



NewsLine

The Federation for Children with Special Needs

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Old and New Friends Meet at Federation Open House

On June 21, over 130 people attended the Federation's "Open House." To celebrate our new office space, the Federation doors and offices opened to greet new and old friends. Special guests included staff members from the Massachusetts Departments of Education, Mental Health, and Public Health, Brandeis University, Children's Hospital, and Greater Boston Arc, as well as students, self-advocates, and parents. Balloons, flowers, and paintings by Jessica Vohs adorned the newly renovated offices and hallways of Suite 420 at 1135 Tremont Street. All agreed that the Federation's new home was worth waiting for. Why not come and see for yourself?



Federation Project Updates

MIYD - Massachusetts Initiative for Youth with Disabilities (MIYD):

Sandy Blanes, Coordinator of the Federation's satellite office at the Greater New Bedford ARC, has met with local groups to generate interest in social and recreational activities for youth between the ages of 14 and 22. The groups have formed the Greater New Bedford Youth Social and Recreational Activities Coalition.

MIYD aims to support the long-term inclusion of youth with disabilities into community recreational activities. The project will work first with youth to identify their interests in a particular activity. Then, the young people will receive the information and support they need to participate. The intention is to provide support until the young people are confident and able to continue on their own.

The local YMCA is very supportive of this initiative. Once a survey has been conducted to identify overall interests in the areas of social and recreational activities, the Coalition will approach other groups to invite their collaboration.

Portuguese Outreach Program:

POP is going strong, giving presentations (in Portuguese and English) on special education at community-based organizations, churches, and clubs across the state. In addition, Portuguese translations of *The Parent Manual* and articles for *NewsLine* continue. POP has conducted several Basic Rights Workshops in Portuguese and looks forward to preparing more parents who are bilingual or who have limited proficiency in English to advocate for their children. In addition, several Portuguese-speaking parents and professionals have completed the Parent Consultant Training Course. These parents are much needed additions to the Federation's growing list of bilingual advocates trained by the Federation!

For more information, call Sandy Blanes at 617-236-7210 or 800-331-0688.

PAL METRO BOSTON Family Fair

To celebrate Children's Mental Health Week (May 2-8), the Federation's Parent Professional Advocacy League (PAL) Metro Boston Project held a Family Fair on Saturday, May 1, at the Federation's new offices in Roxbury.

Children's Mental Health Week is intended to raise awareness of children's mental health and to reduce the stigma associated with mental illness. The goal for the Fair was to accomplish these purposes in a fun, relaxed environment that encouraged family and community participation. Often, families of children with special needs are uncomfortable bringing their children into social situations, fearing that they will be perceived as difficult or disruptive. Families from a variety of ethnic and linguistic backgrounds and children with varying

Legislative & Policy Update

Major Efforts to Change Special Education Law

Major changes to Chapter 766, the Massachusetts special education law, are moving forward in two separate but interrelated forums. First, as described in previous issues of *NewsLine*, several bills have been filed in the State House calling for significant changes to the law itself. The Joint Education Committee is scheduled to hold a hearing on these bills in the fall, after completion of the Legislature's study of "maximum feasible benefit," the state standard for the provision of special education services.

Meanwhile, the Massachusetts Department of Education (DOE) issued proposed changes to the Chapter 766 Regulations for public comment during April and May. Public hearings elicited testimony from parents, educators, and advocates, as well as the Federation.

The state legislature was concerned that DOE was attempting to circumvent the legislative process by implementing a major overhaul of the Chapter 766 Regulations *before* the study of the maximum feasible benefit standard was completed. To prevent this, the Legislature passed an amendment banning any change to the Regulations until the study is completed.

To complicate the situation even further, the Massachusetts Board of Education considered a *revised* set of proposed regulations at its June meeting. The revisions to the proposed Regulations took into account issues raised at public hearings. At the meeting, the Board voted to delay voting on the majority of the proposed regulations until March of 2000.

However, the Board did vote to change certain key provisions of the current Chapter 766

Regulations which are in effect for the upcoming school year. These changes include:

- **Discipline:** The current Chapter 766 regulations for discipline (Section 338) are replaced by federal IDEA-97 regulations for discipline.
- **Individualized Education Program (IEP):** The current Chapter 766 regulations for IEP development and required



elements of the IEP (Sections 322 and 114) are replaced by federal IDEA-97 regulations (Sections 300.340 - 300.350).

- **Three-Year Program Plans:** The requirement that school districts submit three-year program plans for special education (Section 501) has been eliminated.

At its July meeting, the Board will vote on the removal of Section 205 of Chapter 766 which pertains to the rights of children attending private schools at public expense.

Readers are encouraged to keep in mind that the *changes (with the above noted exceptions) are proposed changes: the current Chapter 766 Regulations will*

remain in effect during the upcoming school year.

Among the revised proposed regulatory changes to Chapter 766 that the Board plans to vote on next March are the following:

- **Extended timelines** for IEP development which could result in undue delays, e.g., a child could wait more than half a school year before receiving services.
- **Reductions in transportation rights and protections**, such as reductions in required in-service training on carrying children, equipment inspections, and provisions to allow students who use wheelchairs to remain in their wheelchair while in transit. The revised proposed regulations require these protections "as appropriate" and in a much less prescriptive manner than do the current Regulations.
- **Elimination of the Parent Advisory Councils (PAC) requirement.**
- **Substantial weakening of parents' rights to independent evaluations** by limiting independent evaluations at school expense to families eligible for free and reduced cost lunch. For other families, the school may refuse to pay for independent evaluations, thus forcing parents to enter into the appeals process.
- **Elimination of any reference to the "maximum possible development" standard** and replacing it with the lower federal standard (free and appropriate public education).

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New IEP Form and Process to be Piloted Fall 1999

This fall, the Massachusetts Department of Education (DOE) will pilot a new process and form for developing Individualized Education Programs (IEPs) in 14 school districts. The new process and IEP form are designed to align goals and objectives (now called "benchmarks") with the Massachusetts Curriculum Frameworks to ensure that all children have access to the general education curriculum.

