



# NewsLine

The Federation for Children with Special Needs

Volume 22, Number 4, Fall 2001

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Anne Howard and Gunnar Dybwad

## From the Executive Director: A Tribute to Gunnar Dybwad

If ever anyone believed in the promise of the human spirit, it was Dr. Gunnar Dybwad. He was Professor Emeritus of Human Development at Brandeis University and former Director of The ARC of the U.S. Gunnar was referred to as the "Grandfather of Mental Retardation" advocacy, a nurturer of the parent movement, and a champion of the Self-Advocacy movement. To us at the Federation, he was a friend and generous supporter. On September 13, 2001, at the age of 92 years, Gunnar passed away in his sleep.

A few years ago, the American Association on Mental Retardation (AAMR) honored him by

announcing the Dybwad Humanitarian Award, in honor of him and his late wife, Dr. Rosemary Dybwad. It was recognized that, "his mind, heart and hand had been visible in virtually every significant legal, ethical, and moral debate during the 20th century on the rights of persons with mental retardation and other disabilities." Gunnar delighted in challenging conventional assumptions, in raising expectations, and in demanding a humane world for all persons, especially those with disabilities.

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## PFRR Joins the Federation

Parents for Residential Reform (PFRR), a grass-roots parent support organization for parents of children with special needs served in residential settings has received funding from the Massachusetts Department of Education. PFRR joins with the Federation for Children with Special Needs in providing information and referral services to families, training activities to assist families in understanding their legal rights, and outreach to families who may require support.

Andrea Watson, parent and founder of PFRR, will staff the project and coordinate its activities. "In the few years PFRR has been in existence, so much has changed. We have better educated consumers, better oversight, less serious incidents, and voices for change that are not only being heard but taken seriously and acted upon. It has been a long haul and so much more needs to be done. Now the next phase begins. Our move to the Federation for Children with Special Needs will benefit all involved. We can learn from each other, and because the Federation is a nationally recognized agency, families and providers involved with residential care will have better access to available resources."

"The addition of PFRR to the Federation's expertise and knowledge base could not come at a better time," commented Suzanne Peyton of the Massachusetts Association of Special Education Parent Advisory Councils. "Students in residential placement are often overlooked when implementing training and outreach programs because they are such a small population. Andrea Watson has worked long and hard for these students' voices, for their concerns, their education, and their lives. We are all enriched by her efforts. We need more outspoken and involved parents such as Ms. Watson to make changes in the bureaucratic morass in which these students are enmeshed."

The Federation, is pleased to welcome PFRR. PFRR has given voice to a group of families who have traditionally been unheard and their needs neglected. Parents need to feel connected and understand their rights under the law. In the past, horrendous abuses have occurred. Families were isolated and lacked knowledge about the systems and services their children were receiving. Our goal is to ensure that every parent is knowledgeable and able to advocate for their child's best interests.

PFRR provides training, workshops, resources, and information. Contact them at 1-800-672-7084, 617-927-0495, [www.pfir.org](http://www.pfir.org), or E-mail: [pfir@fcsn.org](mailto:pfir@fcsn.org).

## GALA 2001: Thanks for a Successful Fundraising Event!

On May 11, 2001, over 300 guests sporting suits, ties, and dazzling dresses, gathered at the Royal Sonesta Hotel in Cambridge to celebrate the 26th Anniversary of the Federation for Children with Special Needs. Not only was it a night packed with fun, food, and lively entertainment, it was also the Federation's most successful fundraising event ever!

It was a picture perfect night that began with a reception in the Skyline Room, overlooking the scenic Charles River. Guests happily enjoyed delectable appetizers, mingled with old friends,

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**Bulletin**  
Parents Learning About Children's Education

## Legislative & Policy Update

# Testimony to the Joint Committee on Education Regarding Massachusetts Special Education Legislation

September 12, 2001

*The following are excerpts from the Federation's testimony. To receive a copy of the entire testimony, call the Federation at 1-800-331-0688 or visit [www.fcsn.org](http://www.fcsn.org).*

Thank you for providing this opportunity to testify about pending legislation on Special Education issues. My name is Richard Robison. I am the Executive Director of the Federation for Children with Special Needs, a parent advocacy organization.

First, I would like to commend this legislature for maintaining or restoring many provisions of special education reform that were passed last year.

However, this body also took action, which as of January 1, 2002, will phase out the Maximum Feasible Benefit (MFB) standard of the pioneer Massachusetts' special education law. This standard, which currently requires public schools to provide special education services that enable all children to reach their maximum potential development, regardless of the severity of their disability, will be replaced by the lesser legal standard known as Free Appropriate Public Education. This issue has been long-debated; this legislature even commissioned a special study, but the impact of this change remains unclear. Yet we know, based on the number of parent calls received at the Federation, that many school districts are using the repeal of the MFB standard as an excuse to cut critical services which are essential to the thousands of children who receive special education services.

More than 80% of all 10th grade students who receive special education failed the MCAS (Massachusetts Comprehensive Assessment System) test. While we are pleased the state has provided more test accommodations, including the alternate versions of the exam, we still have a very long way to go towards ensuring that all students have access to the general curriculum, and the opportunity to learn the material necessary to pass the test. It is a contradiction in policy to reduce the legal standard of service while at the same time, proceeding with the full implementation of a high-stakes educational accountability system. We need to do

everything possible to assist all students in meeting the rigors of education reform, and not remove the educational foundation upon which they must stand. **We urge this legislature to support any legislation (HB 2481, SB310, or SB332) that would maintain the MFB standard.** At a minimum, we urge the support of any legislation (HB998 and SB 333) that would delay any change in standard until students with disabilities are performing at acceptable levels on the MCAS.



For the past decade, the United States Department of Education, Office of Special Education Programs (OSEP) has documented the Massachusetts Department of Education's (DOE's) failure to ensure the full implementation of the IDEA (Individuals with Disabilities Education Act). At present the Massachusetts' Office of Special Services has proposed a "Continuous Improvement Plan" to OSEP, as required in response to our most recent monitoring visit during the 1999-2000 school year. It is also too soon to know if any of the activities proposed by the Massachusetts DOE, or those already implemented, will properly safeguard the needs of students with disabilities in Massachusetts. We urge this legislature to ensure that the Massachusetts DOE is fully equipped to be accountable fulfilling its responsibilities under federal law as the State Educational Agency for the implementation of IDEA. **Therefore, we urge support of SB229 that would delay any change in standard until the state has the systems and procedures in place to comply with the federal law.**

Finally, this legislature promised to provide more resources to school districts that were financially strapped due to the costs

of providing special education services under the MFB standard. Massachusetts is among the states that provide the least support to local school districts for reimbursement of special education costs. It has been argued that there should be no change in the funding formula for special education reimbursement until the MFB issue is resolved. There was even talk of full funding of IDEA at the federal level. While the Congress has called for full funding this year, the Bush Administration is calling for a delay in full funding. **The State must fulfill its responsibility to the local districts and increase special education funding at the local level.**

The Federation for Children with Special Needs believes and the law requires that no student should be denied a free appropriate public education despite the severity of his or her disability. We have actively supported the implementation of education reform with its high standards for all students. The words "No Child Left Behind" are frequently cited, but we are far from that reality. We need this legislature to take strong, decisive action and ensure—for the good of all our children—that no child is left behind.

