IDEA Regs Are In!
The Individuals with Disabilities Education Act (IDEA) Regulations based on the 1997 reauthorization were published in the Federal Register on March 12, 1999. The new IDEA focuses on establishing high expectations for all children with disabilities. The Regulations reflect the many changes to the law and provide guidance in key areas. Among the areas of critical interest to parents are: Students and the General Curriculum, Student Assessment, Regular Education Teacher Involvement, Graduation with a Diploma, and Student Discipline. Future issues of NewsLine will include more information on the Regulations.

Access the regulations (approximately 268 pages) through our website, www.fcsn.org. Or, order a copy for $8.00 by calling the Government Printing Office, at 202-512-1800 or by writing to Government Printing Office, Superintendent of Documents, PO Box 37195-7954, Pittsburgh, PA 15250.

For alternative formats (Braille, large print, audiotape, or computer diskette), contact Katie Mincey (katie_mincey@ed.gov), Director of Alternate Formats Center, Telephone: (202) 260-9895.

FEDS AWARD STATE IMPROVEMENT GRANT: FEDERATION IS A PARTNER
The U.S. Dept of Education announced recently a $1 million grant award to Massachusetts, one of 19 states to receive a State Improvement Grant (SIG). Developed by the Mass. Department of Education with assistance from a broad cross-section of Massachusetts citizens, the SIG is intended to equip teachers to meet the newest requirements of IDEA-97, the federal special education law, which call for all students with disabilities to have meaningful access to the general education curriculum.

The Federation, pleased to be a partner with the state in implementing the SIG, will provide training activities for parents. The Institute for Community Inclusion (UAP) at Children’s Hospital and U. Mass, Boston, is also a major partner in the SIG. The grant is administered through the Massachusetts Department of Education, Office of Special Services.

WHAT IS FAMILY TIES?
The Family T.I.E.S. (Together In Enhancing Support) program at the Federation is a statewide information and support network for families of children with disabilities or chronic illness, funded by the Department of Public Health. Located in the DPH Regional offices, the Family Ties Parent Coordinators are all parents of children with disabilities or special health care needs. Parent Coordinators provide up-to-date information on available services for families, such as community resources and support groups, and match parents with another parent of a child with the same diagnosis or health concern. Polly Sherman is the Statewide Director of Family Ties.

To receive a Resource Directory and to get on the Family TIES mailing list, call 800-905-TIES.

For information in Spanish, please call 617-727-1115. Also, please visit Family Ties website at: www.massfamilyties.org

Federation Project Updates
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Organizers for “There’s Room for Us All,” the Federation’s annual Conference co-sponsored this year with PAL (Parent Professional Advocacy League) and Family Ties, discovered ironically that there was not enough room as registrations in record numbers poured into the Federation office. By Friday, March 5, the registration deadline, the Federation had already received registrations for a more than capacity crowd.

On Saturday, March 13, over 470 parents and professionals gathered at the World Trade Center in Boston to demonstrate their commitment to students with special needs and to participate in workshops and presentations. Nancy Verderber, a self-advocate and educator from St. Louis, Missouri, and her sister Katie Stollhans, an early childhood educator, presented “Sister Act” a poignant and humorous dialogue about their life growing up. The audience was inspired by the sisters’ quick wit and thoughtful presentation, while genuinely moved by their courage and determination as together they faced the discrimination and attitudinal barriers so familiar to people with disabilities.

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This is the year that Ch.766 will be changed, according to many leaders in the Massachusetts State House, where special education reform is a major priority. However, the approach to reform remains very controversial. This year, bills that have been filed reflect two very different ways to address special education costs: (1) retain strong protections for children with special needs while providing $60 million in state aid, or (2) weaken the protections for youth with disabilities and provide only $19 million in state aid.

Two bills filed in the Senate (S. 309 and S. 208) retain the higher Massachusetts special education standard of maximum feasible benefit (MFB), requiring programs to provide the “maximum possible development in the least restrictive environment.” These bills also call for $60 million in state funding. The House, on the other hand, has filed a bill (H. 2678) to repeal the MFB standard and adopt the lower federal standard of a “free and appropriate public education.” This bill calls for $18 million in state funding.

Three issues generate the most controversy:
• repeal of the “maximum feasible benefit” standard,
• weakening of the independent evaluation requirements, and
• the amount of state funding to help schools pay for the costs of educating students with more severe disabilities.

In addition, all three of these bills address many other critical areas, including: proposals to address special education enrollment and eligibility; teacher training; pre-referral; establishment of Parent Advisory Councils (PACs); and state monitoring.

The following information may be useful when comparing the different bills.

FACT: “Maximum feasible benefit” is the program standard used to ensure equal educational opportunities for children with special needs, and to level the playing field. The MFB standard has nothing to do with eligibility; removing it will not reduce the number of children receiving special education.

FACT: In Massachusetts, the state pays for less than a quarter of special education costs. Nationally, states on average pay for more than half of these costs.

FACT: Massachusetts costs increases are consistent with the national rise in special education costs. Our costs are consistent with the rest of the country; our state funding is not.

FACT: Special education costs in Massachusetts are increasing due to the increasing proportion of young children with more severe disabilities.

