Founding Stories
Gunnar Dybwad’s Legacy

The Federation is proud to feature Gunnar Dybwad, a “Great Grandfather” of the disability rights movement, in our Founding Stories series. At the Federation’s 25th Anniversary Gala, Gunnar tapped his reservoir of 60 years of vigorous advocacy to illuminate critical junctures and stunning successes along the way. Gunnar has been part of every significant legal, ethical, and moral victory with and for people with disabilities during the last century. He and his wife Rosemary sparked an international movement of parent empowerment decades before such ideas were even dreamed. They nurtured parent groups struggling to establish themselves everywhere. Gunnar and Rosemary’s profound legacy and belief in families and individuals, no matter how disabled, is the bedrock upon which the Federation is built.

In the speech excerpted below, Gunnar referred to the decade of the 1970’s as “the most exciting and most rewarding for me as a committed person in this field.” He concluded his speech with these words which still ring true for him today:

“But as always, I am an optimist. I rejoice how far we have been allowed to travel, and I have no doubt that the journey will go on.”

Feds Cite Mass. DOE for Violations of Federal Law

The U. S. Department of Education’s Office of Special Education Programs (OSEP) has released the report of findings from its review of Massachusetts’ special education programs during the 1998-99 school year. OSEP was assessing Massachusetts’ compliance with federal special education law, the Individuals with Disabilities Education Act (IDEA). OSEP reviewed special education services for students aged 3 through 21 in four key areas: parent involvement, the provision of a free appropriate public education in the least restrictive environment, transition for young adults, and the overall supervision of special education by the state. The results of the report were based on interviews with parents, agency administrators, local program and school administrators, service providers, teachers and service coordinators, reviews of children’s records, and results of a survey the Federation distributed through NewsLine.

The single strength that OSEP identified in programs for school-age students was the Mass. Department of Education’s (referred to as MASS-DE in the report) partnership with the Federation. OSEP reported that Massachusetts needs improvement in four areas, and is in “longstanding, serious noncompliance” with the federal law in fourteen areas. The fourteen areas are:

- Denial of parents’ right to participate in the decision-making process regarding their children.
- An IEP development process that results in delays in services and in children with disabilities not receiving services agreed to in IEP meetings.
- Psychological counseling not always provided as a part of a free appropriate public education when needed to enable children with disabilities to benefit from special education.
- Extended school year services not always available.
- Lack of opportunities for children in substantially

Bicyclists Greeted as Celebrities!

Many of you have been following the journey of the Bryant family cyclists as they traverse the country from Washington state to the coast of Maine, raising funds for the Federation. We have posted regular updates of their trek on the Federation’s website since May 17, Day 1 of Pedal Power 2000. Here is an excerpt from the June 24 entry:

Moorhead, MN to Hitterdal, MN, 35 miles in 3 hours. This was probably the best day of the trip so far with a very unexpected experience. It was a beautiful, sunny day as they bicycled from the prairie land of eastern North Dakota to the forests of Minnesota. After 28 miles of pedaling they hit a road closed sign. A road closed due to flooding opened the way to a great adventure for our Pedal to Empower team!

After crossing the flooded road and wading through knee-deep water, the cyclists found themselves in Hitterdal, population 200. Hearing music as they were eating their lunch, they discovered there was an

Federation 25th Anniversary Gala– A Night to Remember!

see page 10 for details!
Special Education Changes—A Mixed Bag

Highlights of Key Changes
After years of intense debate, lawmakers approved a major overhaul of Ch.766, our state special education law. Thousands of parents of children with special needs, advocates, educators, and other interested parties throughout Massachusetts worked tirelessly to try and keep our laws strong. Thus, it was extremely disappointing that in the end, the legislature and Governor decided to repeal the Massachusetts “maximum feasible benefit” (MFB) service standard.

It is important to note that the change from “maximum feasible benefit” to the federal standard of “free and appropriate public education” does not go into effect until January 1, 2002—therefore your school district can not propose any changes to your child’s program based on repeal of MFB at this time. More importantly, parents and advocates have pledged to continue advocacy efforts in the legislature, at the State Department of Education, in local communities, and in the courts to ensure that children continue to receive essential services and equal opportunities.

As result of all the input and involvement from parents and others, lawmakers in the State House did vote to maintain other key protections and safeguards for children with special needs (despite Governor Cellucci’s veto of these provisions). It is very clear that input from parents made the difference when lawmakers voted to maintain these protections. These hard-won victories (which were achieved with the leadership and intense work of many supportive legislators) include:

Immediate Changes That Take Effect Now
1. All school districts must continue to maintain Parent Advisory Councils on special education (replacing a former regulation with statutory requirement)
2. Requires Board of Education to maintain former regulations regarding:
   • 45-day timeline for development of IEPs and provision of services
   • IEP Team’s right to determine specific placement for a child with a disability
   • Transportation protections and requirements
   • Extended-day programs
   • Parent consent and native language requirements
   • Parents’ right to observe programs
   • Program and safety requirements for private special education schools
   • Protections regarding special education facilities
   • The definition of parent
   • Content of evaluation requirements
   • Waiver provisions
3. Requires Board of Education to adopt regulations on use of restraints.
4. Maintains eligibility for children with disabilities who require only related services, and requires Massachusetts Department of Education (DOE) to amend its regulations and notify districts accordingly
5. Requires DOE to develop a curriculum for annual parent/student rights workshop, in collaboration with various parent and advocacy organizations.
6. Requires school districts to hold annual parent/student rights workshops in cooperation with local PACs.
7. Creates and funds ($9 million) a state risk pool to allow school districts to share the risk of fluctuations in special education costs.
8. Requires school districts to implement curriculum accommodation plans to help ensure that all efforts have been made to meet students’ needs in regular education
9. Schools must consult with parents about evaluators being used and the content of evaluations.
10. Requires school districts to report special education data, including information on the number of children in inclusive and segregated programs (reflecting old prototypes).

Changes Effective January 1, 2002
1. The standard for special education programs and services changes from maximum feasible benefit to free and appropriate public education.

Changes effective July 1, 2002
1. Creates a new funding formula whereby the state will pay for 80% of all “in-district” special education costs that exceed three times the state average per-pupil foundation budget and 65% of all costs for all “out-of-district” special education costs that exceed four times the state average per-pupil foundation budget (exception for private schools enrolling hearing-impaired students). “In-district programs” includes separate schools operated by a school district and some collaborative programs.
2. Requires as part of certification that all educators and administrators have training in effective strategies for inclusion of children with disabilities

Changes effective July 1, 2004
Requires that as a condition of re-certification, all educators and administrators have training in inclusion strategies.