Participation in the pilot program is voluntary and will target specific grades or schools within a system. Participating schools represent a broad range of student demographics and needs. Schools piloting the new IEP are: Ayer, Barnstable, Boston, Chicopee, Concord, Gateway Regional Schools, Hamilton-Wenham, Keefe Technical Vocational High School, Southbridge, Worcester, Berkshire Meadows, Evergreen School, North Hampton Center for Children, and Willow Hills School.

Parents of children selected to participate in the pilot program will be provided further information by their local Directors of Special Education Services. The DOE will seek feedback on the new form and process from parents and professionals within these communities. The projected date for statewide use is September 2000.

For more information, please contact Margaret Smith at the Federation at 617-236-7210.

From the Executive Director How Long is 25 Years?

I have been reflecting on this question because this fall the Federation will begin a year-long celebration of our first 25 years and of the progress that has been made for—and by—students with disabilities. Twenty-five years seems like a long time in so many ways. Yet, the first students to benefit from Chapter 766, Massachusetts special education law, have just recently come of age. Only now are we as a society beginning to see the tremendous difference special education services have made for individual children as well as for transforming societal expectations and attitudes about people with disabilities.

Chapter 766, was passed during the 1972-73 legislative session with implementation to begin in 1974. The Federation for Children with Special Needs was formed in November 1974 out of a broad coalition of disability advocacy groups. As a parent-run organization, the Federation's purpose was to give voice to parent-specific concerns and to assist parents with the implementation of this unique and comprehensive law. In May 1975, the Federation moved officially from the "kitchen table" (the birthplace of many parent revolutions) to its first office on Boylston Street, thus establishing the first

Parent Training and Information Center in the country.

A veteran Federation staff member, Phyllis Sneirson, recalls that when the Federation first began, the staff believed that once parents and

In May 1975, the Federation moved officially from the "kitchen table" to its first office on Boylston Street, thus establishing the first Parent Training and Information Center in the country.

others were notified about the existence of the new law, the job would be done. No one could have predicted the number of parents, teachers, and other professionals the Federation staff would assist, only to find so many today who

still need this help. Today, Federation staff answer over 7,000 calls a year, and the demand for workshops is constant.

An enterprise that began with a specific focus on special education has now grown to encompass health care, early childhood and early intervention, education reform, and preparation for life after school and community living. The original staff of two or three has grown to nearly 50 people. Martha Ziegler, a Federation founder, served as its first executive director for 22 years. I am very pleased and humbled to serve as only the second Executive Director in the Federation's proud history.

Twenty-five years is a long time and there have been many accomplishments. Despite the struggles that inevitably lie ahead, we are excited about the opportunities future generations will have to build upon what has been gained over these past twenty-five years.

To honor the Federation's history of accomplishment and to launch ourselves into the next 25 years, the Federation's Board of Directors has designated May of 2000 as the time for a gala celebration. We hope all of you will be able to join us. Watch our website and future issues of *NewsLine* for details.

Richard J. Robinson

Supreme Court Upholds ADA "Integration Mandate"

People with disabilities and their advocates scored a big victory in the battle for community living options when the Supreme Court announced its ruling in *Olmstead v. L.C. and E.W.* on June 22. Although the decision is narrow and middle-of-the-road in some ways, it does affirm a key civil rights provision in the Americans with Disabilities Act (ADA), known as the "integration mandate," which maintains that people with disabilities must be offered services in the "most integrated setting."

President Clinton said: "I am pleased that the Supreme Court decision in the *Olmstead* case upholds the purposes of the ADA by recognizing that unjustified isolation of institutionalized persons with disabilities is prohibited discrimination. . . . I am asking Secretary Shalala and Attorney General Reno to work with all interested parties to carry out today's decision in a fair

and effective manner. . . . Our ultimate goal is a nation that integrates people with disabilities into the social mainstream, promotes equality of opportunity, and maximizes individual choice."

On the same day, the Supreme Court announced negative decisions in three employment cases that charged discrimination under ADA. These decisions raised more questions than they answered. John Hockenberry, a national broadcasting anchor who uses a wheelchair, echoed many disability advocates when he called for Congress to define more clearly some of the fundamental terminology in the law. He said, "To deal with the problem of full access for the disabled, we must define what changes are to be made, for which disabilities, and then get on with it." Hockenberry's comments appeared in an op ed article in the *New York Times* on June 29th.

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Ask Eileen

Empowerment Through Information

by Eileen Souza,
Federation Information Specialist

This column highlights questions that Eileen and the other Federation Information Specialists are most frequently asked.

Dear Eileen,
My son has been receiving speech and language services under an IEP (Individualized Education Program) for the past few years. Now the school wants to take him off of an IEP and give him services through a "504 Plan." Can the school do that? I am worried that my child may not get the help he needs.
Confused Parent

Dear Confused Parent,
The bottom line is that under our state law, schools should not be taking children off of IEPs if they are only receiving speech and language therapy or other related services. There has been a lot of confusion about this issue recently so you are in good company. Perhaps some background information can help pinpoint the confusion. Before that, though, there are some basic things you should know so that your child continues to get the help he needs.

First, know your rights.
Current Chapter 766 law and regulations remain in effect. Your school district cannot arbitrarily refuse to write an IEP for your child. Before making a decision that a student no longer requires special education services, the school must evaluate the student and convene the Team, of which you are an important member, to discuss evaluation results.

If the school finds that your son no longer needs special education services, you can reject this finding. Your son is entitled to receive special education services consistent with the last agreed upon IEP until the dispute is resolved. In addition, you can request an independent evaluation. Frequently, independent evaluation findings validate a student's need for continued special education services.

Why the confusion?
Attention to Sec. 504 plans intensified following a Massachusetts Department of Education (DOE) memo dated November 2. The memo, in question and answer format, directs school

administrators to review eligibility for special education with an eye toward limiting eligibility.

Question 5 of DOE's memo asks, "*If a student needs some type of related service, such as occupational therapy, or speech and language therapy, is the student eligible for special education?*" DOE's answer suggests that a student who requires only speech and language therapy is not eligible for special education.

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Alarmed by many calls from parents who, similar to you, suddenly found themselves facing possible loss of IEPs or termination of special education services, three major disability advocacy organizations, Disability Law Center, Massachusetts Advocacy Center, and Center for Law and Education, responded to DOE's memo. In it, the advocates expressed concern over a "misleading and inaccurate statement of the law" and requested that DOE issue a clarification. Citing federal law and Chapter 766, the advocates emphasized that "...students may have speech

and language therapy services only under state law and be receiving 'special education. . .'" (DLC memo, April 12, p. 5). In Massachusetts, speech and language therapy is included in the definition of special education and, therefore, *requires an IEP*. The same holds true for OT, PT, or only consultation services, for example.