The Massachusetts Senate and House have jointly funded a study of “maximum feasible benefit.” If you have views or opinions about these bills, it is important for your local legislators to hear from you. For more information, visit the Federation’s website, www.fcsn.org, or call Johanne Pino at the Massachusetts Advocacy Center, (617) 357-8431, ext. 34.

NOTE: The Massachusetts Board of Education considered changes to the Ch.766 Regulations in its March meeting. During the public comment period in the coming weeks, parents will have an opportunity to respond to the proposed changes. These changes include increased class size for special education, elimination of the Parent Advisory Councils (PACs), modification of timelines for the IEP process, and adoption of the federal standard for independent evaluations. To read the Massachusetts proposed regs, visit www.fcsn.org.

Ziegler concluded, “Historically, institutional living has been the most expensive and the least dignified and respectful form of ‘housing’ for people with disabilities. We are pleased that our Attorney General learned from consumers and reversed his action.”

On April 21, 1999, the U.S. Supreme Court will hear 
Olmstead v. L.C. and E.W.

Two rallies are scheduled in Washington, D.C., on the steps of the Supreme Court: a candlelight vigil on April 20, and a national rally on May 12. For more information, contact ADAPT (American Disabled for Attendant Programs Today) at (512) 442-0252, or e-mail: adapt@adapt.org.
MCAS is Back!

This spring, for the second year, Massachusetts students will participate in the now infamous MCAS (Massachusetts Comprehensive Assessment System) tests. Last year’s statewide results indicated that 93% of students on IEPs who took the tests placed in the categories of “failing” or “needs improvement.” The good news was that over 97% of all students were included in the testing process. But these results have left some parents asking why students with special needs should take the MCAS at all. They fear their children are being set up for failure and may suffer negative effects, including a blow to their self-esteem. However, with proper support and planning, the experience can be an esteem booster as every child can take pride in a job well done.

It is important to remember that both federal and state laws require the participation of all students in the MCAS tests. The laws also require that students with disabilities be appropriately included in the tests, either through the use of accommodations or an alternate exam. Parents of students who are on IEPs and slated to take the MCAS this year should speak with their team liaison about how their child will participate in the tests: under routine conditions, with specific accommodations, or through an alternate assessment. IDEA-97 requires the state to provide alternate tests by July 1, 2000, for students who can’t show what they know or are able to do through a regular test even with accommodations. The Massachusetts Department of Education is in the process of creating such exams, but they will not be ready this year. Therefore, for this year, each school district must develop any alternate assessments they deem necessary and report on them to the state.

With proper support and planning, the experience can be an esteem booster as every child can take pride in a job well done.

Opening Doors: Decisions about Life and Work after High School

The Federation is working with the Institute for Community Inclusion (ICI) at Children’s Hospital, Boston, and the Disability Law Center on the Opening Doors Project. The aim of the Project is to increase the use of Supplemental Security Income (SSI) Work Incentives by young adults between the ages of 16 and 22.

SSI is a federal income support program for people with disabilities who have limited work experience. In Massachusetts, SSI cash recipients are also automatically eligible for health insurance through Medicaid. Work incentives allow individuals who receive SSI to return to work and still maintain some of their benefits.

Opening Doors, funded by the U.S. Dept. of Education, Office of Special Education Programs, is helping young adults, teachers, and families in Brockton, Worcester, Malden, and Chicopee understand SSI eligibility and work incentives rules. The Project is also working with students and families in each district to tailor career plans or facilitate person-centered planning.

Statewide efforts include compiling information and resources for families and educators statewide, including a list of experts on work incentives, and assisting teachers by gathering examples of work support needs as listed in students’ IEPs.

For more information, contact Sheila Fesko at fesko@al.tch.harvard.edu or (617) 355-6271.

There’s Room for Us All

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Please accept my best wishes for improved results for all the students to be assessed this spring.

Richard J. Robinson

Several state officials brought greetings to the conference, including: Commissioner Mary Lou Sudders, Department of Mental Health; Commissioner Gerald Morrissey, Department of Mental Retardation; and Dr. Debbie Allen, Director of the Division of Special Health Needs, DPH.

Over 100 presenters, volunteers, and exhibitors made this conference one of our largest and most successful ever. Thanks to all who took the time to participate, thus moving us closer to the time when there is, indeed, room for us all in classrooms and communities across the country.
Dear Readers:

I receive many questions from parents about a school's responsibility to provide (and pay for) nursing and other health-related services. So, I've decided to devote this column to updating you about a recent U.S. Supreme Court decision that reinforces a school's responsibility in these areas.

On March 3, the U.S. Supreme Court decided Cedar Rapids v. Garret F. in favor of a student with disabilities and his parents. This decision is a very important one for all students with disabilities. It reaffirms the law of the land that except for services that can only be provided by a physician or in a hospital, schools must provide anything that students with disabilities need to enable them to reach, enter, exit, or remain in school during the day. Justice John Paul Stevens wrote: “Congress intended to open the door of public education to all [disabled] students. This case is about whether meaningful access to the public schools will be assured.”

Garret F., who attends regular classes at school, has a spinal cord injury and is paralyzed from the neck down. He speaks and drives a power wheelchair through the use of a puff-and-suck straw. He operates a computer with a device that responds to his head movements. He also uses a ventilator to breathe.