For more details about these and other changes to special education law, check the Federation website at www.fscn.org. If you are interested in receiving more information (materials will be available in September) or want to arrange a workshop regarding the changes to Ch.776, call Massachusetts Advocacy Center, Johanne Pino at 617-357-8431 x234. To schedule an IEP 2000 workshop, call the Federation at 800-331-0688.
From the Executive Director

Historic Legislative Action Lowers Standard

The Massachusetts legislature has finally succeeded in undoing “Maximum Feasible Benefit.” After many years of strong advocacy to keep these key words and their promise of a high-quality education as part of our state special education law, kids with disabilities and their parents have been dealt a huge blow. People are constantly asking, “What difference will this really mean?” One way to begin is to think about the law and the court decisions that originally gave these words their meaning. Our state law has said that we must educate students with disabilities to enable them to reach their maximum potential development. The federal law was interpreted by the courts to say that a school must assist a student with disabilities in making some measurable progress.” In other words, our long-standing reputation in Massachusetts as leaders in special education has been because we have insisted on doing our best—for even the most vulnerable students.

Maximum development is not only for students with disabilities. It is interesting to note that the preamble of the Massachusetts Education Reform Act (MERA) passed in 1993 calls for all students to be educated to reach their greatest potential. MERA has established high expectations and performance standards for all students. In fact, high quality education as described in MERA specifies that all children—and this law does specifically include students with disabilities—should learn and grow to fulfill their maximum potential!

One Example:

As a way to measure progress toward meeting those high expectations and standards, MERA and IDEA now insist that all students—those with disabilities included—participate in the statewide large-scale testing system known as MCAS. In 2001, all students will be required to pass the MCAS test in order to graduate. We know that 96% of the students with disabilities who took MCAS last year scored either in the failing or needs-improvement categories. MERA promises extra help and support to students in danger of failing to pass MCAS.

So, ironically, the repeal of the Maximum Feasible Benefit standard from our state special education law could mean the reduction of the level of services and supports provided to students. At the same time, the implementation of high-stakes testing means more students with disabilities need more supports and services to get over the graduation “bar.” These two policies are on a collision course, and vulnerable students with disabilities are truly paying the price.¹

No one knows for sure what the long-term impact of this change is going to mean for individual children. Will it save money?

SUGGESTIONS FOR IMPROVED RESULTS FOR CHILDREN WITH DISABILITIES

OSEP provides the following suggestions for improved results for children with disabilities:

• A renewed emphasis on building partnerships and cooperation between parents and the educational community.
• Heightened efforts to facilitate the participation of non-English speaking parents in special education.
• Consideration for providing continuity in children's programs in districts that utilize “school choice.”
• Addressing challenges to ensure that children with disabilities are given appropriate supports in the State-wide assessment.

¹. Ironically, in spite of maximum feasible benefit’s promise of a high quality education for children with disabilities in Massachusetts, a recent federal report highlights the tremendous gap between the 25-year old promise and the reality. The U.S. Department of Education’s Office of Special Education Programs visited Massachusetts and found our state to be in non-compliance with the implementation and monitoring of the federal law. That means that Massachusetts has yet to rise even to the level of providing the lower federal standard. (See article on page 1).

**OSEP’s report can be read in its entirety on the Federation’s web site at***

www.fcsn.org
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,
I requested an evaluation twice for two consecutive years and was told my son did not need special education. How do I find out if my child is eligible for special education?

I have had many requests lately regarding eligibility guidelines. Below is information about federal and state eligibility guidelines that should help you decide your next steps.

The Massachusetts Special Education Regulations effective September 2000 define an eligible student to mean:“a person aged three through twenty-one (3-21) who has not attained a high school diploma or its equivalent, who has been determined by a Team to have a disability(ies), and as a consequence is unable to progress effectively in the general education program without specially designed instruction. An eligible student shall have the right to receive special education and any related services that are necessary for the student to benefit from special education. In determining eligibility, the school district must thoroughly evaluate and provide a narrative description of the student’s educational and developmental potential.” [Emphasis added.]

THE FEDERAL LAW (IDEA)
The Individuals with Disabilities Education Act (IDEA) gives eligible children with disabilities the right to receive special services and assistance in school. These services are known as special education and related services.

The first step is to find out if your child has a disability. To do this, ask the school to evaluate your child. Call or write the Director of Special Education or the principal of your child’s school. Say that you think your child has a disability and needs special education help. Ask the school to evaluate your child as soon as possible.

The public school may also think your child needs special help, because he or she may have a disability. If so, then the school must evaluate your child at no cost to you.

However, the school does not have to evaluate your child just because you have asked. The school may not think your child has a disability or needs special education. In this case, the school may refuse to evaluate your child. It must let you know this decision in writing, as well as why it has refused.

If the school refuses to evaluate your child, there are two things you can do immediately:

First, ask the school system for information about its special education policies, including parents’ rights to disagree with decisions made by the school system. These materials should describe the steps parents can take to challenge a school system’s decision.

Second, get in touch with the Federation for Children with Special Needs by calling (800) 331-0688. The Federation is a great resource to learn more about special education rights and responsibilities under the law. The Federation’s Parent Training and Information staff can tell you what steps to take next to find help for your child.

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 2000**
9/11, Marblehead, 7:30-9:30pm, IEP 2000
9/11, Springfield, 7:00 – 9:00pm, Basic Rights
9/12, Westfield, 7:00-9:00pm, Basic Rights
9/12, Springfield, 6:00 – 8:00pm, Basic Rights
9/14, Southbridge, 7:00-9:00pm, Basic Rights
9/14, Northampton, 2:00-4:00pm, Basic Rights
9/14, Boston, 11:00-1:00pm, Transition
9/18, Norwell, 7:00-9:00pm, IEP 2000
9/18, Springfield, 10:00-12:00pm, Basic Rights
9/19, Milford, 7:30-9:30pm, Communication
9/19, Rockland, 7:30-9:30pm, MCAS
9/20, Great Barrington, 7:00-9:00pm, Basic Rights
9/20, West Boylston, 7:00-9:00pm, Basic Rights
9/21, Lowell, 9:30-11:00am, Basic Rights
9/25, Springfield, 7:00-9:00pm, Basic Rights
9/27, Hadley, 7:00-9:00pm, IEP 2000
9/28, Upton, 7:00-9:00pm, IEP 2000
9/28, Nashoba, 6:30-8:30pm, IEP 2000
9/28, Boston, 10:00-12:00pm, Basic Rights