Incidentally, the advocates' memo goes on to point out that students who have IEPs with only a "related service" (such as speech/language) without consultation by the therapist to the classroom or without instructional strategies for implementing the related services may not have properly developed IEPs which fully meet the needs of the student.

The educational rights of your son and every student who has a disability are protected by many laws in addition to Chapter 766 and its regulations. Among them are IDEA (federal special education law), Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA).

Section 504 is itself a strong civil rights act with many protections and benefits for students which parallel in many respects the requirements of IDEA. *Like IDEA, it guarantee a free appropriate public education for all students with disabilities.* This means that students are entitled to the services they need to meet their needs, whether they need extensive services, such as residential placements, or less extensive services, such as speech therapy.

Residential Support Services Available



Community Housing for Adult Independence (CHAI), a program of Jewish Family & Children's Service, now has openings in residential services offering 24-hour support.

Located in attractive, small, community-based settings, close to shops, recreation and places of worship, CHAI is a DMR-certified program with a two year "Certification with Distinction." We specialize in meeting individual needs for people of all faiths.



For more information, contact Jim Elkind, LICSW, at 617-558-1278.

Students with Disabilities and MCAS: Alternate Assessments

“You measure what you treasure” and “What gets tested, gets taught” are sayings with special meaning for students with disabilities. Traditionally, students with disabilities have been exempted from large-scale testing that most other students take. One reason often given is that it would be hard on the student to take the test and perhaps not do well. Exemption from the tests, unfortunately, often meant exemption from high expectations and access to the academic life of the school, thereby ensuring that the student will not be able to do well. Participation in tests is a critical way to hold *schools* accountable for teaching students.

In fact, federal and state laws now *require* that all students with disabilities participate in state and district-wide assessment programs. The Massachusetts statewide testing program, MCAS (Massachusetts Comprehensive Assessment System), has received widespread attention. Advocates for students with disabilities are working to ensure that students with disabilities are counted, and that schools are held accountable for their learning. MCAS scores are being used to evaluate the performance of schools, school systems, and administrators. If students with disabilities are excluded from testing, their progress may not be considered important when evaluating schools and allocating resources.

It is also *crucial* that all students with disabilities participate appropriately in state assessments because MCAS is a “high-stakes” test. In the future, students (beginning with current 9th

graders) will have to pass the MCAS test in order to receive a high school diploma. Students with disabilities must receive equal opportunities to demonstrate their knowledge and receive a high school diploma.

Critical Issues

The IEP team must determine *how* a student will participate in MCAS. The vast majority of students with disabilities will be able to participate under routine conditions or with accommodations specified by the IEP Team.

However, a small percentage of students with disabilities will require *alternate* assessments in order to participate. IEP teams must consider alternate assessments for students who are unable to demonstrate their knowledge and skills on the on-demand MCAS tests even with accommodations. This inability to take the test *even with accommodations* could be due either to the nature of the disability or because the design of the on-demand test makes it impossible to provide necessary accommodations. The IEP team has final authority over how a student will participate in MCAS.

Alternate assessments cannot be limited to students with significant cognitive disabilities, nor can it be assumed that students with cognitive disabilities will require alternate assessments. Limiting alternate assessments to students with a particular disability would have the negative effect of creating a category of students for whom expectations might be lowered.

It is also critical that alternate assessments not be linked to a non-diploma “track” of students. Students who demonstrate the graduation competencies set by the Massachusetts Board of the Education through their performance on alternate assessments must have the same opportunity to graduate as students who demonstrate them through their performance on the on-demand MCAS.

The Department of Education is developing statewide alternate assessments for the few students who are unable to demonstrate their knowledge and achievement on the on-demand MCAS tests, even with accommodations. In the spring of 2001, schools and school districts will begin using the new MCAS alternate assessments. Alternate test results will be included in school and school district scores. Until then, IEP Teams must develop their own alternate assessments based on the state’s curriculum frameworks. DOE plans to field test the MCAS Alternate Assessments during the 1999-2000 school year and to conduct workshops for parents and educators.

For more information, call Daniel Wiener, MCAS-Alt Project Director, Department of Education at 718-388-3300, ext. 264, or go to the DOE website at www.doe.mass.edu/mcas. The document *MCAS: Requirements for the Participation of Students with Disabilities (A Guide for Educators and Parents)* is available on the website or can be obtained by calling DOE.

Work Group Convened for Alternate Assessments

The Federation is actively participating in the Massachusetts Department of Education’s (DOE) 32-member Work Group to develop guidelines around the participation of students with severe or complex disabilities in the statewide assessment system.

At its first meeting in June, members of the Work Group reviewed the Massachusetts

Learning Standards and identified ways that students with severe disabilities who take alternate assessments could demonstrate their mastery of the standards.

The alternate assessments are being developed for students who are unable to demonstrate what they know and are able to do even with accommodations or for whom accommo-

dations are not available. Very few students with disabilities (less than 2%) are expected to need an alternate assessment.

Federation staff are pleased that the Work Group has chosen not to reduce or limit the standards for students who take the alternate assessment. Instead, the Group is compiling examples of how students with a range of disabilities could demonstrate competence for each standard. IEP Teams will determine how individual students will have access to the standards and the general education curriculum.

Summer Reading Tips for Parents

Summer shouldn't mean taking a break from learning, especially reading. Studies show that most students experience a loss of reading skills over the summer months, but children who continue to read actually gain skills. Efforts should be made during the summer to help children sustain reading skills, practice reading, and read for enjoyment.

Reading builds visualization, thinking, and language abilities. Taking the time to read with your child can help you evaluate your child's reading skills. If you discover that your child is having trouble with reading, he or she may have a learning disability. 80% of children with a learning disability have difficulty with basic reading and language. But early identification of such a disability gives a child the chance to develop ways to learn how to read effectively and skills to lead a successful and productive life. A recent National Institutes of Health study showed that 67% of young students at risk for reading difficulties became average or above-average readers after receiving help in the early grades.