He needs help with maintaining his ventilator, catheterization once a day, suctioning of a tracheostomy tube as needed, and getting into a reclining position five minutes of each hour.

Cedar Rapids wanted to deny staff to perform these procedures and thought Garret should get homebound instruction a few hours a week.

About the decision in favor of Garret F., Judith E. Heumann, Assistant Secretary for Special Education and Rehabilitative Services at the U.S. Department of Education, stated, “Obviously we are pleased with the Supreme Court’s interpretation of . . . IDEA. As we argued before the court, we believe students like Garret should receive the services necessary to ensure access to an appropriate education.”

SOURCES:

“U.S. Supreme Court Finds in Favor of Family in Garret F. Case,” by Reed Martin.

“Talking Points for Garret F.” by National Parent Network on Disabilities.
Students with disabilities now must be included in state and district assessment programs with appropriate accommodations, as required by recent amendments to the Individuals with Disabilities Education Act (IDEA) and by Chapter 766, the state special education law.

Q: WHY SHOULD MY CHILD PARTICIPATE?
There are several reasons why it is important for students with disabilities to participate. First, test scores will be used to judge individual schools, school systems, and administrators. If students with special needs are excluded from testing, then the progress of these students will not be considered important when evaluating the performance of schools and their administrators, and when allocating resources.

Second, beginning with the Class of 2003 (current 8th graders), students will have to pass the 10th grade (MCAS) test in order to receive a high school diploma. Third, participation in assessments is one way to ensure that students with disabilities have meaningful access to the general education curriculum and high standards that drive education for all other students.

Fourth, information from assessments can be used to improve programs. If students with disabilities are included, their needs will be considered in shaping education policies, programs, and practices.

Q: HASN’T MY CHILD ALREADY BEEN TESTED ENOUGH?
Statewide assessments are different from the three-year individualized evaluations required by IDEA to inform decisions about students’ educational needs. In contrast, statewide large-scale assessments are usually standardized, “paper and pencil” tests to: (1) provide information about individual student achievement, (2) gauge the success of schools and school systems, and (3) hold educators accountable for student attainment of educational outcomes.

Q: WHAT IS THE TESTING PROGRAMS?

3rd-Grade: Reading Test
Type of questions: Multiple choice test of reading comprehension, vocabulary, and spelling. (Iowa Test of Basic Skills)
Time: Approximately one hour
Report: Individual and school scores reported

4th-, 5th-, and 10th-Graders: Massachusetts Comprehensive Assessment System (MCAS) in English/Language Arts, Math, Science, Social Studies/History
Types of questions: Multiple choice, short answer, essay
Time: Approximately 14 hours
Report: Individual and school scores reported

Q: WHEN WILL THE TESTING OCCUR?
3rd-Grade reading tests will be administered during the week of April 12.

4th-, 5th-, and 10th-Grades MCAS tests will be administered May 17-28, 1999. Open-ended, long composition questions for language arts will be administered during the week of April 26.

Q: WHO SHOULD TAKE THE TESTS?
All students, including students with disabilities, must participate in the state testing programs. Previous exceptions from statewide testing contained in a student’s IEP do not apply to these new assessments.

Q: WHAT IF MY CHILD NEEDS ACCOMMODATIONS?
If your child needs testing accommodations, they should be listed on the IEP. The IEP team must meet before the state assessment is conducted to decide if your child will participate: (1) under routine conditions, (2) with accommodations, or (3) through an alternate assessment.

If the Team decides your child will participate with accommodations, the Team should identify which accommodations are needed. The Massachusetts Department of Education (DOE) has provided a List of Accommodations. However, it is not an exhaustive list. Students must receive whatever accommodations are recommended by the IEP Team.

Q. WHEN MIGHT AN ALTERNATE ASSESSMENT BE NECESSARY?
Alternate assessments provide students who are unable to participate in the testing program, even with accommodations, an equal opportunity to demonstrate their knowledge and skills, and to demonstrate whether they can meet state standards. By July 2000, the Department of Education will have developed alternate assessments. Until these assessments are developed, however, the IEP team should decide what type of alternate assessment the student will receive.

Remember, whenever an IEP review is conducted, the IEP team addresses the manner of participation in the state or district testing programs.

[Adapted from information by the Massachusetts Advocacy Center for the Massachusetts Inclusion Initiative, and publications of the Federation’s PEER Project.]
Los estudiantes con discapacidades tienen que estar incluidos en los programas de evaluación del estado y del distrito con las acomodaciones apropiadas como es requerido por los recientes enmiendas en el Acta de Educación para Individuos con Discapacidades (IDEA) y por el Capítulo 766, la ley de educación especial del estado.

**P: ¿POR QUÉ DEBE PARTICIPAR MI NIÑO/A?**
Hay muchas razones por las cuales es importante que los estudiantes con discapacidades participen. Primero, los resultados del exámen serán usados para evaluar cada escuela, sistemas escolares y administradores. Si los estudiantes con necesidades especiales son excluidos de estos exámenes, su progreso no será considerado importante cuando se evalúe el rendimiento de las escuelas o los administradores y cuando se estén distribuyendo recursos.