**OCTOBER 2000**
10/3, Sharon, 7:00-9:00pm, IEP 2000
10/3, Springfield, 10:00-12:00pm, Basic Rights (Spanish)
10/5, Newton, 7:30-9:30pm, Basic Rights
10/5, Wakefield, 7:00-9:00pm, IEP 2000
10/5, Groton, 6:00-8:00pm, Communication
10/10, Tewksbury, 7:00-9:00pm, Basic Rights
10/12, Webster, 7:00-9:00pm, Basic Rights
10/16, Marlborough, 7:30-9:30pm, Basic Rights
10/17, Littleton, 7:00-9:00pm, IEP 2000
10/17, Hopkinton, 7:00-9:00pm, IEP 2000
10/18, Andover, 7:00-9:00pm, Transition
10/18, West Boylston, 7:00-9:00pm, IEP 2000
10/18, Longmeadow, 7:00-9:00pm, IEP 2000
10/21, Quincy, 9:30-11:30am, Basic Rights
10/24, Northampton, 7:00-9:00pm, IEP 2000
10/25, Great Barrington, 7:00-9:00pm, IEP 2000
10/26, Chicopee, 6:30-8:30pm, IEP 2000
10/26, Southbridge, 7:00-9:00pm, IEP 2000

**NOVEMBER 2000**
11/2, Hanover, 7:00-9:00pm, Basic Rights
11/2, Wakefield, 7:00-9:00pm, Basic Rights
11/7, Fall River, 6:30-8:30pm, IEP 2000
11/8, Andover, 7:00-9:00pm, IEP 2000
11/15, Greenfield, 7:00-9:00pm, IEP 2000
11/15, West Boylston, 7:00-9:00pm, Communication
11/16, Chicopee, 6:30-8:30pm, Transition
11/20, Milton, 7:00-9:00pm, IEP 2000

**WORKSHOP DESCRIPTIONS**

**Basic Rights:** 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.)

**Communication:** Offers conflict resolution and communication skill-building for parents as members of the Team.

**IEP 2000:** An in-depth look at the Team process of IEP development, with a focus on standards-based education for all students.

**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 community life that will help prepare students for adult life.
Bicyclists Greeted as Celebrities!

continued from page 1

antique car show. Invited to “come join rural America at its best,” who could resist? Ralph and Dustin entered the pie-eating contest where their hands were tied behind their backs and a pie placed in front of them. Then they joined the slow bike riding contest, lawn mower obstacle race, and the bake and crafts sale. These activities gave the group a chance to meet almost everyone in town.

In the midst of their activities, they noticed two new model homes for sale next to the park. The Mayor explained that he had them built with State funds in an effort to attract new young families to their town. He gave them a tour and invited them to spend the night in one of the homes. Thanks to the Mayor they had hot showers, comfortable beds and plush carpets. Hitterdal has a predominately Norwegian population, and after treating the celebrities to lefse bread, the Mayor invited the guests to the pork feed at the community center. The after-dinner entertainment included a dance at the Senior Center with Accordion Dave playing.

One townsperson commented that they felt as if the town had their very own foreign exchange visitors. The next morning, after the pancake feed at the Community Center, the town of Hitterdal sent the pedalers off with many good wishes. Needless to say, the bikers left with very warm hearts, full stomachs, a good night’s sleep, and lots of new friends.

Note: As we go to print, the bikers are arriving in Bar Harbor, ME, completing their journey.
Education after High School: Myths and Possibilities

As a parent, you see your child’s life unfold and your vision for your son or daughter is a constant reminder of future possibilities. During their early years, ever-present demands of day-to-day home and school routines take precedence. Often discussions at school focus on therapies, supports, and what the student “cannot do” as opposed strengths and skills. High expectations and dreams can easily end up altered or erased. Adolescence and planning for adult life seem so far away . . . .

IDEA (the federal special education law) requires schools to begin transition planning for students receiving special education at age 14. Transition plans must be driven by a student’s preferences, interests, and vision for adult life. All students’ high school programs should thoroughly prepare them for desired post-high school goals. Parents need to encourage teachers and other school personnel to raise their expectations of students with disabilities as they work together to develop and implement comprehensive, long-range transition plans.

Postsecondary options mean school or continued learning opportunities after high school. They should be part of every student’s future. Typically, students choose high school courses that support their dreams of college, technical school, or work. Students with disabilities need to prepare the same way. IDEA requires that IEPs contain a statement of the student’s “transition service needs.” The statement should identify the appropriate courses of study in high school that support the post-school vision. Participation in the general curriculum, including appropriate accommodations and/or modifications, is essential preparation for meaningful postsecondary options.

Myths about learning after high school:
1. True or False? You won’t need to continue your schooling after high school.
False. According to education and employment experts, to earn a good living and participate in this technological culture, you will most likely need to continue your education beyond high school.

2. True or False? There is no Special Education in college.
True. In college there is no Special Education entitlement but there are supports and services.

A student must present documentation of the disability so that a learning specialist at the college can design needed academic accommodations, such as extended time for testing. Find out more at the Office of Disability Services (may go by another name) at the college.

3. True or False? Students are in charge of their education after age 18.
True. At age 18, (the “age of majority”) students make their own decisions including agreements about school after high school. Disability-related information is confidential and at age 18 must come from the student.

4. True or False? “Ask my mother (father, teacher)” is no longer an acceptable answer. True. The student must know about his or her learning strengths and weaknesses and how to communicate that information.

5. True or False? Postsecondary education means four years of full-time college.
Maybe true, maybe false. Learning after high school might include an adult education course, evening or day courses at a college, workshops and job training through your local vocational rehabilitation agency or employer. It’s the student’s choice that counts.

How can parents help?
- Discuss your child’s visions and goals for the future and make sure the steps to achieve them are reflected in the IEP.
- While in high school, encourage exploration of many different work experiences to stimulate student choice and identify possible postsecondary and/or career options.
- Consider taking self-advocacy and self-determination courses to develop leadership skills, enhance self-esteem, and increase student participation at IEP meetings.
- Form a team with your child and his/her guidance counselor.
- Access as many learning opportunities in the general curriculum as possible and identify the supports necessary to succeed.
- Look for postsecondary learning opportunities during high school. Many colleges offer summer programs on particular topics or career exploration for high school students.
- Invite someone from the Office of Disability Services of a college to speak at a special education or high school PAC meeting.
- Visit the local community college early and often. Community college classes open to all (plays, fairs, open houses) present low-stress ways to experience a college setting.
- Invite key adult human service agency representatives to IEP meetings. For instance, a Massachusetts Rehabilitation Commission (MRC) counselor can help design the steps to reach work-related goals.

To find out more:
- Visit the Guidance Department and/or career center in your high school.
- Check college catalogues. Call and ask if there are summer programs for high school students and how to apply for them.
- Ask your town librarian to help you locate all the places where information on postsecondary education is available.
- Surf the web for governmental or professional organizations concerned with college experiences. For example, the federal Department of Education has a great site called “Think College Early” at:
  www.ed.gov/thinkcollege/early/educators/mind.htm
- Disability-related information can be found through AHEAD (Association for Higher Education and Disability) at: www.ahead.org
- For lots of other resources, go to the Institute for Community Inclusion website and click on Post Secondary Options www.childrenshospital.org/ici/forum/links.htm

Back to School 2000: FRESH IDEAS FOR A FRESH START

The Federation’s Community Outreach and Empowerment (COEP) and Parents’ PLACE projects are jointly sponsoring a conference for families on Saturday, September 9, from 10 am to 4:00 pm.