Respectfully Submitted,  
Richard J. Robison

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Richard Robison

## From the Executive Director

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Gunnar, always the optimist, constantly reminded us that much has been accomplished for people with disabilities over the

last century. In 1994, he presented a paper at the 118th meeting of AAMR entitled *From Feeble-mindedness to Self-Advocacy, A Half Century of Growth and Self-Fulfillment*. In this paper he articulated the accomplishments that took us from the Eugenics movement to the Inclusion movement of today.

Robert Perske, in his book *Hope for the Families*, wrote, "It was Gunnar and Rosemary Dybwad, leaders in the voluntary parent movement in North America, who began calling our attention to the principle of normalization . . ." As a result of their work, Perske noted in another book *New Life in the Neighborhood*, "Today we find that when persons with disabilities are given the same freedom and support to grow and develop as anyone else, they often surprise us. When you begin watching the measurable progress of your neighbor that closely, you get hooked and learn that your friend develops according to his or her own

blueprint of growth—as the rest of us. And you wonder, why wasn't I aware of this before?" By modeling this wondrous awareness, Gunnar and Rosemary helped each of us

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**Even for those  
who never knew  
Gunnar, his imprint on  
this world has brought  
acceptance and hope  
to those society had  
deemed unworthy.**

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to become aware, whether we were their student, a parent of a child with a disability, or a person with a disability.

It's been nearly nine years since Rosemary passed. Some of us speculated that Gunnar would be lost without her—and he was in many ways—but he did not let that squelch his spirit. He went on with his work, and sharing his love, wit and wisdom with so many of us.

In recent years, he finally finished his book *New Voices* and worked with his former students to edit his speeches into the volume *Ahead of His Time*. I always loved to receive his Year-End Letter. In 1998, he spoke of his sadness about the deaths of two younger friends, Herb Lovett and Mary Ann Allard. He wondered why they should precede him in death since their work was not yet done. Recently, he finished organizing the last of his papers and notes and declared his work done.

For me personally, I had the privilege of sitting on his deck, driving him to meetings and using the time for some personal tutorials. During my time here at the Federation, he was a guide, a counselor, and a friend.

Gunnar was aware of the tragic events of September 11, 2001 and remarked in a quiet voice, "I'm not able to fix this one." At 12:30 a.m. September 13, Gunnar entered a peaceful rest. Though his body grew tired, his mind was alive and burning with ideas to the very end. His spirit of optimism lives on in those who have been touched by his love, his urgency, and his passion for all humanity. Even for those who never knew him, his imprint on this world has brought acceptance and hope to those society had deemed unworthy. May he rest in peace.

*Richard J. Robison*

## news in brief

### PASTERNAK TAKES OATH OF OFFICE

On August 8, 2001, **Robert Pasternak** took the oath of office to become the next Assistant Secretary of the Office of Special Education and Rehabilitation Services (OSERS) of the U.S. Department of Education. Pasternak was the state Director of Special Education for New Mexico prior to assuming this position. OSERS oversees the Office of Special Education Programs, which is largely responsible for the implementation of the Individuals with Disabilities Education Act (IDEA).

On August 27, 2001, **Patricia Morrissey** became the Commissioner of the Administration on Developmental Disabilities (ADD) in the U.S. Department of Health and Human Services. Previously, Pat served on Senator Jeffords' staff and was the Deputy Commissioner of OSERS in the U.S. Department of Education.

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# Ask Eileen

## Empowerment Through Information

by Eileen Souza,  
Federation Information Specialist

*Editorial note: Eileen Souza, information specialist at the Federation, retired on August 30, 2001 after 23 years. Graciously, she agreed to submit one last edition of "Ask Eileen." Best wishes, Eileen!*

It has been nearly 25 years since I became an information specialist at the Federation for Children with Special Needs. I've learned a lot over the years as the parent of Elizabeth, my daughter with Down syndrome, and from you, when you called for advice or needed information or a resource. I always thought that once parents understood their rights under special education law my job would be done and there would no longer be a need for a parent center like the Federation. Sad to say, I was wrong.

And so, after reflecting on the kinds of questions I have been asked over the years, I want to conclude this column with what I

think were, and continue to be, the most important things you need to know and do to work effectively on behalf of your child.

- **You are the expert.** No one knows your child better than you do. Through observation, you gather (and store) information about your child's participation in the family, the neighborhood and in the community. This knowledge, when shared, helps others to understand your child. Learn as much as you can about your child's disability(ies). You can do this through reading, lectures, joining your local parent advisory council, attending disability-specific conferences and support groups.
- **Know how the special education laws protect you and your child.** It is important to learn what your rights and responsibilities are under special education laws and to keep up-to date with the periodic changes in the laws, which affect your

child. During the school year, the Federation offers a variety of workshops across the state to help you. If you don't know what the laws say, you can't very well use them to help your child.

- **Learn to clearly communicate your knowledge of your child.** Work cooperatively with the professionals who work with your child. Be prepared to talk about your understanding of your child's needs in a clear, concise, and positive manner. Listen carefully and ask questions so that you understand what others are saying to you.
- **Hold onto your senses.** Common sense combined with a sense of justice and a sense of humor will help you when times are tough.
- **Have a vision.** What are your dreams for your child, your child's dreams for herself or himself? Unless you have an idea about where you're headed you won't know whether you are on the right road or when you have arrived.
- **Use your community voice.** Tell your family's story to help others understand disability issues and to open minds so that diversity is welcomed as an important part of a vibrant community.
- **Take care of yourself.** Parenting a child with a disability requires a lot of time and energy. Give yourself permission to take some time off. Read a good book, go to a movie, take a nap or a walk, and know when to say no.

It has been my privilege to serve so many of you for so long. Your courage and your determination to find the resources to help your children have been an inspiration to me. As I take my leave, rest assured that Federation staff will continue to ask, "How can I help you?" and will be available to listen, to help solve a problem or find a resource.

## Discover IDEA: Supporting Achievement for Children with Disabilities



### Discover IDEA: Supporting Achievement for Children with Disabilities

A video produced by the IDEA Partnership Project and the Council for Exceptional Children

This 15-minute video lets you hear from educators, administrators, family members, and children themselves across the nation who attest to the impact of IDEA in ensuring that children with disabilities learn and achieve to their potential.

Discover IDEA:  
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Disabilities received an Honorable Mention in  
the 2000 Communicator Awards.