Segundo, comenzando con la Clase del 2003 (actualmente en grado 8), los estudiantes tendrán que pasar el exámen (MCAS) en el 10 grado para recibir el diploma de la escuela secundaria.

Tercero, la participación en estas evaluaciones es una manera de asegurar que los estudiantes con discapacidades tengan un acceso significativo al currículo de educación general y a normas altas de aprendizaje. El currículo y las normas son la base de la educación de todos los estudiantes.

Cuarto, la información de las evaluaciones puede ser usada para mejorar programas. Si los estudiantes con discapacidades son incluidos, sus necesidades serán consideradas cuando se desarrollen políticas, programas y prácticas educativas.

**P: ¿OTRA EVALUACIÓN? NO HA SIDO MI NIÑO/A EVALUADO BASTANTE?**
Las evaluaciones del estado son distintas de las evaluaciones individualizadas que ocurren cada tres años como es requerido por IDEA. Las evaluaciones individualizadas proveen información acerca de las necesidades educacionales del estudiante. Por otra parte, las evaluaciones en gran escala son usualmente estandarizadas y en forma escrita para (1) proveer información acerca del progreso de cada estudiante, (2) evaluar el éxito de las escuelas y el sistema escolar, y (3) hacer a los educadores responsables por los logros educacionales de los estudiantes.

**P: ¿CUÁLES SON LOS EXÁMENES?**
**Grado 3:** Exámen de lectura
**Tipos de preguntas:** Examen de selección múltiple en comprensión de lectura, de vocabulario, y de deletrear palabras (Examen de Destrezas Básicas de Iowa)
**Tiempo:** Aproximadamente 1 hora
**Reportes:** Se reportan resultados individuales y de la escuela

**Grados 4, 8, y 10:** Sistema de Evaluación Comprensivo de Massachusetts (MCAS) en Inglés “Arte de Lenguaje,” Matemáticas, Ciencia, Sociales/Historia
**Tipos de preguntas:** selección múltiple, respuesta corta, composiciones
**Tiempo:** Aproximadamente 14 horas
**Reportes:** Se reportan resultados individuales y de la escuela

**P: ¿CUÁNDO SERÁN LOS EXÁMENES?**
Los exámenes de lectura para estudiantes en tercer grado serán tomado durante la semana del 12 de abril.

Los exámenes MCAS para estudiantes en grados 4, 8, y 10 serán tomados entre el 17-28 de mayo de 1999. Composición para el arte del lenguaje serán tomado durante la semana del 26 de abril.

**P: ¿QUIÉN DEBE TOMAR LOS EXÁMENES MCAS?**
Todos los estudiantes, incluyendo los estudiantes con discapacidades, tienen que participar en los programas de exámenes del estado. Excepciones previas de exámenes estatales incluidos en el IEP del estudiante no aplican a estas nuevas evaluaciones.

**P: ¿QUÉ PASA SI MI NIÑO/A NECESITA ACOMODACIONES?**
Si su niño/a necesita acomodaciones para tomar el exámen, éstas deben de estar escritas en el IEP de él o ella.

El Equipo del IEP tiene que reunirse antes de que se lleven a cabo las evaluaciones del estado para decidir si su niño/a va a participar: (1) bajo condiciones regulares, (2) con acomodaciones, o (3) a través de una evaluación alternativa.

Si el Equipo decide que su niño/a va a participar con acomodaciones, el Equipo debe identificar cuales acomodaciones son necesarias. El Departamento de Educación de Massachusetts (DOE) ha publicado una Lista de Acomodaciones. Esta lista no es exhaustiva. Los estudiantes tienen que recibir cualquier acomodación que sea recomendada por el Equipo del IEP.

**P: ¿CUÁNDO PUEDE SER NECESARIA UNA EVALUACIÓN ALTERNATIVA?**
Evaluaciones alternativas proveen estudiantes que no pueden participar en el programa del exámen aún con acomodaciones, la misma oportunidad de demostrar su conocimiento y destrezas, y de demostrar si ellos pueden alcanzar las normas del estado. Por julio del 2000, el Departamento de Educación habrá desarrollado evaluaciones alternativas. Hasta que estas evaluaciones se desarrollen, el Equipo del IEP debe decidir que tipo de evaluación alternativa debe recibir el estudiante.

Recuerde, cuando se revisa el IEP, el Equipo tiene que decidir y planear la participación del estudiante en el exámen del estado o distrito.

[Esta fue adaptada de información escrita por Massachusetts Advocacy Center for the Massachusetts Inclusion Initiative, y de publicaciones del PEER Project in the Federation.]
Perguntas e Respostas sobre ‘MCAS’
(COSistema Geral de Avaliação de Massachusetts)

Estudantes com deficiências devem ser incluídos nos programas de avaliações do distrito escolar e do estado com as modificações apropriadas, conforme exigido nas emendas feitas recentemente ao IDEA (Individuals with Disabilities Education Act) - a lei federal que regulamenta a educação para indivíduos com deficiências — e também pela lei estadual de educação especial, conhecida como “Capítulo 766”.

PERGUNTA: POR QUE A MINHA CRIANÇA DEVE PARTICIPAR?
Existem várias razões que justificam a exigência da participação das crianças com deficiências.