Parents should remember that children need free time in the summer to relax and enjoy the pleasures of childhood. So summer reading should be fun. Following are a few tips to make reading enjoyable for your children this summer:

Read aloud together with your child every day. Make it fun by reading outdoors on the front steps, patio, at the beach or park. Also, let your children read to you. For younger children, point out the relationship between words and sounds.

Set a good example! Parents must be willing to model behavior for their children. Keep lots of reading material around the house. Turn off the TV and have each person read his or her book, including mom and dad.

Read the same book your child is reading and discuss it. This is the way to develop habits of the mind and build capacity for thought and insight.

Let kids choose what they want to read, and don't turn your nose up at popular fiction. It will only discourage the reading habit.

Buy books on tape, especially for a child with a learning disability. Listen to them in the car, or turn off the TV and have the family listen to them together.

Take your children to the library regularly. Most libraries sponsor summer reading clubs



with easy-to-reach goals for preschool and school-age children. Check the library calendar for special summer reading activities and events. Libraries also provide age appropriate lists for summer reading.

Subscribe, in your child's name, to magazines like *Sports Illustrated for Kids*, *Highlights for Children*, or *National Geographic World*.

Encourage older children to read the newspaper and current events magazines, to keep up the reading habit over the summer and develop vocabulary. Ask them what they think about what they've read, and listen to what they say.

Ease disappointment over summer separation from a favorite school friend by encouraging them to become pen pals. Present both children with postcards or envelopes that are already addressed and stamped. If both children have access to the Internet, email is another option.

Make trips a way to encourage reading by reading aloud traffic signs, billboards, notices. Show your children how to read a map, and once you are on the road, let them take turns being the navigator.

Encourage children to keep a summer scrapbook. Tape in souvenirs of your family's summer activities, picture postcards, ticket stubs, photos. Have your children write the captions and read them aloud as you look at the book together.

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Sugerencias para los Padres sobre la Lectura Durante el Verano

El verano no debe significar tomarse un descanso del aprendizaje, especialmente el leer. Estudios demuestran que la mayoría de los estudiantes pierden sus destrezas de leer durante los meses de verano, pero los niños que continúan leyendo aumentan sus destrezas. Durante el verano, los padres deben hacer esfuerzos para asegurar que los niños mantengan sus destrezas de lectura, practiquen la lectura, y lean para disfrutarla.

La lectura aumenta las habilidades de visualización, de pensar, y de lenguaje. Tomarse el tiempo para leer con su hijo puede ayudarle a usted a evaluar las destrezas de lectura de su hijo. Si usted descubre que su hijo está teniendo problemas con la lectura, él puede tener una discapacidad de aprendizaje. 80 por ciento de los niños con problemas de aprendizaje tienen dificultad con lectura y lenguaje básico. Pero identificación temprana de tales discapacidades le da a su niño

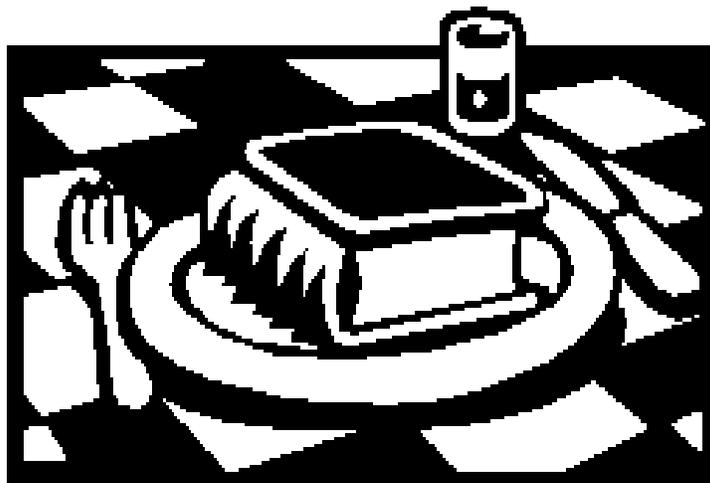
la oportunidad de desarrollar maneras de leer efectivamente, y las destrezas para llevar una vida productiva y exitosa. Un estudio reciente de los Institutos Nacionales de la Salud demostraron que 67 por ciento de los estudiantes jóvenes que están en riesgo de tener dificultades con la lectura, al recibir ayuda al comienzo de los cursos, han mejorado su lectura a un nivel promedio o por encima del promedio.

Los padres deben recordar que los niños necesitan tiempo libre en el verano para relajarse y disfrutar los placeres de la niñez. La lectura en el verano debe ser divertida. Las siguientes son algunas sugerencias para que usted y sus niños disfruten la lectura este verano:

Lea en voz alta con sus niños todos los días. Hágalo divertido leyendo fuera de la casa, o en el portal, en el patio, en la playa, o en el parque. También, deje que sus niños le lean a usted. Para los niños más jóvenes,

muéstreles la relación entre las palabras y los sonidos.

Dé un buen ejemplo. Los padres tienen que estar dispuestos a dar un buen ejemplo a sus niños. Mantenga en la casa materiales de lectura (libros, revistas, periódicos). Apague el televisor y haga que cada persona lea un libro, incluyendo mamá y papá.



Lea el mismo libro que su niño está leyendo y discútalos. Ésta es la manera de desarrollar “hábitos de la mente” y crear capacidad para pensar y discernir.

Deje que los niños escojan lo que ellos desean leer, y no los limite si desean leer novelas populares. Si lo hace, desanimará el hábito de la lectura en los niños.

Compre libros en casete, especialmente para un niño con discapacidad de aprendizaje. Escúchelos en el carro, o apague el televisor para que toda la familia pueda escucharlo.

Lleve a sus niños con regularidad a la biblioteca. La mayoría de las bibliotecas tienen clubs de lectura en verano con metas fáciles de alcanzar para los niños en pre-escolar y en la escuela. Mire el calendario de actividades y eventos especiales en verano. Las bibliotecas también proveen listas de libros que los niños de

diferentes edades pueden leer durante el verano.