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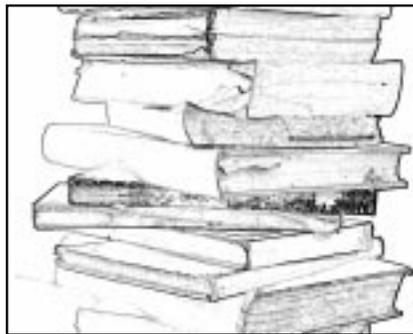
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# Teaching Students with Disabilities to Read

Reading is very important for success in our society, yet as many as one in five students has difficulty learning to read. Most students with learning disabilities, and many students with other types of disabilities, have problems in the areas of reading, writing, and spelling. Most students with disabilities, however, can learn to read. Parents and teachers should consider the different aspects of effective reading instruction when teaching reading to students with disabilities, such as phonological awareness, systematic phonics instruction, word identification, supported passage reading, fluent reading, reading comprehension, and early intervention in reading. (See below for definitions.)

The following information describes key issues or general principles to keep in mind in reading instruction for students with disabilities. These issues are important, regardless of the age or ability level of a student.

- Students with all types of disabilities have the *right* to quality reading instruction, whether they are in elementary, middle, or high school. Parents have the *right* to insist that the school provide instruction designed to help their children with disabilities improve their reading skills. These issues should be addressed in a student's Individualized Education Program (IEP).
- Reading programs for students with disabilities must 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 diagnosis. Every individual student's abilities, needs, and life situation must be carefully evaluated and considered in the IEP in order to design the best reading program for that student.
- Many 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. While modifications are very important, *they should not take the place of*

*instruction* designed to help students with disabilities improve their reading skills.

- Parents should, first and always, communicate with their child's teacher(s). Parents can simply ask their child's teacher(s) what can be done to help the child at home. Parents are also important sources of information about their child's interests, abilities, and effective teaching strategies. Coordination of school and home efforts is one of the best ways to help a student succeed. Strategies to ensure communication and coordination between school and home can be addressed in the student's IEP.
- 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.
- 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 is not the case. 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.
- Although different methods of teaching reading may work equally well with students having various disabilities, students benefit from instruction that is very 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 they master each skill before new ones are introduced.
- **Note for Second Language Learners:** Students who come to school unable to speak English should first be taught to read in their *native language*. Later, as they gain proficiency in spoken English, they should

be taught to extend these skills to reading in English. This practice is not possible in all school situations, however. Instructional materials may not be available in the child's native language, or there may not be a teacher who can speak and read in the child's native language. If students cannot speak English, and they cannot be taught to read in their native language, they should be given time to develop their proficiency in *spoken* English before they begin reading instruction. They need to learn English speech sounds and vocabulary. English reading instruction should begin *after* the student can speak English well enough to benefit from instruction.

Most students with disabilities can learn to read. Reading can open the door to success, enabling students to live independent lives and to succeed in a variety of careers.

*Excerpted and adapted from the PEER Project Literacy Series publication Teaching Students with Disabilities to Read (2000) by Carolyn A. Denton and Jan E. Hasbrouck. PEER (Parents Engaged in Education Reform) is a project of the Federation. To order this publication, see p. 13.*

## Useful Definitions

**Phonological awareness:** the ability to hear separate words, syllables, and sounds in speech; also called phonemic awareness.

**Systematic phonics instruction:** teaching students in a deliberate, organized way to use the sounds of letters and letter groups to read words they do not know.

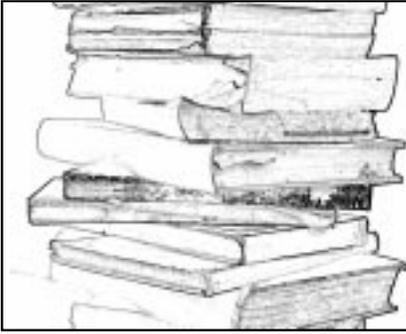
**Word Identification:** recognizing and reading a word.

**Supported passage reading:** An adult or other person is present to assist the student, as needed, in the reading of actual text (stories, books, or articles).

**Fluent reading:** reading smoothly and quickly; recognizing words automatically.

**Reading comprehension:** understanding and remembering what is read. We read to find out what the author of a book, story, or article is telling us.

**Early intervention in reading:** providing a special program to help young children improve their reading and writing skills before they fall behind the other students in their classes.



# Ensinando Os Alunos Portadores de Deficiência a Ler

A leitura é muito importante para o sucesso em nossa sociedade, mas, ainda assim, um em cada cinco alunos tem dificuldade em aprender a ler. A maioria dos estudantes com deficiência de aprendizagem, e muitos outros com outros tipos de deficiência, têm problemas nas áreas de leitura, escrita e de soletrar. Os pais e os professores devem considerar os diversos aspectos de instrução de leitura efetiva, quando ensinam alunos portadores de deficiência a ler, tais como cognição fonológica, ensino sistemático de leitura oral e de soletrar palavras (“systematic phonics instruction”), identificação de palavras, apoio na leitura de passagens, leitura fluente, entendimento de texto e intervenção precoce na leitura.

As informações seguintes descrevem os temas-chaves, ou os princípios gerais, para ter-se em mente quanto ao ensino da leitura para os estudantes portadores de deficiência. Estes tópicos são essenciais, não importando a idade ou o nível de habilidade do aluno.

- Alunos com qualquer tipo de deficiência têm o *direito* a uma ensino de leitura de qualidade, estejam na escola primária (“elementary”), na média (“middle”), ou na secundária (“high school”). Os pais têm o *direito* de insistir que a escola forneça uma instrução designada a auxiliar seus filhos portadores de deficiência a aprimorarem sua habilidade de leitura. Esses tópicos devem ser tratados no Programa de Educação Individualizada (IEP, sigla em inglês, leia-se *ai-i-pi*).
- Os programas de leitura para alunos com deficiência devem ser individualmente planejados com base em suas facilidades e necessidades. Pais e professores não devem fazer julgamentos sobre a capacidade de aprendizagem do aluno, ou sobre a melhor maneira de ensiná-lo(a), baseado somente em sua condição de deficiente ou de algum rótulo. Toda as habilidades individuais do aluno, as necessidades e a situação de vida, devem ser cuidadosamente avaliadas e consideradas no IEP para que se planeje o melhor programa de leitura para aquele aluno.
- Muitos estudantes portadores de deficiência podem precisar de modificações (mudanças) no modo em que recebe asinstruções, assim como no modo em que compreen os requerimentos das aulas, para que obtenham sucesso em áreas como ciências, estudos sociais e de linguagem. Essas modificações são importantes, mas *elas não devem tomar o lugar do ensino* planejado para auxiliar os estudantes com deficiência a aprimorar suas habilidades de leitura.
- Os pais devem, primeiro e sempre, comunicar-se com o(s) professor(es) de sua criança. Eles podem simplesmente perguntar ao professor o que pode ser feito para ajudar a criança em casa. Os pais também são uma fonte de informação importante a respeito dos interesses da criança, das habilidades e de estratégias de ensino efetivas. A coordenação de esforços entre a escola e o lar é uma das melhores maneiras de auxiliar a criança a obter sucesso. Estratégias que garantam a comunicação e a coordenação entre a escola e o lar podem ser endereçadas no IEP do estudante.
- O material utilizado para o ensino de leitura tem de ser, ao mesmo tempo, “nem muito difícil, nem muito fácil”, mas adequado ao nível correto de cada aluno. Verdadeiras leituras de histórias reais, ou outros materiais, devem fazer parte do programa de leitura de todo estudante.
- No passado, acreditava-se que certos métodos de ensino de leitura eram melhores para alunos com certos tipos de deficiência: alguns métodos seriam melhores para alunos com dano no cérebro, outros seriam melhores para alunos com deficiência de aprendizagem, e ainda outros métodos que seriam melhores para alunos com retardamento mental. Este não é o caso. O sucesso de um método de ensino de leitura depende do conteúdo do programa, da maneira como é ensinado, da intensidade da instrução (por quanto tempo e quão ativamente ele é ensinado), assim como das necessidades e facilidades de cada individuo.
- Mesmo que métodos diferentes de ensino de leitura possam funcionar igualmente bem para alunos que tenham deficiências variadas, eles se beneficiam do ensino que seja bem estruturado e sistemático. A técnica de leitura deve ser apresentada em ordem e com cuidado, devendo-se dar aos alunos uma boa dose de prática e repetição em cada nível, para que aprendam bem cada etapa antes que outras sejam introduzidas.
- **Nota aos estudantes que têm o Inglês como Segunda Língua:** Os estudantes que vão para a escola sem saber falar inglês devem, primeiro, serem ensinados a ler em sua *língua materna*. Mais tarde, quando adquirem mais