“Back to School 2000: Fresh Ideas for a Fresh Start” will have information and ideas to help families launch their children on a productive and successful school year.

For more information, call T.J. Hutson or Diana Rocha at 617-236-7210 ext. 113 or 117, or toll-free at 877-471-0980. The conference will be in English and Spanish.
Educación Después de la Secundaria: Mitos y Posibilidades

Como padre de familia, usted ve que la vida de su hijo se desenvuelve y la visión que tiene de él o ella le recuerda constantemente las posibilidades futuras. Durante los primeros años, demandas siempre presentes en la rutina de la vida diaria de la casa y la escuela tienen precedencia. Frecuentemente, muchas discusiones en la escuela se limitan a terapias, apoyos, y a señalar lo que el estudiante “no puede hacer”, en lugar de mirar sus fortalezas y habilidades. Grandes expectativas y sueños pueden ser fácilmente alterados o borrados por completo. Adolescencia y planeación para la vida adulta parecen ser muy lejanas.

IDEA (La ley federal para la educación especial) pide a las escuelas que comiencen un programa de planeación transicional para estudiantes que reciben educación especial a la edad de 14 años. Planes de Transición tienen que estar movidos por por las preferencias de los estudiantes, intereses, y visión de la vida adulta. Todos los programas de secundaria deben preparar a los estudiantes para alcanzar las metas de la post-secundaria. Los padres de familia necesitan motivar a los profesores y otras personas que trabajen en la escuela a que eleven la visión que se tienen para después de la secundaria. Esta afirmación debe ser congruente con sus sueños y a largo plazo.

Opciones para después de la secundaria quiere decir oportunidades de aprendizaje continuadas después de secundaria. Estas opciones deben ser parte del futuro de cada estudiante. Típicamente los estudiantes escogen las clases en la secundaria que están en consonancia con sus sueños de universidad, escuela técnica, o trabajo. IDEA pide que los Programas Educativos Individualizados contengan una declaración sobre las “necesidades del servicio de transición” de los estudiantes. Esta afirmación debe identificar las clases apropiadas en la secundaria que apoyen la visión que se tiene para después de la escuela. Participación en el currículo general, incluyendo acomodaciones y/o modificaciones apropiadas, es una preparación apropiada para tener opciones después de la secundaria que tengan sentido.

Mitos relacionados con el aprendizaje después de la escuela

1. ¿Falso o verdadero? Usted no necesita continuar estudiando después de la secundaria.
Falso. De acuerdo con los expertos en educación y empleo, para ganar un buen sueldo y participar en esta cultura tecnológica, usted probablemente necesitará continuar su educación después de la secundaria.

2. ¿Falso o verdadero? No hay programas de Educación Especial en la Universidad.
Verdadero. En la universidad no hay programas de Educación Especial, pero hay apoyos y servicios. Un estudiante debe presentar documentos relacionados con su discapacidad de tal manera que un especialista del aprendizaje en la universidad pueda diseñar un programa adecuado de acuerdo con las necesidades académicas, tal como más tiempo para los exámenes. Usted puede encontrar más información sobre esto en la Oficina de Servicios para Discapacitados (o puede tener otro nombre) en la universidad.

3. ¿Falso o verdadero? Los estudiantes son responsables de su propia educación a los 18 años.
Verdadero. A los 18 años (la edad de la adultez), los estudiantes toman sus propias decisiones, incluyendo convenios sobre educación después de la secundaria. La información relacionada con discapacidades es confidencial, y a los 18 años tiene que ser provista por el estudiante.

4. ¿Falso o verdadero? “Pregúntele a mi mamá (papá o profesor)” no es una respuesta aceptable ahora.
Verdadero. El Estudiante tiene que saber sobre sus fortalezas y debilidades para aprender, y cómo comunicar esa información.

5. ¿Falso o verdadero? Educación después de la secundaria significa 4 años de estudio en la universidad, tiempo completo.
Puede ser verdadero o falso. Aprender después de la secundaria puede ser un curso de educación para adultos, clases en la universidad en el día o la noche, talleres y capacitación laboral a través de su agencia de rehabilitación o empleador local. Lo que cuenta es la decisión del estudiante.

¿Cómo pueden ayudar los padres?
• Discuta las visiones y metas de su hijo para el futuro y asegúrese de que los pasos para alcanzarlas estén reflejados en el Programa Educativo Individualizado.
• Mientras el niño esté en la escuela secundaria, motive la exploración de diferentes experiencias de trabajo para estimular la elección del estudiante e identificar opciones para una carrera después de la secundaria.
• Considere el tomar algunos cursos de auto-terminación para desarrollar habilidades de liderazgo, promover su auto-estima e incrementar participación de los estudiantes en las reuniones del Programa Educativo Individualizado (IEP).
• Forme un equipo con su hijo/a y su consejero escolar.
• Procure acceso al mayor número de posibilidades de aprendizaje presentes en el currículo e identifique las fuentes de apoyo necesarias para para tener éxito.
• Busque oportunidades de aprendizaje después de la secundaria mientras esté estudiando. Muchas universidades ofrecen programas de verano sobre temas en particular o exploración de carreras para estudiantes de escuela a la que estén reflejados en el Programa Educativo Individualizado. Por ejemplo, un consejero de la Massachusetts Rehabilitation Commission puede ayudar a diseñar los pasos para lograr metas relacionadas con el trabajo.

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Need An Advocate?

Helping Special Needs Students Maximize Their Educational Opportunities

Dennis M. Gould
Parent Consultant / Advocate
45 Catherine Drive • Northborough, MA 01532
Tel: 508-393-9114 • E-mail: godennis@usa.net
Educação após a High School: Mitos e Possibilidades

Como pai, você vê o desbrochar da vida da sua criança e sua perspectiva para o seu filho ou sua filha é um sinal constante de possibilidades futuras. Durante os primeiros anos deles, as exigências sempre presentes do dia a dia da rotina do lar e da escola são prioritárias. Em geral, as discussões na escola são centralizadas em terapias, apoio, e o que o aluno “não pode fazer” em detrimento de suas qualidades e habilidades. Sonhos e expectativas muito altas podem facilmente serem alterados ou apagados. Adolescência e o planejamento para a vida adulta parecem tão distantes...