Suscriba en revistas el nombre de su hijo como *Sports Illustrated for Kids* (Deportes Ilustrados para Niños), *Highlights for Children* (Puntos más Destacados para Niños), y *National Geographic World* (El Mundo Geográfico Nacional). Anime a los niños mayores a leer el periódico y revistas con eventos actuales para mantener el hábito de la lectura y para desarrollar el vocabulario durante el verano. Pregúnteles qué piensan de lo que leyeron y escuche lo que ellos le dicen.

Disminuya la desilusión de su hijo después de una separación de un amigo favorito de la escuela, sugiriéndole que le escriba al amigo. Provea a los dos niños con postales y sobres que ya tienen dirección y estampillas. Si los niños tienen acceso al Internet, el correo electrónico es otra opción.

Anime a los niños a leer durante los viajes. Lea en voz alta los signos de tráfico, carteleras, avisos. Muéstreles a sus niños como leer un mapa, y cuando estén en la calle, déjeles ser los guías.

Anime a los niños a mantener un cuaderno de notas durante el verano. Coloque los recuerdos de las actividades que su familia realizó durante el verano, como postales, boletos, y fotos. Haga que su niño lea en voz alta lo que escribió en el cuaderno cuando estén revisando el cuaderno juntos.

Reimpreso con permiso de The Coordinated Campaign for Learning Disabilities (La Campaña de Coordinación de Discapacidades de Aprendizaje). Para recibir un folleto gratuito sobre discapacidades de aprendizaje, llame al 1 800 GR8MIND o visite www.ldonline.org.

Sugestões de Leitura de Verão Para os Pais

O verão não significa interromper os estudos, especialmente as leituras. As pesquisas têm demonstrado que a maioria dos alunos experimentam uma perda nas capacidades de ler durante os meses de verão. No entanto as crianças que continuam a ler realmente desenvolvem habilidades. Durante o verão devem ser aplicados esforços para ajudar as crianças a manter capacidades de leitura por pura diversão.

A leitura desenvolve as habilidades de visualização, pensamento e linguagem. Dedicar tempo em ler com seu filho pode ajudá-lo a avaliar as capacidades de leitura do seu filho. Se você descobrir que o seu filho está tendo problemas em ler, ele pode estar tendo uma falta de capacidade de leitura. 80% das crianças com este problema tem dificuldades em ler e ter conhecimentos lingüísticos básicos. Mas se identificarmos prematuramente tal lapso de habilidade, permitiremos que tal criança tenha a chance de desenvolver meios de aprender como ler efetivamente, assim como levar uma vida bem sucedida e produtiva. Um estudo recente dos Institutos Nacionais de Saúde mostrou que 67% de jovens em risco de terem dificuldade de ler, tornaram-se leitores medianos ou acima da média após receberem ajuda nos primeiros anos de escola.

Os pais devem lembrar-se que as crianças precisam de tempo livre no verão para descansar, assim como apreciar as alegrias da infância. Portanto ler durante o verão pode ser divertido. Daremos a seguir algumas sugestões para que seus filhos se divirtam lendo durante este verão.

Leia com seu filho em voz alta todos os dias. Faça com que esta atividade seja divertida, lendo nos degraus da escada na frente de casa, no pátio, na praia ou no parque. Também deixe que seus filhos leiam para você. Se as crianças forem menores, saliente a relação entre palavras e sons.

Seja um bom exemplo! Os pais devem querer ser um modelo de comportamento para seus filhos. Tenha bastante material de leitura em sua casa. Desligue a T.V. para que cada um leia o seu livro, inclusive a mãe e o pai.

Leia o mesmo livro que o seu filho está lendo e discuta a respeito. Esta é a maneira de

desenvolver hábitos mentais e a capacidade para pensar e compreender.

Deixe que as crianças escolham o que elas querem ler e não menospreze as ficções populares. Isto apenas desencorajaria o hábito de leitura.

Compre livros gravados em cassete, especialmente para uma criança com dificuldades de aprendizagem. Escute-os no carro ou desligue a



T.V. e faça com que toda a família escute as gravações ao mesmo tempo.

Leve seus filhos seguidamente à biblioteca. A maioria das bibliotecas promove clubes de leitura durante o verão com objetivos fáceis de serem alcançados para crianças em níveis pré-escolar e escolar. Verifique o calendário de atividades e eventos de leituras especiais da sua biblioteca para o verão. As bibliotecas também

providenciam listas apropriadas de leituras a serem feitas durante o verão.

Subscreva revistas no nome do seu filho como "Sports Illustrated for Kids" (Esportes Ilustrados para Crianças), "Highlights for Children" (Pontos Importantes para Crianças) ou "National Geographical World" (Mundo Geográfico Nacional). Encoraje os filhos mais velhos a lerem jornais e revistas que retratem acontecimentos do dia-a-dia para que mantenham o hábito de ler durante o verão e aumentem o seu vocabulário. Pergunte-lhes o que pensam sobre o que leram e escute o que dizem.

Diminua o desapontamento do seu filho com a separação do seu colega predileto durante o verão, encorajando-os a tornarem-se correspondentes. Dê a seus filhos postais ou envelopes com endereços e selos. Se ambas crianças tiverem acesso com a Internet, esta seria uma outra opção.

Faça com que suas viagens estimulem seus filhos a lerem sinais de trânsito, "outdoors" e avisos. Mostre-lhes como ler um mapa, e quando estiverem viajando, deixe que cada um dos filhos tenha a sua vez de ser o guia.

Encoraje os seus filhos a manterem um álbum de recortes de verão. Colecione lembranças de atividades de verão de sua família, como postais, talões de passagens, fotos. Faça com que seus filhos escrevam as legendas e as leiam em voz alta, enquanto vocês olham o livro juntos.

Re-impresso com a permissão da Campanha de Coordenação dos Incapacitados de Aprendizagem ("The Coordinated Campaign for Learning Disabilities"). Se quiser receber uma brochura grátis sobre Incapacidades de Aprendizagens, telefone para 1-800-GR8MIND ou visite a Internet www.ldonline.org.

KOTIN, CRABTREE & STRONG, LLP, ATTORNEYS AT LAW

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Health News

*from Family Voices
at the Federation for Children with Special Needs*

Family Voices Updates

Results of our family survey, "Your Voice Counts: Health Care Experiences of Families of Children with Special Health Care Needs," are now being analyzed, with reports anticipated by summer's end. Thanks to all the families who participated in this extensive effort to ensure that the voices of families count! Check the Family Voices website for a survey update.