proficiência no inglês falado, eles devem ser ensinados a ampliar essa habilidade para ler em inglês. Essa prática, contudo, não está garantida a todo momento e em todas as escolas. Os materiais de ensino podem não estar disponíveis na língua materna da criança, ou pode ser que não haja um professor que leia e fale a sua língua. Se os alunos não falam inglês e não há como serem ensinados em sua própria língua, deve-se conceder-lhes um tempo para que desenvolvam o inglês *falado* antes que iniciem o ensino de leitura. Eles precisam aprender os sons da fala inglesa e o vocabulário. O ensino de leitura em inglês deve ser iniciado *depois* que o aluno possa falar bem o inglês, para que se beneficie, assim, da instrução.

A maioria dos estudantes portadores de deficiência podem aprender a ler. A leitura pode abrir as portas para o sucesso, capacitando-os a viver independentemente e a obter êxito numa variedade de carreiras.

Citado e adaptado do PEER Project Literacy Series publication *Teaching Students with Disabilities to Read* (2000), de Carolyn A. Denton e Jan E. Hasbrouck. PEER (Parents Engaged in Education Reform) é um projeto da Federação. Para solicitar essa publicação, veja p. 13.

## Definições úteis

**Cognição fonológica:** a habilidade de ouvir palavras separadas, sílabas e sons da fala; também chamada de cognição fonética (ou fonêmica).

**Ensino sistemático de leitura oral e de soletrar palavras (“Systematic phonics instruction”):** ensinar os alunos de um modo deliberado e organizado a como usar os sons das letras e dos grupos de letras para ler palavras que ainda não conhecem.

**Identificação de palavra:** reconhecer e ler uma palavra.

**Apoio na Leitura de Passagens:** ler textos de verdade (histórias, livros, artigos) com a ajuda de um adulto ou outra pessoa para auxiliar o aluno, de acordo com a necessidade.

**Leitura fluente:** ler suave e com rapidez, reconhecendo as palavras automaticamente.

**Entendimento de texto:** entender e lembrar o que é lido. É o propósito da leitura. Lemos para saber o que o autor de um livro, história ou artigo está a nos dizer.

**Intervenção precoce na leitura:** um programa especial para ajudar as crianças mais novas a melhorar a sua leitura e escrita, antes que se atrase em relação aos demais alunos da classe.



# Enseñando a Leer a Estudiantes con Discapacidades

Leer es muy importante para tener éxito en nuestra sociedad. Sin embargo uno de cada cinco estudiantes tiene dificultades para aprender a leer. La mayoría de los estudiantes con discapacidades de aprendizaje, y otros estudiantes con otras clases de discapacidades, tienen problemas en las áreas de lectura, escritura y ortografía. Los padres de familia y los profesores al momento de enseñar a leer a estudiantes con discapacidades deben considerar los distintos aspectos de instrucción de lectura efectiva tales como conocimiento fonológico, instrucción sistemática fónica, identificación de palabras, apoyo en la lectura de pasajes, lectura fluida, comprensión de lectura e intervención temprana en lectura.

La siguiente información describe aspectos claves o principios generales para tener en cuenta al enseñar a leer a estudiantes con discapacidades. Estos aspectos son importantes sin importar la edad o el nivel de habilidad de un estudiante.

- Los estudiantes con toda clase de discapacidades tienen el *derecho* a una enseñanza de la lectura con calidad sin importar si se encuentran en la escuela elemental, media o superior. Los padres tienen el *derecho* de insistir que la escuela provea la instrucción diseñada para ayudar a sus hijos con discapacidades a mejorar sus habilidades para leer. Estos aspectos deben ser señalados en el Programa de Educación Individualizado (IEP) del estudiante.
- Los programas de lectura para los estudiantes con discapacidades tienen que ser diseñados de manera individual basados en las fortalezas y necesidades del estudiante. Los padres y los profesores no deben hacer ningún juicio sobre la habilidad de un estudiante para aprender, o cuál es la mejor manera de enseñarle, basados solamente en la condición o en el nombre de la discapacidad. Cada una de las habilidades, necesidades y situaciones de la vida del estudiante como individuo tienen que ser evaluadas cuidadosamente y consideradas en el IEP para así poder diseñar el mejor programa de lectura para el estudiante.
- Muchos estudiantes con discapacidades pueden necesitar de modificaciones (cambios) en la manera como reciben la instrucción y en la manera como cumplen con los requisitos para tener éxito en áreas tales como ciencias, estudios sociales y lenguaje. Estas modificaciones son muy importantes pero *éstas no deben tomar el lugar de la instrucción* diseñada para ayudar

a los estudiantes con discapacidades a mejorar sus habilidades de lectura.