IDEA (a lei federal para educação especial) requer que as escolas iniciem um plano de transição para os estudantes a partir dos 14 anos que recebam educação especial. Os planos de transição devem estar de acordo com as preferências e os interesses do estudante assim como para a perspectiva de uma vida adulta. Todos os programas da high school devem preparar os alunos, inteiramente, para os seus almejados objetivos após o ensino secundário. Os pais precisam encorajar os professores e o quadro de pessoal da escola a elevar suas esperanças para os alunos portadores de deficiência, já que trabalham juntos para desenvolver e implementar planos de transição que sejam abrangentes e de longo alcance.

Opções pós-secundárias significam escola ou aprendizagem contínua após a high school. Elas deveriam fazer parte do futuro de todo estudante. Tipicamente, os estudantes escolhem cursos da high school que dão suporte aos seus sonhos de faculdade, escola técnica, ou trabalho. Estudantes com deficiência precisam, igualmente, estar preparados. A IDEA exige que os IEPs (Plano de Educação Individual) contenham uma declaração das “necessidades dos serviços de transição” do estudante. Essa declaração deve identificar os cursos apropriados na high school que auxiliem a perspectiva pós-escolar. A participação no currículo geral, incluindo as apropriadas adaptações e/ou modificações, é uma preparação essencial para as significativas opções pós-secundárias.

Mitoses sobre a aprendizagem após a high school:
1. Verdadeiro ou Falso? Você não presisará continuar seus estudos após a high school.

Falso. De acordo com especialistas nas áreas do trabalho e da educação, para adquirir-se um bom modo de vida e participar nesta cultura tecnológica, você terá necessariamente de continuar seus estudos além da high school.

2. Verdadeiro ou Falso? Não há Educação Especial na Faculdade.

Verdadeiro. Não há qualquer denominação de Educação Especial na faculdade, mas há, contudo, algum tipo de apoio e serviços. O estudante deve apresentar a documentação que comprove a sua deficiência, de forma que um especialista em aprendizagem da faculdade possa designar as adaptações acadêmicas necessárias, tais como um tempo maior para os testes. Informe-se melhor no “Office of Disability Services” (o nome pode variar) da faculdade.

3. Verdadeiro ou Falso? Os estudantes são responsáveis pela sua educação após os 18.

Verdadeiro. Aos 18 anos (quando são “maiores de idade”) os estudantes tomam as suas próprias decisões, incluindo contratos escolares após a high school. Informações relacionadas a qualquer tipo de deficiência são confidenciais e, a partir dos 18 anos, devem ser relatadas somente pelo próprio estudante.

4. Verdadeiro ou Falso? “Pergunte ao meu pai, mãe ou professor” já não é mais uma resposta aceitável.

Verdadeiro. O estudante deve saber sobre suas potencialidades e fraquezas de ensino e, também, como comunicar essas informações.

5. Verdadeiro ou Falso? Educação pós-secundária significa 4 anos de faculdade em período integral.

Pode ser verdadeiro ou falso. Educação após a high school pode ser um curso para adultos, noturno ou diurno, na faculdade, bem como workshops e treinamento para o trabalho através da sua agência de reabilitação vocacional ou do seu empregador. A escolha do estudante é que conta.

Como os pais podem ajudar?
• Discutam as perspectivas e objetivos do seu filho e estejam certos de que os passos para realizá-los estão refletidos no IEP.
• Enquanto na high school, encorajem a exploração de muitas e variadas experiências de trabalho que estimulem a escolha do estudante e identifiquem possíveis opções pós-secundárias e/ou de carreira.
• Considere fazer cursos de auto-ajuda e auto-determinação para desenvolver técnicas de liderança, elevar a auto-estima e aumentar a participação do aluno nas reuniões do IEP.
• Formem um grupo com o seu filho ou filha e a sua orientadora escolar.

• Acessem tantas oportunidades de ensino quanto possível no currículo geral e identifiquem os suportes necessários para que tenham sucesso.
• Procurem pelas oportunidades de educação secundária ainda durante a high school. Muitas faculdades oferecem programas de verão em tópicos específicos ou pesquisa de carreiras para estudantes da high school.
• Conviram alguém do “Office of Disability Services” de uma faculdade para dar uma palestra na área de educação especial ou numa reunião de educação especial ou do PAC (conselho de orientação aos pais) da high school.
• Visitem a faculdade comunitária local (community college) logo e com frequência. Os eventos da faculdade comunitária (jogos, feiras, “open houses”), são abertos para todos e apresentam, de modo simplificado, como experienciar a entrada numa faculdade.

Para saber mais:
• Visitem o “Guidance Department” e/ou o centro de carreiras na sua high school.
• Dêem uma olhada nos catálogos das faculdades. Telefonedem e pergutem se há programas de verão para estudantes de high school e como registrar-se neles.
• Peçam ao bibliotecário de sua cidade para ajudá-los a localizar todos os lugares onde há informação sobre educação pós-secundária disponível.
• Surfem na Internet em busca de organizações profissionais ou governamentais relacionadas com a prática universitária. Por exemplo, o Departamento de Educação federal dispõe de continuação na página 9
We begin the following excepts from Gunnar’s essay “From Feeblemindedness to Self-Advocacy: A Half Century of Growth and Self-Fulfillment” with 1975, the year the Federation opened its doors and one year after the passage of Chapter 766:

In 1975, Congress passed PL 94-142, The Education for All Handicapped Children Act [now known as IDEA, the Individuals with Disabilities Education Act], a mighty step forward toward school integration even though in actual practice the “all” carried with it a few grains of salt. Still, all in all, the legislative process was impressive, but it was matched by a new phenomenon in the human services field—a steadily growing number of judicial actions...
The first case was filed by the Pennsylvania Association for Retarded Children against Pennsylvania state agencies. After listening to one day of testimony by PARC’s expert witnesses, the three-judge Federal District Court suggested that since the State had not contested plaintiffs’ claims that no child should be deemed ineducable and thus excluded from schooling, the parties should work out a consent agreement. This was done and in due time, the Court approved it.

Shortly after the PARC case had been started, a class action suit Mills v. Board of Education was filed in Washington, DC, and in that case, the plaintiffs represented not just children with mental retardation but with a cross-section of disabilities. This case ended in a judgment by the U.S. District Court which makes for very interesting reading. In response to the district’s claim that they needed additional funds before they could admit children excluded on account of disability, Judge Waddy stated:

“The District of Columbia’s interest in educating the excluded children clearly must outweigh its interest in preserving its financial resources. If sufficient funds are not available to finance all of the services and programs that are needed and desirable in the system, then the available funds must be expended equitably in such manner that no child is entirely excluded from a publicly supported education consistent with his needs and ability to benefit therefrom. The inadequacies of the District of Columbia Public School system whether occasioned by insufficient funding or administrative inefficiency, certainty cannot be permitted to bear more heavily on the ‘exceptional’ or handicapped child than on the normal child.” Mills v. Board of Education (1972).