Primeiro, os resultados dos testes vão ser usados para avaliar cada escola individualmente, assim como também os sistemas escolares e os administradores. Se as crianças com necessidades especiais são excluídas das avaliações, o progresso destes alunos não vai ser considerado importante quando se estiver avaliando o desempenho das escolas e seus administradores, e também quando forem distribuídos recursos.

Em segundo lugar, começando com a turma que vai se formar no ano 2003, (isto é, a dos alunos que agora estão cursando a oitava série) os alunos vão ser obrigados a passar nos testes do MCAS para receber o diploma do curso secundário.

Terceiro: a participação nas avaliações é uma maneira de se ter certeza que os alunos com deficiências têm acesso significativo ao currículo de educação regular e aos altos padrões que definem o nível de educação dado a todos os alunos.

Quarto: as informações das avaliações podem ser usadas para melhorar os programas. Se os alunos com deficiências estão incluídos, suas necessidades serão consideradas na hora de se determinar os programas educacionais e de implementá-los.

P: SERÁ QUE A MINHA CRIANÇA NÃO ESTÁ SENDO AVALIADA DEMAIS?
As avaliações estaduais são diferentes das avaliações feitas a cada três anos, requisitadas por meio de demandas especiais. As avaliações estaduais são diferentes das avaliações feitas recentemente ao IDEA (Individuals with Disabilities Education Act) - a lei federal que regulamenta a educação para indivíduos com deficiências — e também pela lei estadual de educação especial, conhecida como “Capítulo 766”.

P: QUais SÃO OS TESTES?
Terceira série: Avaliação de Leitura
Tipo de perguntas: De múltipla escolha, nas áreas de compreensão, vocabulário, e grafa de palavras, ou seja, ditados (Teste de Habilidades Básicas de IOWA)
Duração: mais ou menos uma hora.
Resultado: As notas individuais e da escola em geral serão divulgadas.

Quarta, oitava e décima séries: MCAS — nas áreas de inglês/linguagem, matemática/Artes/Ciências, Estudos Sociais/História
Tipo de perguntas: Questões de múltipla escolha, respostas curtas e redação
Duração: Mais ou menos 14 horas
Resultado: As notas individuais e a colocação da escola serão divulgadas.

P: QUANDO VÃO SER FEITOS OS TESTES?
Os testes da terceira série serão administrados durante a semana de 12 de Abril.

Os testes da quarta, oitava e décima séries serão administrados na semana de 17-28 de maio de 1999.

As questões de redação para as áreas de linguagem e artes serão administradas durante a semana de 26 de abril de 1999.

P: QUEm DEVERÁ FAZER OS TESTES DO MCAS?
Todos os estudantes, incluindo estudantes com deficiências, deverão participar dos programas estaduais de avaliação. Isenções anteriores de avaliações estaduais incluídos no IEP do aluno não se aplicam a essas novas avaliações.

P: O QUE ACONTECE SE A MINHA CRIANÇA PRECISAR DE MODIFICAÇÕES OU ADAPTAÇÕES?
Se a sua criança precisa de modificações dos testes, isto deve ser anotado no IEP. A junta do IEP, ou o “team,” deverá se reunir antes do teste estadual ser administrado para decidir se sua criança participará: 1) de acordo com as condições rotineiras; 2) com modificações; 3) através de avaliações alternativas.

Se a junta do IEP ou “team” decidir que sua criança participará com modificações, a mesma junta deverá indentificar quais são as modificações necessárias. O Departamento de Educação de Massachusetts (DOE) tem uma lista de modificações, mas não é uma lista completa. Estudantes deverão receber todas as modificações recomendadas pela junta do IEP ou “team.”

P: QUANDO É NECESSÁRIA UMA avaliação ALTERNATIVA?
As avaliações alternativas oferecem aos estudantes que não conseguem fazer parte das avaliações, mesmo com modificações, uma oportunidade similar de demonstrar seus conhecimentos e habilidades e demonstrar ainda se podem ou não atingir os padrões de educação exigidos pelo estado. Até julho do ano 2000, o Departamento de Educação desenvolverá avaliações alternativas. Até que as alternativas estejam prontas, a junta do IEP deverá decidir que tipo de avaliação alternativa o aluno deve receber.

Lembre-se: sempre que uma revisão do IEP for feita, a junta do IEP ou “team” deve discutir também a maneira em que o aluno participará dos testes nos programas do estado e do distrito escolar.

[Adaptado de informações do Centro de Advocacia para a Iniciativa de Inclusão em Massachusetts, de informações do PEER Project no Federação.]
by Robert K. Crabtree

In part one of The Paper Case, Mr. Crabtree discussed what documents should be kept and why. In part two, he continues to explore the guidelines for managing documents under IDEA.

What documents should you create?

Why create any documents? One simple reason is that you may have to tell your child’s story to another person — perhaps to an evaluator, an advocate or lawyer, or a hearing officer — in order to get help, and documenting events as they occur will help you tell the story accurately and in good order. Another reason is that documents can help clarify understandings you reach with people — particularly with service providers or school administrators. Yet another reason is that documents written at the time something happens help to support you when you need to prove to another person that the event happened the way you claim it happened.