- Los padres deben, primero que todo y siempre, comunicarse con el o los profesores de su niño. Los padres simplemente pueden preguntarles a los profesores que pueden hacer para ayudar a sus hijos en la casa. Los padres también son fuentes importantes de información sobre los intereses, habilidades y estrategias efectivas de aprendizaje del niño. La coordinación de los esfuerzos entre la escuela y el hogar es una de las mejores maneras de ayudarlo al estudiante a alcanzar sus metas. Las estrategias para asegurar la comunicación y la coordinación entre la escuela y la casa pueden ser anotadas en el IEP del estudiante.
- El material que se use en las clases de lectura no debe ser “ni muy difícil, ni muy fácil” sino de acuerdo al nivel del estudiante. La lectura de historias reales u otros materiales debe ser parte del programa de lectura del estudiante.
- En el pasado algunas personas creían que ciertos métodos de enseñanza de la lectura eran mejores para estudiantes con discapacidades: que algunos métodos eran mejores para estudiantes con lesiones cerebrales, que otros eran mejores para estudiantes con discapacidades de aprendizaje, y aún otros eran mejores para estudiantes con retardo mental. Este no es el caso. El éxito de un método de enseñanza de la lectura depende del contenido del programa, la manera como es enseñado, la intensidad de la instrucción (cada cuando y cuán activamente es enseñado), y de las necesidades y fortalezas de cada estudiante.
- Aunque diferentes métodos de enseñanza de la lectura pueden funcionar bien con estudiantes que tengan varias discapacidades, los estudiantes se benefician cuando se les provee una instrucción sistemática y estructurada. Las habilidades para leer se deben introducir cuidadosamente en orden, y los estudiantes tienen que tener la oportunidad de practicar y repetir cada habilidad de tal manera que puedan dominar cada una antes de que una nueva sea enseñada.
- **Nota para quienes aprenden un segundo idioma:** Los estudiantes que vienen a la escuela sin poder hablar inglés primero deben aprender a leer en su *lenguaje materno*. Más adelante, a medida que ganan habilidad para hablar inglés entonces deben ser llevados a aplicar estas destrezas al leer en inglés. Sin embargo, esta

práctica no es posible en todas las situaciones escolares. Los materiales para la instrucción pueden no estar disponibles en el idioma materno del niño, o puede que no halla un profesor(a) que hable y lea el idioma del niño. Si los estudiantes no pueden hablar inglés y tampoco se les puede enseñar a leer en su propio idioma, deben recibir el tiempo necesario mientras ganan las habilidades necesarias para hablar inglés antes de comenzar las clases de lectura. Estos estudiantes necesitan aprender los sonidos de las combinaciones en inglés y vocabulario. La enseñanza de la lectura debe comenzar *después* de que el estudiante pueda hablar suficiente inglés para que se pueda beneficiar de la instrucción.

La mayoría de los estudiantes con discapacidades pueden aprender a leer. El hecho de leer les puede abrir las puertas al éxito capacitándoles para tener vidas independientes y para sobresalir en una gran variedad de carreras.

[Tomado y adaptado de PEER Project Literacy Series publication *Teaching Students with Disabilities to Read (2000)* por Carolyn A. Denton y Jan E. Hasbrouck. PEER (Parents Engaged in Education Reform / Padres Unidos en la Reforma de la Educación) es un proyecto de la Federación. Para ordenar esta publicación, vea la página 13.]

## Definiciones Útiles

**Conocimiento fonológico:** Habilidad de escuchar palabras, sílabas y sonidos por separado en un discurso. También es llamado conocimiento de fonemas.

**Instrucción sistemática fónica:** Enseña a los estudiantes como usar de manera deliberada y organizada los sonidos de las letras y grupos de letras para leer palabras desconocidas.

**Identificación de palabras:** Reconocer y leer una palabra.

**Apoyo en la lectura de pasajes:** Leer un pasaje simplemente consiste en leer un texto concreto (historias, libros o artículos.) En el apoyo de lectura de pasajes un adulto u otra persona está presente para ayudar al estudiante según lo necesite.

**Lectura fluida:** Leer suave y rápidamente reconociendo palabras de manera automática. Comprensión de lectura: Entender y recordar lo que se ha leído. Es el propósito de la lectura. Leemos para saber lo que el autor de un libro, historia o artículo nos está diciendo.

**Intervención temprana en lectura:** Proveer un programa especial para ayudar a niños pequeños a mejorar sus habilidades para leer y escribir antes de que se queden atrás de los demás estudiantes en sus clases.

# Upcoming Federation Workshops

For more information about a workshop, or to register, call the Federation at 1-800-331-0688. Call to find out about Basic Rights workshop in Portuguese. Ligue para informação sobre aulas iniciando em Português.

## NOVEMBER 2001

- 7th:** Milford, 7-9 PM, *IEP 2000*  
**8th:** Sharon, 7-9 PM, *Access to the General Curriculum*  
**13th:** Beverly, 7-9 PM, *Basic Rights*  
**14th:** Townsend, 7-9 PM, *Basic Rights*  
**15th:** Haverhill, 7-9 PM, *Basic Rights*  
**19th:** Somerville, 7-9 PM, *Access to the General Curriculum*  
**27th:** Sudbury, 6-8 PM, *Access to the General Curriculum*  
**29th:** Marlboro, 7-9 PM, *Effective Communication*

## DECEMBER 2001

- 3rd:** Georgetown, 7-9 PM, *MCAS*  
**5th:** Ashland, 7-9 PM, *Basic Rights*  
**5th:** Lawrence, 6:30-8:30 PM, *Basic Rights in Spanish*  
**6th:** Holyoke, 7-9 PM, *IEP 2000, simultaneously in English & Spanish*  
**6th:** Danvers, 7-9 PM, *Effective Communication*

## JANUARY 2002

- 5th:** Needham, 7-9 PM, *Basic Rights*  
**14th:** Marblehead [snow date 2/11], 7-9 PM, *Access to the General Curriculum*  
**15th:** South Medford, 7-9 PM, *Basic Rights*  
**16th:** Medway, 7-9 PM, *IEP 2000*  
**17th:** Lunenburg, 7-9 PM, *MCAS*  
**24th:** Melrose, 7-9 PM, *IEP 2000*

## WORKSHOP DESCRIPTIONS

**Basic Rights:** Covers basic information about state (Chapter 766) 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 and conflict resolution skill building for parents' members of IEP Teams.

**IEP 2000:** 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 IEP Development (14-22):

The IEP 2000 for students 14 and older. The workshop provides basic information on the state and federal laws, which require IEPs to address goals in areas such as competitive employment, independent living and full integration into community life that will help prepare students, 14 and older, with planning transition to adult life.

## 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 criteria that will allow students with disabilities to more fully participate in, and have access to, the general curriculum.

## Effective Inclusion of Students with Disabilities in the MCAS Testing System:

Includes information about IEP Team determination of the appropriate method for students to participate in the MCAS testing system. The workshop covers taking the standard paper-and-pencil version of MCAS, accommodations available to students with disabilities, and information on the MCAS Alternate Assessment.

Lawrence Kotin, Esq., Robert K. Crabtree, Esq., Richard F. Howard, Esq.

### Welcome to their practice: Maura J. Kelly, Esq.

Providing representation to children and adults with disabilities, and their families.

Ms. Kelly was most recently at Holland and Knight. Prior to that she served as General Counsel for Lesley College and was a staff attorney at the Center for Law and Education.

## 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, representation of child care and other organizations, real estate, taxation and mediation.

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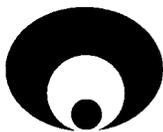


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## Early Childhood Corner



Highlighting information of interest to parents of children under five and their professional partners, particularly Early Intervention service providers. Sponsored by the Federation's Early Intervention Training Center.