[In a later speech. “Beginnings and Endings: The Quality of Life for Young and Old (1988), Gunnar expressed the following “lasting verities,” truths which have much relevance for us today.]

I continue to be an optimist. We are making progress, we are gaining ground, and I still believe in some lasting verities. Some of you have heard them before, but they bear repeating:

In dealing with the problem of human growth and development, one should never say “never”—there is always change, the dynamics of which so far have not become clear to scientific exploration. No one can predict as a human being is born, where the limits of the person’s growth and development will be. I reject and resent the arrogance of [those] who predetermine another human being’s potential.

[Many] may continue trying to apply measurements to intellectual functioning, adaptive behavior, and emotional maturity, but the inherent dignity of a human being, no matter how severely disabled, cannot be quantitatively assessed.

— Gunnar Dybwad, 1988

In searching for solutions to human problems, I am more and more impressed with the overwhelming importance of one's personalized environment—for the child, the family; for the adult, in addition to his family, his own living space. Thus, home support looms ever larger on my list of priorities... Much of my most significant learning in the field of disability I owe to parents of children with disabilities.

More and more I am convinced that we must listen to a far greater degree to the individuals with disabilities. For a long time we thought those with more severe disabilities could not learn; now we know we did not yet know how to teach. Similarly, what we call the inability of persons with severe disabilities to communicate, may well be our ineptness in listening.

Edugacion Después de la Secundaria: Mitos y Posibilidades

Para saber más:
- Visite el Departamento de Orientación y/o el Centro de Carrera de su escuela.
- Revise los catálogos de las universidades. Llame y pregunte si existen programas de verano para estudiantes de secundaria y cómo aplicar para recibirlas.
- Pida al bibliotecario/a de su ciudad o pueblo que le ayude a localizar los lugares en donde información sobre educación post-secundaria es disponible.
- Navegue por la Red (Internet) y busque organizaciones gubernamentales o profesionales relacionadas con experiencias universitarias. Por ejemplo, el Federal Department of Education tiene una buena página llamada: “Think College Early”. Véala en: www.ed.gov/thinkcollege/early/educators/mind.htm
- Información sobre discapacidades puede ser hallada a través de AHEAD (Association for Higher Education and Disability). Véala en: www.ahead.org
- Otras fuentes pueden ser halladas en la página del Institute for Community Inclusion. Entre a la sección de Post Secondary Options www.childrenshospital.org/ici/forum/links.htm

Educação após a High School: Mitos e Possibilidades

um grande “site” denominado “Think College Early” (Pense Cedo na Faculdade) no: www.ed.gov/thinkcollege/early/educators/mind.htm
- Informações relacionadas aos excepcionais podem ser encontradas na AHEAD (Association for Higher Education and Disability) no: www.ahead.org
- Para muitos outros recursos, vá para o “web-site” do Institute for Community Inclusion e clique no link “Post Secondary Options” www.childrenshospital.org/ici/forum/links.htm
Federation 25th Anniversary Gala—
A Night to Remember!

On May 12, 2000, over 350 celebrants gathered at the Royal Sonesta Hotel to honor the Federation’s twenty-fifth year as a national leader providing advocacy, training, and information services for families with children with disabilities and special health care needs.

The night began with a cocktail reception accompanied by sumptuous hors d’oeuvres and music, served in a scenic room overlooking the Charles River. As guests mingled, munched, and chatted, they bid on over 120 silent auction items. Donated goods, services, and gift certificates ranged from exquisite pieces of art to weekend getaways at places like the Red Lion Inn in the Berkshires.

Mary Richardson of WCVB-TV’s Chronicle was emcee, providing wit, warmth and enthusiasm that captured the spirit of celebration throughout the evening. Professor Gunnar Dybwad, Honorary Chairperson, crystallized over 25 years of progress when he quoted from a speech he delivered in September 1974. His historical perspective reinforced the importance of continuing to strengthen and empower families and people with disabilities themselves.

Hold Fast to Dreams, a video presentation by students from the Patrick O’Heam Elementary School brought guests back to the present as students expressed their dreams for the future. Special musical entertainment was provided by Michael Heraty, an aspiring saxophonist who has realized many of the benefits of Chapter 766. We have come a long way!

To further mark the accomplishments of the Federation, President of the Board, Dan Heffernan, announced the establishment of the Martha Ziegler Founders Award. [See Dan’s speech at the bottom of this page.]

Senator Edward M. Kennedy was presented with the first Martha Ziegler Founder’s Award in recognition of his contributions to the disability community. Connie Garner, Disability Advisor to the Senator and parent of a child with special needs, accepted the award for Senator Kennedy. She spoke of her personal experiences raising a child with a disability and the challenges that arise for her family on a daily basis. She praised the Senator for his long-time record of promoting public policy that supports the lives of individuals with disabilities and their families.

The evening ended with a rousing applause and grand send off to the Bryant family who would begin bicycling across the country, from Townsend, Washington, to Bar Harbor, Maine. [See “Pedaling to Empower” update, p. 1 ] All

continues on next page

The Board Honors Martha Ziegler

“As the Board prepared for this special occasion, we wanted to find a suitable way to acknowledge the accomplishments of Martha Ziegler, our founder and first director. Martha brought her dreams to their fulfillment in the establishment of the Federation and subsequently with the establishment of the national parent center network. We decided that a lasting tribute to Martha would be to establish an award that would bear her name and continue her legacy. Therefore, this evening we are establishing the Martha H Ziegler Founder’s Award.

“Martha, it is with gratitude and deep-felt appreciation that we recognize your work and inspiring leadership. On behalf of the Board of Directors, we thank you.”

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Federation 25th Anniversary Gala continued from previous page

proceeds from their efforts will support the establishment of a new program at the Federation. We are delighted to have had such an impressive cast of people to honor and recognize. It was a night to remember! Special thanks to all of those who attended the 25th Anniversary Gala. It is through the collective support of those who volunteered their time, energy, and financial support that we are able to continue to grow to meet the challenges of the next century. Our special thanks to the following contributors:

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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.

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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 membership benefits.

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The Hausslein Parent Leadership Awards

Excerpted from an article by Beth Dworetzky in the Early Intervention Parent Leadership Project’s Parent Perspective newsletter.

Last year, staff from the Massachusetts Department of Public Health (DPH), the lead agency for the early intervention (EI) system, and the Early Intervention Parent Leadership Project, created a mechanism to allow families to take a leadership role in creating new supports for themselves. Parents who wrote their ideas and met certain criteria received a $1000 award to fund and implement their initiatives.