It sometimes takes years before parents realize that they should have kept better notes of meetings, telephone calls, and significant events in their child’s educational career. If you are the parents of a very young child with a disability in need of special education, you can be ahead of the game by developing this habit now. The notes you take may be important later when you need an accurate description of what key people said at a TEAM meeting, in the hall after a parent meeting, in an evaluator’s office after you were given a report, and so on.

Some parents keep a journal or simply a running chronology with dates, short descriptions of events or conversations and names of people concerned. This does not need to include every tiny detail of your child’s life, but a well-kept journal or chronology can help you explain to others (or to yourself) how you got to the current situation if you record key events and communications along the way. Among other events, you should record dates of meetings with school personnel, dates you received key documents (notices of TEAM meetings, etc.), dates you sent or delivered key documents (e.g., “December 1, 1999 — hand-delivered our consent to the proposed school evaluations”), dates on which you gave school personnel important information (e.g., “January 7, 1999 — told Mary’s teacher that she’d been spending three hours every night trying to do 15 minute math homework assignments”), dates on which your child was suspended or otherwise disciplined, and so forth.

Some documents are created in order to record understandings reached with others. The most formal example of this type of document is a contract signed by the parties who agree to its terms. (An IEP is really a contract. It records an agreement reached between parents and school systems to govern the types of services to be delivered to a child for a specific period of time, the location of those services, the identity of service providers and so on, and is signed by each party.)

Even without such an official agreement, however, you can create a document yourself that can help prove that an understanding was reached. Suppose, for example, that you have a child wondered what precipitates his/her aggressive outbursts? Keep a record of things said or done immediately before such explosions for a while — whether seen by you personally or reported to you. Perhaps you can help solve the mystery and focus service providers on developing a plan to work with those behaviors.

Documents in the hearing process:
Preparing to meet your lawyer

When parents ask an attorney or lay advocate to advise them about their child’s rights under IDEA, the first thing the adviser must do is review all the relevant documents. How should you organize them?

We ask parents to send copies of all their documents in strict chronological order before we meet so we can read them and get as full a picture as possible about who the child is and what has been done for him or her in the special education system. Unless the attorney or advocate asks you to do so, don’t try to organize your documents by category (e.g., placing all the IEPs in one file, all the evaluations in another, all the correspondence in another, etc.). The most efficient way for the advocate or attorney to get the picture and the history is to see the development step by step.

Because any document might eventually have to be introduced as an exhibit at a hearing or in court, we ask that parents not write any comments on them. (You can point out particular items or ask questions by using sticky notes.)

You should also give the attorney or advocate a chronology of the events that have led you to consult with him/her — not an extremely detailed description of every thing that happened, but an outline that will give the advisor a perspective on what led to your child’s current situation.

Finally, you should give your attorney or
AN UPDATE FROM MASSACHUSETTS HEALTH CARE FOR ALL:

Today, every child in Massachusetts has access to some form of health insurance. That accomplishment is due in part to the success of the Massachusetts Children’s Health Access Coalition. While building on a grassroots base of parents, Boston-based Health Care for All has been reaching out to new allies and former opponents to build a very broad-based coalition to win health coverage for children.

In 1996, this coalition advocated successfully for the passage of a law that (1) made every child in Massachusetts eligible for at least some form of health coverage and (2) expanded programs for parents, the unemployed, people with disabilities, and seniors.

Legislation in 1997 further expanded children’s access to health insurance by using funds from the federal Children’s Health Insurance Program (CHIP). In August of 1998, MassHealth (the Massachusetts Medicaid program) was expanded for all children. Now, families can earn up to 200% of the federal poverty level, ($33,400 for a family of four in Massachusetts) and still qualify. Children’s Medical Security Plan (CMSP) continues to be available for children whose family incomes are above 200% of the federal poverty level.

Questions? Contact Allison Staton, Health Care for All at (617) 350-7279 ext. 110 or visit www.hcfa.org.

Family Voices applauds Garret F. and his family for a well-deserved victory and commends the Supreme Court for stating that the financial and delivery responsibility for integrating students with significant health needs lies with the public school. Family Voices had joined the Garret F. Supreme Court case in an amicus brief with the American Academy of Pediatrics and the National Association of School Nurses. See page 4 for details about the decision.

1999 Family Voices’ Selected Promises to our Children with Special Health Care Needs

What should our hopes and dreams be in 1999 as we prepare for the 21st Century? What promises can we make for our children with special health care needs?

We promise that…

• Every child in this nation, including youngsters with special health care needs, will receive quality, timely, affordable health care, no matter their diagnosis, family circumstances, ability to pay, or where they live.
• State Children’s Health Insurance Programs (CHIPs) will provide quality coverage for every eligible child, including those with disabilities and/or chronic health conditions. Families will have a role in CHIP policy development and monitoring in every state.
• Working with families and providers, public and private managed care systems will provide children with special health care needs access to specialists, therapists, equipment, and needed medicines; coordination of care; and mental health coverage – with ease and goodwill.
• Public schools, Medicaid, private insurance programs, and families will work together so that students with special health care needs receive health and related services in coordinated ways. This includes resolution of difficult payment and delivery questions in the schools.
• Most importantly, we families caring for our sons and daughters with special health care needs for 24 hours a day, 365 days a year, will be honored and respected for our dedication, work, and love.