Family Voices of Massachusetts is in the process of planning how to expand state-level activities. Call Family Voices at the Federation if you would like to take part in these discussions.

Massachusetts News

Low-Cost or Free Health Insurance for Kids is Here!

No child in Massachusetts should be uninsured! The Massachusetts Children's Health Insurance Program (CHIP) can provide health insurance to many of the 138,000 children presently uninsured. **The best way to find out if a child is eligible is to apply for the program.** For more information, call MassHealth at 888-665-9993 (TTY: 888-665-9997). Interpreters are available.

Newborn Hearing Screening

The Public Health Council recently approved new regulations requiring hearing screenings for all newborns. The Massachusetts Department of Public Health (DPH) will develop guidelines for

hospitals to ensure that all babies are screened before they are discharged. Now, babies with hearing loss will be identified and, therefore, found eligible for programs such as Early Intervention as soon as possible. For more information, call Janet Farrell at 800-844-0898.

National News

The Work Incentives Improvement Act:

The Senate passed legislation last week to guarantee that people with disabilities retain Medicaid while they work. The next important hurdle is convincing the House of Representatives to pass the same legislation.

Patients' Bill of Rights: Congress is debating several different bills on this important issue, some more troubling than helpful. Check the Families USA website (www.familiesusa.org) for the latest information, including a petition urging legislators to enact a comprehensive bill.

Senator Kennedy, in a strongly-worded June 23 statement on Patients' Bill of Rights, said that "doctors, patients, and parents should be making medical decisions, not insurance company accountants" Sen. Kennedy then described the often ignored "common sense rights" his bill would protect:

Our legislation will curb HMO abuse and assure that women and children will get the best possible care—care that will

be just what the doctor ordered. Every child with cancer deserves access to a pediatric oncologist....Every disabled child deserves to have the specialist who is most familiar with his condition coordinate his care. No parent with a child in medical distress should be forced to drive past the nearest emergency room because it is not in the health plan network. (Entire statement available on Sen. Kennedy's website www.senate.gov/~Kennedy).

Meanwhile, **Medical Records Privacy** legislation to protect the privacy of patient medical records, including mental health records, is stalled at the committee level because of disagreements along party lines. Congressman Markey from Massachusetts is one of the sponsors seeking to create a bipartisan movement for action.

The Massachusetts delegation, particularly Senator Kennedy and Representative Markey have taken strong leadership roles in both of these initiatives. Be sure to thank them and encourage their continued efforts!

Visit the Family Voices website (www.familyvoices.org) for information on **Family to Family Health Information Centers**, a national initiative to ensure that families receive needed information on health policy issues.

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 offices in Boston.

Home Modifications Bill is Now Law

Individuals with disabilities, elders, and families with children with disabilities will soon be eligible for loan guarantees and interest subsidies for improvement/modifications of their homes to increase accessibility and independence. The new law allows for \$10,000,000 in bond funding. The program is administered by the Massachusetts Executive Office of Health and Human Services (EOHHS) which has established an Advisory Committee on program design and implementation. The program will provide for loan guarantees based on a sliding fee scale according to income and assets. Interest subsidies will also be income-based according to standards to be developed by EOHHS.

To learn more about or become involved in program design and implementation, contact Lisa Sloan at Massachusetts Rehabilitation Commission, 617-204-3637 (voice) or 413-443-6655 (TTY).

Reprinted from MATP Update, Volume 3, No. 1 (Winter 1999).

EARS Auditory Integration Training

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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.

U.S. DOE Identifies Early Intervention Strengths, Weaknesses

The U.S. Department of Education visited Massachusetts in November and February to monitor compliance of special education and early intervention programs with the federal special education law, Individuals with Disabilities Education Act (IDEA). (See reports in *NewsLine* Fall 1998 and Winter 1999). Federal monitors visited four early intervention programs and conducted public meetings around the state to gather information and identify issues. In their interview with the state Department of Public Health (DPH) following the visits, the monitors noted the following strengths and weaknesses:

Areas of strength:

- Well-qualified and multilingual early intervention staff,
- A significant focus on reaching out to and serving underrepresented populations,

- A real intent to find children and families who are eligible for early intervention services, and
- Successful outreach and child-find strategies that have resulted in a high percentage of eligible children and families receiving early intervention services.

Areas in need of improvement:

- Insufficient partnerships at the state level to ensure coordination of early intervention services with childcare services, and
- Insufficient efforts in community colleges, colleges, and universities targeted to recruit professionals who speak languages other than English.

Areas out of compliance:

- Continued existence of playgroups that are segregated and separate (i.e., that include only infants and toddlers who are receiving early intervention services),
- Individualized Family Service Plans (IFSPs) that do not reflect outcomes for individual children, and
- Failure of DPH to monitor early intervention programs according to federal law (IDEA), not just the state requirements.

DPH has convened "Stakeholders," a group representing members of the Interagency Coordinating Council (ICC), family members, providers, and staff from DPH and other state agencies. The Stakeholders are developing an action plan that will build on the strengths and address areas needing improvement.

Turning Three Training to be Offered Again Next Year

This spring, 200 parents and early intervention providers attended eight workshops across the state on planning for a smooth transition from early

intervention programs to preschool services at age three. In response to the success of this intensive effort, the Federation will sponsor eight more

workshops starting in September. (Look for details in the fall *NewsLine*.)

Early Intervention Training Center Workshop Schedule

Welcome to EI	<i>Lowell</i>	July 12
Welcome Back to EI	<i>Boston</i>	July 21
IFSP Process	<i>Worcester</i>	July 28
Gathering Information	<i>Worcester</i>	August 3
Welcome to EI	<i>Boston</i>	September 23
Welcome to EI	<i>Worcester</i>	October 7

To register for these workshops, call Brad Arndt at 617-236-7210, ext. 154.

**Representing Children
with Special Needs**

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PAL Responds to the Littleton Shootings

In the aftermath of the Littleton, Colorado, shootings, all of us have been deeply touched by recent reports of school violence. With funding from the Massachusetts Department of Mental Health, the Federation and the Parent Professional Advocacy League (PAL) sent information to Massachusetts school districts to promote greater awareness of children's mental health and to ensure safe, secure educational environments.