## Early Intervention Training Center Workshop Schedule: November - December 2001

Early Intervention staff, families and other early childhood personnel are invited to attend. Unless otherwise noted, workshops are from 9 AM to 3:30 PM. Attendance is free; snacks and lunch are provided. For more information, call 800-331-0688 ext. 159, or register on-line at [www.eitrainingcenter.org](http://www.eitrainingcenter.org).

### NOVEMBER 2001

#### November 7:

*Team Collaboration: Making it Work Together*  
Federation for Children with Special Needs, Boston

#### November 13:

*Building a Community, Part 1*  
Department of Public Health, Northampton

#### November 27:

*About Families: Implementing a Family-Centered Approach*  
Merrimack College, North Andover

### DECEMBER 2001

#### December 11, 2001

*Partnerships with Families: Implementing Services and Supports*  
College of the Holy Cross, Worcester

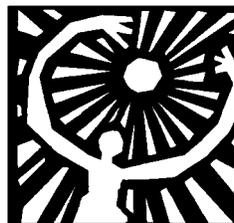
#### December 14:

*Building a Community, Part 2*  
Reggie Lewis Center, Boston

#### December 19:

*Building a Community, Part 1*  
Stonehill College, Easton

*The Early Intervention Training Center at the Federation is funded by the Massachusetts Department of Public Health.*



## Creating a World of Opportunities

### SAVE THE DATE! Annual Federation Conference Earlier Date February 9, 2002

At the Boston World Trade Center

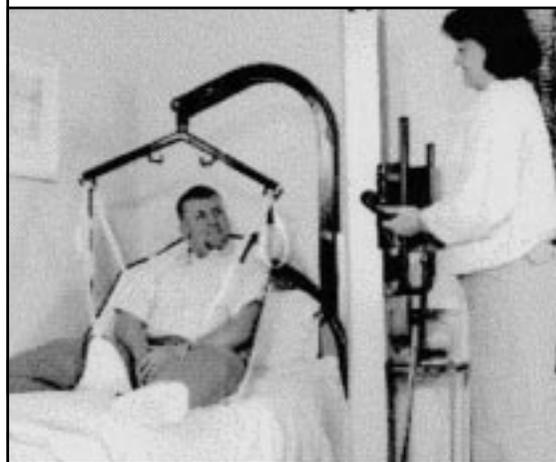
See page 16 for details, or go to our website for additional information and registration materials: [www.fcsn.org](http://www.fcsn.org).

You can also call 617-236-7210 ext. 199 or email [conf2002@fcsn.org](mailto:conf2002@fcsn.org) to register.



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## Project Update: National ICC Parent Leadership Support Project

In May, the National ICC (Interagency Coordinating Council) Parent Leadership Support Project held an Institute in Atlanta, under the leadership of co-directors, Rich Robison and Barbara Popper. Massachusetts and Rhode Island were among the five states that sent a team of parents to participate in this four-day training, which covered various topics, including communication, conflict resolution, and reciprocal outreach. Each team created a plan to carry out in their state, which would help provide leadership training to other parents. The Massachusetts' team presented their plan to the Massachusetts ICC in June. They are working towards

the implementation of a Family Mentoring Program for the statewide early intervention system. Rhode Island, working with the Federation, is planning an October retreat for parent leaders, facilitated by Barbara Popper and Ruth-Ann Rasbold. In October, the National ICC Parent Leadership Support Project will hold an Institute in Framingham. Maine and Connecticut will be two of the five participating states. A third Institute is planned for Spring 2002. For more information about this project and its goals, check out the website at [www.iccparent.org](http://www.iccparent.org) or contact Brad Arndt or Marilyn Gutierrez at the Federation.

# Help Us to Help You: The Federation Annual Campaign 2001

Dear NewsLine Reader,

On January 1, 2002, Massachusetts will formally replace the Maximum Feasible Benefit standard with the federal standard known as Free Appropriate Public Education. As you are aware, this is a change the parent and advocacy communities had hoped to avoid. On September 12, 2001, the Joint Committee on Education of the Massachusetts Legislature heard testimony on several bills to restore or delay this change. Despite our best efforts, this change in language will be implemented as planned.

Parent advocacy must remain strong and vigilant as this dramatic change takes place. It is crucial that parents know their rights and become familiar with the special education laws. In past years the Federation provided training events statewide on a host of essential topics, including Basic Rights, How to

Develop IEP's, Access to the General Curriculum, Discipline, MCAS for students with disabilities, and others. More than 600 people attended our annual conference. Our web site is receiving more than 35,000 hits a month, a 30% increase over last year. *NewsLine* circulation is up by 26% and is now mailed to 26,000 readers.

Last year, more than 350 individuals and families contributed \$35,000 to the Federation's annual fund campaign, which supports many of these activities. While there are many compelling causes that need your support this year, **even a small donation from every *NewsLine* reader will help keep us strong.**

Please consider a \$1, \$5, \$10 gift or more. Send it today or visit [www.fcsn.org](http://www.fcsn.org) to donate online.

Thanks for your generosity.



**Parent advocacy must remain strong and vigilant as this dramatic change takes place. It is crucial that parents know their rights and become familiar with the special education laws.**

**\* \* \* PLEASE MAKE A CONTRIBUTION TODAY \* \* \***

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# GALA 2001

continued from page 1

made new acquaintances, purchased balloons with surprise gift certificates and actively bid on a vast array of silent auction items. There was something for everybody—whether it be museum passes, a Newbury Street haircut, an elegant dinner for two at L’Espalier Restaurant, a night’s stay at the Seaport Hotel, or a getaway weekend in the Berkshires.

Our emcee for the evening was Ed Harding from Channel 5 News. Ed’s sense of humor was in keeping with the festive spirit of the evening. Red Sox fans were grateful for his periodic updates of the evening’s game. After an elegant dinner, a sumptuous dessert was served, while Jake Armerding and his father, Taylor played the violin and mandolin to a bluegrass beat that had guests’ toes tapping.

The climax of the evening was the presentation of the Martha Ziegler Founder’s award. This year’s recipient was Dr. William Henderson, Federation Board Member and renowned principal of the Patrick O’Hearn School in Dorchester. Dr. Henderson’s work as an outstanding principal in a school that fully includes students with disabilities has earned him the love and respect of teachers and parents. Under his leadership, the O’Hearn has gained national recognition for its excellent educators. As teachers read from a selection of student letters about their principal, it was easy to understand why Dr. Henderson is so admired and respected. The students described Dr. Henderson as their “friend,” and as “fun.” They expressed their awe at his ability to greet every child by name as he or she stepped off the school bus. Everyone agreed he is a “totally awesome” principal and gave him a standing ovation.