This award was named the “Hausslein Early Intervention Parent Leadership Award” to honor Evelyn Hausslein’s lifetime work of nurturing families and children of all ages, in hospitals, in schools, and in communities. Evelyn, a long-time staffer at the Federation, was the founding director of the Federation’s Early Intervention Training Center.

THE HAUSSELEIN AWARDS CEREMONY

Attending a meeting in an ordinary meeting room at the Holiday Inn in Worcester on June 7th, 2000, was anything but an ordinary experience. The room was filled with an extraordinary crowd of people—the Hausslein Early Intervention Parent Leadership Award Recipients and the Award’s namesake, Evelyn Hausslein! These parent leaders came together to be recognized for their hard work and to give presentations about their Award Projects.

Eighteen parent teams received Awards for their unique projects, briefly summarized in the categories below:

COMMUNICATION

- Adult Course in Child Sign Language, designed by parents, for parents, EI staff, and community providers, to enhance communication with their children with speech and language delays.
- A 6-week course in Total Augmentative Communication that offered concrete strategies for communication with children with speech and language delays.
- Computer Library of Speech and Language Software, to be used by EI staff with EI children who received group services alongside children not in early intervention. The software was also available for families to borrow for use at home or public access computers.
- Children’s Book-Making Project, based on the idea that “children learn from pictures,” for making personalized picture books.
- Parent Mentorship around Transition Support
  - A Parent Support and Mentorship Program, to train families experienced with EI to mentor families new to EI, along with a support group for families.
  - Refrigerator Magnets, with the EI contact information and space to add emergency or frequently called numbers. The magnet, along with a welcome letter, written by families, is distributed to each new family.
  - Transition from EI into special education, a network of graduate EI families and special education Parent Advisory Councils (PACs), to help families benefit from the expertise and experience of families who have already transitioned from early intervention to the public school system.
  - Parent-to-Parent Connection, to match parents who have been through transition with families who are approaching transition, along with information about community programs that families were accessing and the accommodations being made to include children with special needs.

BUILDING COMMUNITY CONNECTIONS

- Boston Metro Community Playgroup, to increase awareness of EI services and to provide opportunities for children in EI to interact with community children.
- Family Exploration Project, to help families explore community attractions outside of EI child/group services.
- Parents as Teachers Project, to create an integrated playgroup for children with multiple disabilities.
- Special Needs Book Collection, created at a local library, to provide up-to-date disability-related resources.

PARENT SUPPORT

- Kids With Tubes Newsletter, an expansion of a parent-run support organization, to share information and resources with families and caregivers of tube-fed children.
- Common Bonds, a parent support group, to provide a diagnosis-specific networking opportunities for parents of children with autism. They also purchased books and created a lending library.
- The Down Syndrome Group, to provide networking and social opportunities for families who have young children with Down Syndrome.
- The Down Syndrome Resource Group, to purchase books for area libraries that would be available to any family via the interlibrary loan system.
- Less Stress Support Group, to continue to provide opportunities for parents to share the joys and challenges of being parents.
- The Education and Medical Awareness Project, a series of three workshops for families, early intervention staff, and community members to share information and reduce families’ isolation, especially for families living in rural areas.

Each of these Parent Teams and their collaborators deserve a standing ovation for their ideas, commitment and energy. They have elevated parent leadership to a new level in Massachusetts.

For more information about any of the projects, or to receive an award application (you must be a parent of a child who is currently receiving early intervention services), please call the Parent Leadership Project at 1-877-35-EI-PLP.


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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, administrative proceedings, personal injury law, estate planning, intellectual property, corporations, including representation of private schools and programs, child care and other organizations, health care administration, real estate, and taxation.

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**Celebration 2000 and Abilities Expo**

Abilities Expo, the major national show for independent and assisted living products and services, is coming to Boston on October 20–22 (Friday–Sunday). The Expo will be at the Bayside Expo Center in Boston. Abilities Expo is like a home show for people with disabilities of all ages. More than 200 exhibit booths will display products and services along with a full program of consumer education workshops each day. Admission is FREE.

Featured at the Expo will be **Celebration 2000 Career Fair**, matching employers and people with disabilities. The Massachusetts Rehabilitation Commission (MRC) will host numerous special events during the two day celebration which will include an Exemplary Employer Awards luncheon, Gala Awards dinner, entertainment, and speaking engagements by top level officials. The celebration will feature educational seminars, an Art Exhibit, and a two-day Career Fair expecting to draw over 100 employers interested and committed to hiring qualified candidates from the disability community. Participating employers will include local businesses, national corporations, and staffing agencies.

For more information, visit Abilities Expo website at www.abilitiesexpo.com and Celebration 2000 at www.state.ma.us/mrc/celebration2000.htm

**OSEP Commends Mass EI Service System**

In spring 1999, U.S. Department of Education monitors visited Massachusetts to assess its compliance with IDEA (the federal law governing early intervention services and special education services for school-age students). The monitors visited three early intervention (EI) programs and spoke with scores of family members, service providers, and others about the services available to infants and toddlers and their families.

The just-released report of the federal monitors commends the Department of Public Health (DPH) for the Early Intervention (EI) system. Among the strengths noted were:

- Strong parent participation in service delivery at local and state levels;
- Early identification of infants and toddlers and their families in need of EI services;
- Effective use of funds to provide expanded services to infants and toddlers who are at risk for developmental disabilities;
- Intergency collaboration that helps ensure continuous services and community supports; and
- Leadership by DPH to affect change in the system so that all EI services are provided in natural environments.

OSEP also gives suggestions for improving EI services for infants and toddlers with disabilities. For example, the federal report recommends that efforts be devoted to:

- ensuring consistent application of IDEA requirements for EI across the state;
- using children’s and families’ typical routines in deciding where to provide services within their community, and
- training EI staff on ways to provide services which build upon family and community life.

To ease children’s transition at age three from early intervention to preschool, the report recommends:

- training and guidance for EI staff on finding community options for children who do not qualify for special education services, and
- specific training for parents on how the rules and procedures governing special education differ from those governing early intervention services.

The report identifies one area of non-compliance: justification was not always given for the provision of some early intervention services in settings other than natural environments.

Although the report was just released in June, DPH was aware of the issues and recommendations thanks to their own in-state monitoring and to their active participation in the federal monitoring activities. Immediately after the monitoring visit, DPH convened a group of family members, early intervention service providers, and representatives of community and state agencies to develop a plan to address the concerns.

This plan began to be implemented last summer and is in the process of being revised to reflect progress and other changes in the system.

The monitoring report can be found on the Federation’s web site at www.fcsn.org/.
Every Single Student

Every Single Student: A PEER Resource Manual on Standards-Based Education and Students with Disabilities covers a broad range of topics relevant to the education of students with disabilities in today’s schools. The Manual includes 13 sections comprised of PEER Information Briefs and PEER Fact Sheets.