Among the materials was the following checklist developed by Federation of Families for Children's Mental Health (PAL is the Massachusetts state chapter). This checklist is a guide to help children or students with emotional, behavioral, or mental disorders cope with public tragedies. It is not meant to replace individual therapeutic supports.

WHAT ABOUT THE CHILD WITH SERIOUS EMOTIONAL DISTURBANCE?

A Checklist for Parents and Teachers in the Aftermath of Public Tragedy

WATCH FOR AND ATTEND TO

- Sudden changes in behavior
- Feelings of fear, anger, or hopelessness
- Withdrawal
- Agitation

BE SUPPORTIVE BY

- Listening
- Sharing your own feelings in an honest and "real" way
- Helping children and youth find realistic ways to feel safer
- Supporting children and youth to express their anger, fear, and vulnerability in safe ways
- Walking with children who are agitated or anxious

AT SCHOOL

- Offer small facilitated discussion groups where young people can talk about their feelings of anger and fear.

- Provide an adult partner to walk and walk and walk with the child who cannot sit in a discussion group.
- Identify an adult partner for each child to go to anytime they feel the need to walk, to talk, and to be heard.
- Provide a nurturing "safe place" for the children to retreat when they are anxious. Fill it with books, puzzles, or quiet music.
- Post important resource phone numbers for children and youth in well-traveled areas near telephones.
- Call the national Federation of Families for Children's Mental Health at 703-684-7710 to get information about your local chapter.
- **Always reach out to your local community-based supports: mental health centers, churches, cultural elders, spiritual leaders, friends, and neighbors.**

The Massachusetts State Chapter of the Federation of Families for Children's Mental Health is Parent Professional Advocacy League (PAL), a project of the Federation.

For more information or to reach a PAL coordinator, call: 800-537-0446.

For information about PAL Metro Boston Support Groups, contact Diana Moreno at 617-236-7210 ext. 171.

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Major Efforts to Change Special Education Law

continued from page 2

- **Significant tightening of eligibility**, raising serious concerns that the proposed eligibility requirements would deny services to children with bona fide disabilities in violation of federal and state law.

The Federation has received calls from concerned parents because their school system has begun implementing the proposed regulations and eliminating special education services. Except for the four areas mentioned above, **Chapter 766 remains the law in Massachusetts, and schools must continue to abide by the current regulations.**

For more information, please visit the Federation's website, www.fcsn.org or call Johanne Pino at the Massachusetts Advocacy Center, 617-357-8431, ext. 234.

Family Fair continued from page 1

abilities attended. The day, filled with a spirit of camaraderie and community, proved that our differences, though seemingly great, can be bridged.

While their parents ate, checked out written resources about children's mental health issues, and chatted with each other and Federation staff, the children were treated to a variety of fun activities. Costumed characters were on hand to paint the children's faces. Noticing that painting faces looked like lots of fun, the children soon decided to try out their own artistic ability. Thank you to all the adults who were such good sports and left displaying flowers, snakes and even a whole face painted like a tiger! The children also colored large block letters that were strung together into a banner of this year's slogan for Children's Mental Health Week:

"In a child's life, everyone is accountable." The day ended with a rousing game of bingo and lots of helium balloons, toys, and other souvenirs for the children to take home.



PAL Metro Boston staff thanks everyone who volunteered and helped make the Fair a success.



The Federation says goodbye to PAL Metro Boston. After 10 years, the Massachusetts Department of Mental Health (DMH) has awarded the PAL project to a new provider agency. Thus effective July 1, PAL Metro has moved.

The Federation is grateful that PAL staff Diana Moreno-Rocha and T.J. Hutson will stay on to assist the Federation with new outreach activities. To contact the new PAL Metro office, please call Carol Silva at DMH, 617-727-5500.

Next Steps! Coming Next Fall to a Region Near You

Is your child moving on from Early Intervention or preschool? Is your child in the first few years of grade school? Do you feel the need to build up your own skills to get them through this maze? Do you need answers to questions like:

- How do I get organized?
- How do I involve my child in the community?
- How do I get the school to listen to me?

Well, then, take the **Next Steps!** Come and learn new advocacy skills, record-keeping strategies, and ideas for community inclusion.

Next Steps is a free training course especially geared for parents of young children with special needs, ages 3-8. Of course, everyone with an interest in children with special needs is welcome!

For more information, call Joanne Spencer at Family TIES, 508-947-1231 or 617-727-1440. Family TIES, funded by the state Department of Public Health, is a project of the Federation.

Help Wanted

The Federation is seeking a full-time accounting assistant for the business office. Excellent benefits.

Please send resume and cover letter to Mary Thompson, Business Manager by August 22. Fax: 617-572-2094 or email pblake@fcsn.org. No phone calls, please.

No one can change their past...
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Become a foster or adoptive parent.

1-800-KIDS-508

A Child Needs Your Love & Care

Among Massachusetts' ten thousand foster children are many beautiful special needs children who don't have a protector, a champion, or a hand to hold as tightly as they possibly can. They are victims of abuse and neglect, who need the loving care of a family on a short term, long term, or permanent basis.

Call DSS at 1-800-KIDS-508 to learn more about foster or adoptive parenting. Because no one can change their past, but you can change their future!

Your Support Makes a Difference!

Thank you for supporting the Federation!

Your contributions and membership donations support our ongoing mission to provide information, support, and assistance to parents of children with disabilities, their professional partners, and their communities.

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NewsLine

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The Federation for Children with Special Needs

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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Upcoming Federation Workshops

For more information about any workshops, please call the Federation at 800-331-0688. Call to find out about Basic Rights workshops in Portuguese.

Ligue para informação sobre aulas iniciando em Português.

SEPTEMBER 1999

9/21, New Bedford, 6:30-8:30 pm: *Basic*
9/23, Milford, 7:00-9:00 pm: *Basic*
9/28, Groton, 7:00-9:00 pm: *Basic*

OCTOBER 1999

10/4, Amesbury, 7:00-9:00 pm: *Basic*
10/7, Concord, 7:00-9:00 pm: *IEP*
10/14, Concord, 7:00-9:00 pm: *Transition*
10/14, Natick, 7:00-9:00 pm: *Basic*
10/18, Franklin, 7:00-9:00 pm: *Basic*
10/25, Reading, 7:00-9:00 pm: *Transition*

NOVEMBER 1999

11/17, Andover, 7:00-9:30 pm: *IEP*
11/18, Springfield, 7:00-9:00 pm: *Transition*

DECEMBER 1999

12/2, Lawrence, 6:00-8:00 pm: *Basic*

WORKSHOP DESCRIPTIONS

Basic: Covers basic information about Chapter 766 and other 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*)

IEP: Gives an in-depth look at the parent's role in the development of the IEP.