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.

New Research Projects on Developmental Disorders

The Center for Research on Developmental Disorders (CRDD) at the Shriner Center is conducting research intended to help prevent or treat developmental disorders. Current projects focus on the genetic causes of autism, language impairment, Williams syndrome and Prader-Willi syndrome as well as on the cognitive and behavioral aspects of the disorders. CRDD is interested in learning how social understanding develops and how social knowledge and social skills relate to language and cognitive functioning. CRDD studies are looking at the structure and function of the brain in people with autism or language impairment. For more information on this research or to inquire about participating, contact CRDD at 781-642-0180.

EARS

In Monson (Springfield) and Lowell

Auditory Integration Training

April 2 – 11 & April 16 – 25, 1999

For Children & Adults with:

- Autism, Pervasive Developmental Disorder
- Speech/Language Dysfunction, Cognitive Impairment & Dyslexia
- Vestibular Processing Dysfunction & Central Processing Disorder
- Attention Deficit Disorder (with or without hyperactivity)
- Hyperacute/Hypoacute Sensitive Hearing
- Asperger’s Syndrome, Fragile X Syndrome, Down Syndrome, Dyspraxia Hyperlexia, Tourette Syndrome, Rett Syndrome, Bipolar Disorder & Drooling.

EARS, Sharda Ramlackhan, M.A.
54 Jennifer Road, Lowell, MA 01854 • Ph: (978) 458-3277, Fax: (978) 934-0677
E-mail: ShardaEARS@aol.com • www.web-wisdom.com/ears
Accessing Services for Young Children with Special Needs

- What happens to children receiving Early Intervention services when they turn three?
- What can parents of children over three do when they have concerns about their child’s development?
- How can parents of young children with disabilities find appropriate and available childcare that successfully includes their child in the program?

These questions are near and dear to many parents of young children. The Early Intervention Training Center (EITC) at the Federation has made a commitment to provide support to the early childhood community around these issues. With funding from the 0-8 Coalition, EITC will conduct a series of workshops this spring for the childcare community of Boston. Grouped geographically into nine clusters, Boston’s childcare community includes personnel from childcare (both center and home-based), Head Start, and Early Intervention.

In addition to the Basic Rights workshop, EITC will also offer two pilot workshops: “Questions About Your Child’s Development? Working with Your Childcare Provider to Address Your Concerns” and Making It Work: Childcare for Your Child with a Disability. Questions, a two-part workshop, focuses on parents of children in childcare (ages 3-5), who have concerns about their child’s development. Topics addressed include typical development, potential causes for concern, where to turn for professional advice, and steps for getting an evaluation.

Making It Work, a three-part workshop, focuses on parents of children with disabilities, ages 3-5 who are enrolled in childcare. This workshop will address such issues as how to assess childcare options for your child, how to work with the childcare provider to successfully include your child in the day-to-day life and experiences of the day-care setting; helpful advocacy hints for getting you and your child’s wants and needs met at the day-care site; and how the parent, the childcare provider, and the special services provider – three key players in a child’s life – can work together successfully. Once these two workshops have been presented in Boston, EITC hopes to make them available on a regular basis throughout Massachusetts.

For more information, contact Brad Arndt at (617) 236-7210 x 154.

There are thirteen Child Care Resource & Referral (CCR&R) agencies in Massachusetts.

The CCR&Rs work with 1) parents, 2) providers and 3) the community at large. Each CCR&R maintains a database of all licensed (Office of Child Care Services licensure) childcare providers, in the area that they serve. Parents can call a CCR&R, and the CCR&R will do a customized search around the family’s priorities. They will also help a family figure out the questions they may want to ask, and will provide information about early childhood learning and development. If a family has financial concerns, the CCR&R will help determine eligibility for subsidized child care.

Additionally, each CCR&R has an Enhanced Service that is specifically designed to help families who have children with disabilities and/or special health care needs locate a childcare provider. This Enhanced Service is for both families and providers. Families can have information about providers who are knowledgeable about their child’s diagnosis because the CCR&R has provided disability specific information directly to the provider. This information includes ways to care for and accommodate the child.

Most CCR&Rs charge a modest sliding scale fee for this referral service. There is no charge for families who receive SSI (Supplemental Security Income) or TAFDC (Transitional Aid for Dependent Children). Generally this service is for children up to 12 years of age; however, if a child has special needs, the CCR&R will help you arrange for continuity of care beyond 12 years of age.

To find the CCR&R that serves your area, call 800-345-0131.
The 4th annual Children’s Mental Health Week will be celebrated during the week of May 2 – 8. The Children’s Mental Health Task Force designed an effective campaign to raise awareness of the unique concerns surrounding children’s mental health. The three members of this Task Force were Lisa Lambert, Nancy Collier, and Marian Butler, PAL affiliated Parent Coordinators. The series of activities sparked by this Task Force is now entering its 4th year.