With national attention now focused on improving education for all students, this Manual provides practical information to help parents, teachers, and advocates understand standards-based education reform and ensure that students with disabilities benefit from education reform efforts.

Every Single Student has been reviewed and approved by the U.S. Department of Education, Office of Special Education Programs, to ensure accuracy and consistency with IDEA-97, the federal special education law.

97 pages. 1999. $35.00

The Parent Manual

The Parent Manual outlines parents’ and children’s rights in special education as guaranteed by Chapter 766, the Massachusetts special education law, and the Individuals with Disabilities Education Act (IDEA), the federal special education law.

75 pages. 1996. $25.00

El Manual de Padres

El Manual de Padres explica sobre los derechos de los padres y de los niños en educación especial garantizados por el Capítulo 766, la ley de educación especial de Massachusetts, y La Educación para Individuos con Impedimentos (IDEA), la ley federal de educación.

100 pages. 1996. $25.00

PEER INFO BRIEFS

Each Info Brief is $3.00. Price includes shipping & handling.

• Raising Standards of Learning: Standards-Based Education and Students with Disabilities
• Curriculum and Instruction: Key Strategies to Promote Equity and Excellence
• Accommodations: Examples from State Assessment Policies
• Assessment: A Key Component of Education Reform
• Statewide Assessment: Policy Issues, Questions, and Strategies
• Education Reform and Students with Disabilities: The Legal Basis
• Opportunity to Learn and Education Reform: Ensuring Access to Effective Education for All Students
• Section 504, the Americans with Disabilities Act, and Education Reform
• IDEA 1997: Improving the Education of Students with Disabilities in an Era of Education Reform
• Title I: Tools for Ensuring Quality Educational Opportunities
• Transition in an Era of Education Reform
• Positive Behavior Supports and Functional Assessment of Behavior
• Parent Participation: Crucial to Education Reform
• Site Visits: Seeing Schools in Action

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The three families who testified were bolstered by a room full of advocates, including Family Voices policy staff who had helped organize the hearing.

Another provision of the bill establishes Family-to-Family Health Information Centers in every state, to be run by experienced families. These centers will provide information, education, and assistance to help families negotiate our complicated health systems.

We know how important Medicaid access is to families in Massachusetts who have been able to buy Medicaid through CommonHealth. We also know how crucial family-friendly information, from other families, is in helping families find the resources their children need.

The hearing was an excellent opportunity for “Family Voices” to be heard nationally on these issues. This was just the momentum needed to educate not only members of Congress, but also the public, about the needs of our kids and our families.

We salute Massachusetts’ own Sen. Kennedy for his continued national leadership in developing family-friendly policies for kids with disabilities and their families. Let Senator Kennedy, Senator Kerry, and our Congressmen know we appreciate their efforts on behalf of our families and need their continued support.

Check out our Family Voices website (www.familyvoices.org) for more details on the Family Opportunity Act (FOA), S2274 and H4825.

FAMILIES TO INTERVIEW MANAGED CARE ORGANIZATIONS IN MASSACHUSETTS

Family Voices at the Federation has recently been awarded a grant from the Packard Foundation in California to continue activities documenting how health care is working for children with special health care needs around the country. In Massachusetts, these efforts will be expanded in a collaborative initiative by Family Voices and New England Serve. Plans are under way to recruit, train, and support parents to conduct interviews with health plans across Massachusetts to gather information about their current capacity to identify and serve children with special health care needs.

FAMILY VOICES REPORTS ON “YOUR VOICE COUNTS!” SURVEY AVAILABLE

The 2nd edition of What Do Families Say About Health Care for Children with Special Health Care Needs? Your Voice Counts!! the Family Partners Project Report to Families has just been printed. Contact jcooper@fcsn.org to request a copy.

FAMILY VOICES AND THE FEDERATION URGE ALL TO GET INVOLVED!

Campaign issues are not just about politicians—they are about you. If elected, what a politician decides to do in office can have a lasting impact on your life, your loved ones, and your community. Medscape and CBS Healthwatch are inviting you to share your stories.

• Can your family afford adequate healthcare?
• Would more research into a particular disease give you hope?
• Have you benefited from good legislation?

NEW INITIATIVE TO LEARN ABOUT QUALITY HEALTH CARE FOR CHILDREN

The Federation will be collaborating with Health Care for All’s Children’s Programs on a Cummings Foundation grant. The grant aims to build an informed group of parents, able to influence public policy as it pertains to the way medical services are delivered to their children. The Federation will be inviting parents raising children with special health care needs to regional workshops or focus groups to find out how these families perceive the quality of their children’s health care in Massachusetts. The project will also focus on health care for immigrant children and children in rural areas.

Resource materials and helpful websites will be compiled and made available to families. Federation staff members Barbara Popper and Polly Sherman and the Family Ties regional coordinators will participate. The Federation is excited about the opportunity to continue our collaborative efforts with Health Care for All through this project. (Their website is www.hcfama.org.)

For more information about any of these health related activities contact kcruz@fcsn.org or jcooper@fcsn.org.
SAVE THE DATE!

PAL’s Annual Meeting

When
Thursday, October 5, 2000
11 AM to 7 PM

Where
Indian Meadows Country Club
Westboro, Massachusetts

The Keynote speaker will be
Ross Greene, Author of The Explosive Child

Visit PAL’s website at www.ppal.net

Our website is a work in progress. Please share any comments and suggestions with us.

PAL is the Massachusetts Chapter of the national Federation for Families for Children’s Mental Health and works in collaboration with the Federation for Children with Special Needs. For more information or to order PAL pins and other materials, email the PAL office at: pal@fcsn.org, or call (617) 227-4886.

Congratulations, Glenn!

Glenn Gabbard, Director of the Federation’s ICC (Interagency Coordinating Council) Leadership Project, has accepted a new position at the University of Connecticut. Over his 8 years at the Federation, Glenn has also coordinated the National Early Childhood Technical Assistance System (NECTAS) project and contracted for the Research and Training Center for Service Coordination in Early Intervention. The Federation thanks Glenn for his many contributions to our work on behalf of children with disabilities and their families. We will miss Glenn and wish him the very best in this new venture!

We Need Your Stories!

Family Ties, PAL, and Family Voices are interested in hearing from families whose young adult children have made the transition from pediatric to adult healthcare. What worked? What hasn’t worked? What could have made the transition easier? What tips can you share with other families?

Please contact:
Joanne Spencer, Family Ties
Department of Public Health
109 Rhode Island Road
Lakeville, MA 02347
Joanne.Spencer@state.ma.us

Thanks for your help!

Correction. NewsLine apologizes to Cheryl Califano, a long-time educational and medical advocate, and member of the Dept. of Mental Health Human Rights Advisory Committee. Due to a reporting error, her name was misspelled in the Spring issue.