Transition: Provides basic information on state and federal laws which require that IEPs address goals in such areas as competitive employment, independent living, and full integration into other aspects of community life that will help prepare for adult life.

SSI Permits Students to Work, Keep Benefits

Many high school students who receive Supplemental Security Income (SSI) benefits have been discouraged from working because they are afraid of losing their benefits. Some are afraid that their SSI checks will be reduced to almost nothing. Others are more concerned with losing their access to health benefits through Medicaid which comes automatically with SSI in most states (including Massachusetts).

It is important for students and their parents, teachers, and counselors to know that **Work Incentives** are built into the SSI program. By using these incentives, students who receive SSI may earn money *and* keep their medical benefits and all or part of their cash benefits. One of these Work Incentives is the **Student Earned Income Exclusion**.

The **Student Earned Income Exclusion** allows students with disabilities under age 22 who attend school regularly to keep up to \$400 of their earned income per month before any deduc-

tions are taken from their regular SSI checks. The maximum amount that students can earn per year before deductions are taken from their cash benefits is \$1,620. *Just right for that summer job!*

WHAT PARENTS NEED TO DO:

1. Report the new job to the local Social Security office.
2. Ask to apply for the Student Earned Income Exclusion.
3. Bring with you:
 - A letter from the school stating that your son or daughter is attending school.
 - A letter from you, the parents, stating the date s/he began to work, how much s/he is earning, and how many hours s/he is working per week.
4. Ask the Social Security office what they will need and when they will need it. They may ask for copies of check stubs periodically.

5. Keep copies of *everything* you give to Social Security.

Note to IEP Team members: Including SSI work incentives in a student's IEP and transition plan is a way for students to explore employment opportunities without risking losing SSI benefits while the student is still in school.

Note to parents: If your son or daughter has stopped receiving SSI benefits because of the "turning-18 redetermination evaluation," we would like to learn more about your experiences.

To share your SSI experiences or for more information, call Opening Doors: Planning for Work After High School Project, a collaborative project of the Institute for Community Inclusion, the Federation, and the Disability Law Center, at 617-355-4673.

Autism Project Seeks Parent Input

In July and August, parents of children and youth with autism spectrum disorder will receive a needs-assessment survey instrument. The survey, an important component of the Massachusetts Autism Project at the Federation, is being mailed out by local special education departments and other agencies. If you have a son or daughter with autism spectrum disorder and have not

received your survey by the end of August, or if you want to get a head start, call Martha Ziegler, Coordinator, at 617-236-7210, ext. 131, or email Martha at mziegler@fcsn.org.

Findings from this survey and others being disseminated by the Project will be used to develop a state plan for improving services for children with autism spectrum disorder and their families.

NOTE:

The July issue of National Geographic contains a two-page pictorial featuring Ms. Alex Michaels, an adult with autism spectrum disorder, who lives and works in Massachusetts. Ms. Michaels serves on the Advisory Committee for the Massachusetts Autism Project.

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Postgraduate Fellowships Available in Maternal and Child Health

The Shriver Center University Affiliated Program and the Floating Hospital Alliance announces a Fellowship program funded by the Federal Department of Maternal and Child Health.

This interdisciplinary program is intended to train professionals interested in developing leadership skills in improving the lives of children and adolescents with neurodevelopmental and related disabilities and their families.

The fellowship begins in September 1999 and will require a commitment of one-and-a-half days per week over a 10 month period. A stipend of up to \$8,000 is available for this period.

Masters in Health Administration, Suffolk University offered.

For additional information or application contact:
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CHANGE SERVICE REQUESTED

***We've Moved!
 Check Out
 Our New
 Address &
 Telephone!***

*** * * JOIN THE FEDERATION TODAY * * ***

Become a Member!

The Federation would like to take this opportunity to thank all of our members for their invaluable support. Not only does your membership make a difference to us and all the families we serve, it gives you:

- **A Stronger Federation**
- **Access to current information**
- **Networking opportunities with other parents**
- **Quarterly issues of *NewsLine*.**
- **A 10% discount on all Federation publications, conferences, and workshops.**

I want to join the Federation for Children with Special Needs. Enclosed are my membership dues. Please send me the one-year subscription to *NewsLine*, and other member benefits.

Please make checks payable to: Federation for Children with Special Needs, 1135 Tremont Street, Boston, MA 02120. Thank you!

Please enroll me in the following Federation membership(s):

- | | | | | | |
|------------------|--------------------------|---------|-------------------|--------------------------|-------|
| President's Club | <input type="checkbox"/> | \$1,000 | Donor | <input type="checkbox"/> | \$100 |
| Patron | <input type="checkbox"/> | \$500 | Professional | <input type="checkbox"/> | \$50 |
| Sponsor | <input type="checkbox"/> | \$250 | Family/Individual | <input type="checkbox"/> | \$30 |

I can't join now, but here is my gift of: \$ _____

Name _____
 Address _____
 City, State, ZIP _____
 Enclosed is my check for \$ _____ Please charge \$ MC VS
 Card # _____ exp. date _____
 Signature _____

All contributions in excess of \$4.00 are fully tax deductible.

News from the Western Front

It is with great sadness that we tell you that Mary Quigley, coordinator of our Westfield Office, has announced that she will be leaving the Federation at the end of July.

Mary has been a valuable staff member at the Federation for 7 years. We will miss her and her

special easy-going charm, her dedication to parents who have children with disabilities, and her tireless efforts to improve the lives of people with disabilities.

The Federation remains committed to providing quality services to families in Western

Massachusetts. We are looking for a new staff member to continue to work out of our Federation's Western office. In addition, we are also looking for new office space. For more information about the position, or if you have information about available office space in Western Massachusetts, please contact Richard Robison, Executive Director, at 617-236-7210 or toll-free at 800-331-0688.