The Federation would like to thank everyone who donated their time, energy and financial support to Gala 2001, which raised over \$130,000. We extend our heartfelt gratitude to the countless sponsors, including NSTAR—a new sponsor this year. Thanks also to the silent auction donors and contributors who helped make this event a success. All proceeds benefit the Federation, ensuring our continued growth, as well as enhancing the Federation’s capacity to meet the challenges of this century.



Director of Development Brooke Heraty and Gala Emcee Ed Harding, News Anchor WCVB-TV, Channel 5



Rhea Tavares, Federation Volunteer, and Israel dos Santos, Vice-consul of Brazil



Martha Ziegler presenting the Martha Ziegler Founder’s Award to Bill Henderson, Principal of the O’Hearn School, Dorchester



Rich Robison with Nora Wells, keynote speaker for the upcoming Federation Conference to be held February 9, 2002



Tom Hausslein, Linda Cohen, Beth Glavasky, and Stephanie Weaver

# Transition in Health Care. . .

## Taking Charge of the Transition Planning Process

Transitions are part of everyone's life. They span a lifetime and at each pivotal transition point there is excitement, anticipation, confusion, and anxiety. Nowhere is the process more intense and important than when a child prepares to move on to adulthood. For students with disabilities this transition begins in school at age 14 and continues through age 21, if necessary. At this critical juncture in the transition planning process, parents and students must be informed, proactive, involved, and hopeful.

At age 14, the "statement of transition service needs" on the IEP identifies courses of study that a student needs to take in high school to support his "vision" of life after high school. Typically students choose business, college, and vocational or other key courses to prepare them for future experiences. Students with disabilities need to look at high school preparation in the same way, choosing coursework to prepare them for their next step.

The academic supports/strategies that are necessary for a student to have success in general curriculum choices are included on page 2 of the IEP. Be sure to also check out extracurricular opportunities like drama, chorus, a club, or a sport. These experiences expose students to other learning networks, enhancing both their understanding of a particular subject or interest, while at the same time broadening a student's social experience, affording him/her the opportunity to try out new social connections.

While there are many opportunities in the community that can and should be part of a comprehensive transition plan, be sure you don't give up exciting learning experiences during the school day. Access to daily living skills and community-based activities that support a student's vision can be achieved after school and/or on the weekends.

Transition services should be woven throughout the student's IEP. On page 3, transition services are documented as "Other Educational Needs" and include: social/emotional needs, extracurricular activities, travel training, assistive technology, communication, and vocational education, to name a few. Transition goals are identified to support desired outcomes in adult life and are developed alongside other important IEP goals.

High school is a time to explore a spectrum of learning experiences. Each new opportunity gives the student more insight to future possibilities and choices. Ongoing exploratory experiences enhance a student's decision-making skills, preparing him/her for greater participation in "student-driven" transition plans.

This is also the time to prepare for future good health. Be aware of special health care needs and the skills a student will need to be more independent at home, in school, and in the workplace. Developing responsibility for the management of your health care will increase a student's level of independence in adulthood.



For example, can the student:

- Use a thermometer?
- Understand basic "over-the-counter" medicines.
- Take responsibility for her medications and refill prescriptions?
- Perform basic first aid?
- Access and understand his medical records?
- Share information about her disability as needed?
- Schedule medical appointments and transport himself?
- Talk with a healthcare professional?
- Understand vital statistics, height, weight, birthplace, allergies etc. and have information available in an emergency?

A comprehensive transition plan begins with a vision from which a structured path of learning evolves. The plan is the bridge from high school to a rewarding adult life experience. The better parents and students are at defining a vision, the clearer and easier it will be to achieve it!



*Russ and the Almost Perfect Day* is the latest in Janet Elizabeth Rickert's series of books featuring her son, Russ, a child with Down syndrome. Janet has written stories about Russ since he was a toddler, and now we follow Russ through a seemingly ideal day. Starting with his favorite breakfast of S'mores, Russ encounters a day comprised of simple, unexpected pleasures. On the way

## Book Review:

### *Russ and the Almost Perfect Day*

by Cara Donahue, PTI Associate

to school, Russ even finds a five-dollar bill! Rather than bring the money to the Lost & Found, Russ plans to buy ice cream for himself and his friend Kevin, later at lunch. Kevin reminds him, "Finders keepers, losers weepers."

That phrase, which seemed so logical and easy to agree with in the morning, makes Russ uneasy as Russ and Kevin go to buy ice cream. They see a little girl crying because she's lost her birthday money. Russ goes through all of the questions one should, carefully weighing his and Kevin's anticipat-

ed desires against the sadness of a peer. "We don't even know it's her money," Kevin reminds Russ. Ultimately, however, Russ decides, "maybe losers weepers isn't such a good idea." Maybe satisfying a personal wish is not worth someone else's tears. Russ's thought processes and final decision remind the reader, adult and child alike, that it is the seemingly insignificant choices that can be the hardest, and that often the smallest sacrifices reveal a lot about a person's character. Janet Elizabeth Rickert demonstrates to the reader her son's ability to teach other children to make the right choices, and understand how rewarding that can feel.

Recommended for children ages 3-8.

Rickert, Janet Elizabeth. *Russ and the Almost Perfect Day*. Maryland: Woodbine





# Health News

from FAMILY VOICES

at the Federation for Children with Special Needs

## Family Voices in SCHIP

by Barbara K. Popper, Director

State Children's Health Insurance Program (SCHIP) is a joint program of Medicaid and the Maternal Child Health Title V programs at the National and State level. The Federation's Family Voices in SCHIP Implementation Project is watching out for changes in Medicaid and SCHIP Programs that may result from the Health Insurance Flexibility Accountability Initiative (HIFA), announced by the Bush Administration in August. Family Voices has a fact sheet on its website ([www.familyvoices.org](http://www.familyvoices.org)) outlining some provisions of the initiative.

In collaboration with the Children's Health Advocacy Coalition at Health Care for All, the project is beginning to formulate questions for state officials, in regards to the HIFA Initiative, before the state loses any of the gains made under SCHIP. It is hoped that Massachusetts will not make changes in Medicaid and SCHIP programs, since Massachusetts currently has some of the best statistics for children's health in the country. However, if state funds become limited, all programs are vulnerable and it could potentially impact CommonHealth coverage for children and adults with disabilities.

The project is in favor of providing health insurance to all eligible, uninsured

individuals, but is concerned that having a fixed amount of money to provide coverage to a greater number of children may force states to reduce benefits. For some states, children with special health care needs will have the protection of special programs or wrap-around benefits, but for other children, having only minimal benefits may have a negative impact that is contradictory to the original intent of the SCHIP legislation.

The Schip implementation project has developed SCHIP Profiles for every state (which appear on the Family Voices website). The Massachusetts profile provides information about, and contact information for, the SCHIP Insurance Program under MassHealth. The profile also provides the health performance indicators that the Massachusetts Department of Public Health must report to the federal government as part of their request for Title V funds. Of particular interest is the performance indicator for family involvement in Title V programs.

