized Health Care Plan: Keeping Children with Special Health Care Needs Safe

at School, Questions to Ask When Medical Testing is Recommended for Your Child, and Adolescent Attitudes: Moodiness or Mental Health Issue? This exciting work, entitled "Building Capacity for Family Partnerships with Managed Care Organizations" is supported through a grant from the Center for Health Care Strategies, which was made possible by a separate grant by the Robert Wood Johnson Foundation.

Collaborations in other areas include our quarterly newsletter, The Check Up. We're proud that each issue contains contributions from our member organizations and/or profiles of our member organizations. If you'd like to preview our newsletters, they are posted to our website. We welcome new members; you are invited to join our growing network and receive this free newsletter in the mail.

In May, Mass Family Voices helped sponsor a Leadership Development Conference for Parents about advocating for their children with

special health care needs during times of state budget concerns, presented by Health Care For All's Children's Quality Health Initiative at the Federation and the Boston University School of Public Health. We're also collaborating with the American Academy of Pediatrics and helping to plan the "Every Child Deserves a Medical Home" training, to be held on November 8, 2003 in Western Massachusetts.

Mass Family Voices hosted its third Annual Joining Voices Parent Leader Meeting in October. The Massachusetts Department of Public Health and Massachusetts Families Organizing for Change provided additional support for this conference. This was a wonderful opportunity to catch up with old friends and make new ones, to share resources, learn about the initiatives being sponsored by other parent organizations, and to get re-energized for another year of advocacy on behalf of children with special health care needs.

Massachusetts Family Voices at the Federation for Children with Special Needs is a state chapter of Family Voices, a national grassroots organization of friends and families speaking on behalf of children and youth with special health care needs. For more information about the Mass Family Voices network, visit our website at www.massfamilyvoices.org, e-mail massfv@fcsn.org or leave a message at 1-800-331-0688, ext. 210. Your call will be returned.

Living, Learning, Leading

A Jewish Vocational Service initiative to help connect youths who have a disability to their community and to their future

If you are between 14 and 22, Living, Learning, Leading can help you find an opportunity to contribute to your community as a volunteer. You can work with the environment, work in a kitchen, work in the office, or any other number of jobs that you want to do. Organizations like Habitat for Humanity, Greater Boston Food Bank, and the Museum of Science are just a few examples of places you can volunteer. Plus, you will be paired with a mentor, who will help guide you through this experience.

As a Living, Learning, Leading participant, you will...

- Work with a mentor: you will be paired with a mentor to help keep you excited and to guide you through this learning process
- Build your skills and learn new things: in addition to the enjoyment of being part of a group, you will develop communication, teamwork, and responsibility skills.
- Explore work goals: volunteer at a place where you would want to work as a career
- Begin to develop your career: build your personal network in your area of interest
- Gain personal satisfaction: you will serve your community by helping others in need
- Have fun and make new friends: you will work with people who have the same interests as you
- Start your future today!

MENTORS WANTED!!

Living, Learning, Leading is a Jewish Vocational Service initiative to help connect youths who have a disability to their community and to their future. So many of them need a role model like you. Become a mentor for these youths.

As a Living, Learning, Leading mentor, you will:

- Inspire a youth to become someone more
- Share your knowledge and enthusiasm
- Gain personal satisfaction
- Gain valuable leadership skills
- Build a new relationship
- Have fun

For more information, please contact: Katie Zachary, Living, Learning, Leading coordinator, at 617-542-1993 ext. 216 or email at kzachary@jvs-boston.org



Federation for Children with Special Needs

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CLIP AND SAVE THE DATE!



*A Conference for
Families of Children with Special Needs
and the Professionals Who Serve Them*

March 20, 2004

at the World Trade Center
in Boston, Massachusetts

**Check <http://fcsn.org>
for details!**

The Federation for Children with
Special Needs' Annual Conference
co-sponsored by:

the Early Intervention Parent Leadership Project,
Massachusetts Families Organizing for Change,
Massachusetts Family TIES,
Parents for Residential Reform,
and the Parent/Professional Advocacy League.