Most Children’s Mental Health Week activities take place at the local level. Parent Coordinators collaborate with the Department of Mental Health and interested service providers and families to design programs in their local areas. The Statewide PAL office at the Federation will distribute a special edition of PAL News to highlight Children’s Mental Health Week events, and a poster listing the names and numbers of Parent Coordinators around the state.

For information about activities in your area, call one of the PAL Parent Coordinators below.

**Beverly Area:** Nancy Collier 978-232-9560  
**Boston Area:** Diana Moreno 617-236-7210 x171 and Marcia Duran 617-482-2915 x172  
**Brockton Area:** Kathy Davis 508-927-8779 x17  
**Cape Cod & Islands:** Wendy Watson 508-947-8779 x15  
**Central Mass Area:** Marian Butler 508-795-1197 x1251

The Systems of Care for Children Forum will be held on Thursday, May 6, 1999. Co-sponsored by the System of Care Work Group and PAL Statewide, the Forum will highlight three Massachusetts programs which serve children and families: early intervention, family based-support, and residential care. Presentations will show how each program uses the systems of care principles of individualized, flexibly-funded, interagency, strengths-based and family-focused care planning and delivery. Families and providers will have an opportunity to learn how innovative programming can be implemented for a range of children with emotional and behavioral needs and their families. For more information, please call (617) 227-2925.

### 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.**

**APRIL 1999**  
4/21, Stoneham, 7:30 - 9:30 pm: **Turning Three**  
4/22, Athol, 7:00 - 9:00 pm: **Family Issues**

**MAY 1999**  
5/26, Stoneham, 7:30 - 9:30 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)*

**Turning Three:** Covers special education laws and how to plan for and choose an appropriate pre-school program for a child with special needs.

**Family Issues:** Discusses the ways in which the special needs of a child influence all family members and the adjustments they may need to make. Identifies tools and strategies to manage everyday problems.
Full Page ad
Your contributions and membership donations (totalling over $43,000) 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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Porcell, Patricia & Paul
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Rosenstein, Jonathan & Mary
Rowland, Robin & Milton
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Schotten, Roger
Simon, Family
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Thompson, Mary
Thorpe, Gregory & Carol
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Tinto & George Ziegler
Van Arte, Linda
Vorobch, Joseph
Volker, Lee
Williams, Alice
Ziegler, Martha, in memory of Jack
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NewsLine's mailing list is occasionally made available to organizations in which we believe our readers may have interest. If you wish your name to be withheld, please call or write the Federation's Boston office to inform us.

Our Mission:

We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

Executive Director:
Richard J. Robison
Board of Directors:
D. Heffernan, President; Peter Brennan, Treasurer; Linda Downer, Jack Foley, Robin Foley, William A. Henderson, Anne Howard, Sara Miranda, Deborah Smith-Pressley, Milly W. Iley

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All Kids Count
All Kids Count offers parents, parent leaders, professionals, and other interested parties guidelines for participating in discussions about policies and practices related to inclusion of students with disabilities in large-scale assessments.
100 pages. 1998. Now $15!

Family Guide to Assistive Technology
This guide is intended to help parents learn more about assistive technology and how it can help their children. It aids in the processes of acquiring assistive technology and provides the tools to advocate for your child’s special technology needs.
The Guide includes tips for getting started, ideas about how and where to look for funding, and contact information for software and equipment.
143 pages. 1997. $10.00

Inherently Equal
An Inclusion Action Guide for Families and Educators
Inherently Equal is designed to be a practical resource for people advocating for and working to support the successful inclusion of students with disabilities in general education.
31 pages. 1997. $15.00

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

1999 Summer Camp Directory
A Listing of Day and Residential Summer Camp Programs
Published annually by the Federation, the Summer Camp Directory booklet provides information on 39 day and residential summer camps, plus a listing of local community resources. It provides guidelines for selecting a camp, and suggestions for including children with disabilities in regular camps.
44 pages. $6.25

Federation Publications Order Form

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here are some of the kinds of documents we would typically ask school systems to produce in formal discovery:

- Descriptions of proposed programs;
- Copies of the child’s proposed daily/weekly schedule under the proposed IEP;
- Copies of the daily/weekly schedules of proposed service providers;
- Copies of curricula, materials, behavioral plans, etc. that govern the classroom(s) where the child would be placed;
- Descriptions of proposed programs; plans, etc. that govern the classroom(s) where the child would be placed;
- Descriptions of proposed programs; plans, etc. that govern the classroom(s) where the child would be placed;
- Copies of any program or fiscal audits of the school system proposed to place the child;
- Copies of the child’s proposed daily/weekly schedule under the proposed IEP;
- Minutes taken by school system personnel at any key meetings about the child (particularly TEAM meetings);

**Conclusion**

It is a long road from the beginning to the end of your child’s school life. If your child has a disability, you will be hauling a wagon that grows heavier with documents every year along that road. I hope the guidelines I’ve given you here will help you keep, organize, and use those documents in a way that will help you make the most of your child’s entitlements under IDEA.

All Kids Count

All Kids Count offers parents, parent leaders, professionals, and other interested parties guidelines for participating in discussions about policies and practices related to inclusion of students with disabilities in large-scale assessments, such as MCAS. 100 pages. 1998. Now $15!

Confused about assessments? All Kids Count can help!

See order form, page 14.