The Federation will keep you up-to-date about any proposed changes to the programs in Massachusetts. If you are interested in working on this topic, contact Marilyn Gutierrez or Barbara Popper at the Federation.

about promoting partnerships with families and communities.

*Copies of this publication are \$28.00 and are available from the National Maternal and Child Health Clearinghouse at 1-888-434-4MCH or [www.nmchc.org](http://www.nmchc.org).*

## Joining Voices

On June 13, 2001, Massachusetts Family Voices at the Federation for Children with Special Needs, in collaboration with the Children's Health Quality Initiative at Health Care for All, hosted "Joining Voices, a Conference to Support Parent Leaders in Advocating for Children with Special Health Needs." Parents, those working as paid parent-professionals, and those who volunteer their time to advocate for children with special health needs, had an opportunity to get together with old friends, make new ones, collect resource materials, support each other in their work, network and learn how to balance the demands of their work in the disability field with the challenges of raising their own children with special health needs.

This was also an opportunity for Massachusetts Family Voices to collect information about important health care issues and concerns for children with special health care needs in Massachusetts. These issues include:

1. Educated parents are essential to getting quality health care. They need to educate themselves, trust their instincts, advocate for themselves and others, and find the right people to understand their concerns and support them.
2. Educating health care providers is crucial so they can learn what the child needs, respect information provided by the parents, understand what they hear, and know when it is appropriate to include the child in the discussion.
3. Insurance - many services are not covered, mental health is limited, and some children who need services get caught between educational needs and medical needs on their IEPs.
4. Early screening for mental health issues is crucial.
5. Screenings to identify dental health needs are necessary.

The Children's Quality Initiative invites families to attend a meeting on November 6 in Boston on Dental Health Access for Children in Massachusetts. For more information, contact Barbara Popper at [bpopper@fcsn.org](mailto:bpopper@fcsn.org).

## Bright Futures in Practice: Physical Activity

Patrick, K., Spear, B., Holt, K., Sofka, D., eds. 2001.

Designed for health professionals, this guide provides an overview of physical activity issues and concerns, as well as strategies and tools for health promotion and disease prevention for children, birth to age 21. Developmentally appropriate physical activity supervision is addressed. This publication also includes information

**FAMILY VOICES**

*is a national grassroots organization of families and friends speaking on behalf of children with special health care needs. The Federation is one of the founding members of Family Voices and conducts Family Voices projects from the Federation office in Boston.*

# The Problem of Graduation- Email Responses Received



Our thanks to all who responded to the "Problem of Graduation" article in the last edition of *NewsLine*. Here are some of the situations people are experiencing and questions they have:

- My daughter has been on an IEP since the first grade. On paper she has enough credits to graduate, but her program and our school district agree she would benefit from another year of high school. However, if she remains in school for another year, she will have to face the MCAS requirement. She will never be able to pass the math portion of the test, and I don't want to risk her diploma. I am so angry she is caught in this MCAS bind!
- Can my son go to a community college with a Certificate of Completion? Can he still be on an IEP?
- Last fall I had to put a "Request to Graduate" in writing to our principal, who then convened a meeting of the "academic review panel" to consider the request. We went to the meeting with representatives of several agencies to show that we were willing to collaborate, negotiate, and share responsibility. The request was denied on the grounds that it would set a precedent that students would be supported by the school district after graduation. We expected this response and organized a letter-writing campaign. We won the right for my son to "walk" across the stage with his class and participate in class activities. The school

wasn't opposed to providing services; they were concerned about the graduation ceremony itself. We have since discovered this is a very common concern.

- My daughter, who has Down syndrome, has just graduated with her classmates from our regional high school. She is 19. Now she is enrolled in a community college. She attended her junior and senior proms and even earned a varsity letter in track. While she failed the MCAS, she did score higher than a 220 on the science portion of the test. All of this was accomplished with good people of vision, determination, and perseverance.
- A mother of an 18-year-old son with Down syndrome shared that she has always worked to be sure her child is integrated into the school as much as is possible. When she told his Team she wanted him to go to the prom and wear a cap and gown, the school district representative looked at my son and said, "Well, I don't believe he will pass the MCAS test." This mom continues to advocate for her child and hopes the school will figure out a way to allow students with disabilities to wear a cap and gown so they will know what accomplishment feels like. She doesn't feel like this is too much to ask.

## Support Group in Spanish

The Federation for Children with Special Needs is pleased to announce the return of the Community Outreach and Empowerment Project (COEP), funded by the Boston Foundation.

COEP supports the group "Familias Latinas Unidas por el síndrome de Down," (Latino Families United for Down Syndrome). This group is dedicated to supporting and empowering families of children with Down syndrome. The group meets one Saturday a month from 10 am – 12 noon. For more information, please call Diana Rocha at 617-236-7210, x 171.

## Grupo de Apoyo en Español

La Federación para Niños con Necesidades Especiales se complace en anunciar el regreso de Community Outreach and Empowerment Project (COEP), con fondos del Boston Foundation.

COEP apoya al grupo "Familias Latinas Unidas por el Síndrome de Down." El grupo se dedica a apoyar y aumentar el liderazgo de las familias que tienen niños con el síndrome de Down. Este grupo se reúne un sábado al mes, de 10 a.m. a 12 p.m. Para más información, llame a Diana Rocha al 617-236-7210, x 171.

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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 a grant from the U.S. Department of Education, Office of Special Education and Rehabilitative Services. 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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*The Federation extends its sympathy to all those who have been affected by the recent, tragic events that took place in our nation. See our website for information on how to help children during this difficult time.*

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## EXECUTIVE ASSISTANT

### Summary:

Provides administrative support to the Executive Director and the Director of Development.

### Qualifications for the position:

- Associate's degree required, Bachelors preferred. Additional experience may be substituted for educational requirements.
- Minimum of two years of administrative office experience.
- Excellent computer skills and advanced knowledge of Microsoft Word, Excel, Access, Outlook, PowerPoint, FileMaker Pro, and the Internet.

This is a full-time position, compensation commensurate with experience; full benefits package is available.

The Federation encourages parents of children with special needs to apply. To apply, please send resume and cover letter to:

**Richard J. Robison**  
Federation for Children with Special Needs  
1135 Tremont Street, Suite 420  
Boston, MA 02120

The Federation is an Equal Opportunity/Affirmative Action Employer



# Creating *a World of* Opportunities

## SAVE THE DATE!

### *Annual Federation Conference* **Earlier Date, February 9, 2002**

At the Boston World Trade Center

Co-sponsored by Family Ties, Family Voices, PAL,  
Massachusetts Families for Organizing for Change

**Keynote speaker:** Nora Wells, Family Voices at the Federation  
"Making Your Voices Count"

Note: There will be 30 workshops, many exhibitors, free resources,  
and NEW assistive technology strand.

**Plan to attend! Check our web site for additional  
information and registration materials at [www.fcsn.org](http://www.fcsn.org).**

**You can also call 617-236-7210 ext. 199  
or email [conf2002@fcsn.org](mailto:conf2002@fcsn.org) to register.**