Parents’ PLACE—Parents Learning About Children’s Education— is the Massachusetts statewide Parent Information and Resource Center (PIRC), housed at the Federation. Parents’ PLACE provides information and training to support parents, educators, and others as they encourage and promote children’s healthy growth, development, and learning.

Parents’ PLACE recently received additional support from the U.S. Department of Education Goals 2000 office to conduct violence prevention activities around the state. These activities will include workshops for families about violence prevention and awareness, a half-day conference with the Youth Advocacy Project of Roxbury, and dissemination of 10,000 copies of Bright Futures for Families: What You Can Do to Prevent Violence.

In addition, Parents’ PLACE will publish a special edition of Parents’ PLACE Bulletin, devoted to violence prevention and awareness, in English, Spanish, and Portuguese. For more information, or for a copy of the Bright Futures publication, contact Parents’ PLACE at 1-877-471-0980.

As part of the Federation’s 25th anniversary, we have been looking back at our earliest beginnings. For this edition, Phyllis Sneirson looks back at the Parent Consultant Training Program.

A song from the motion picture “Gigi”, “Ah, Yes I Remember It Well” aptly describes my feelings as I look back on the early days of my son’s schooling. Robert has cerebral palsy and is ambulatory through the use of crutches.

In the early 1970’s, it was not the norm for youngsters with physical disabilities to attend public school; the terms “integration,” “inclusion” and “mainstreaming” were not in anyone’s vocabulary. Children like Robert were routinely placed in schools that catered only to students with disabilities. Upon Robert’s graduation from the segregated pre-school he attended, I apprehensively met with the principal at my local school and asked, as a “favor,” that my son attend her school. Needless to say, her reaction was not what I wanted to hear.

continued on page 5

Phyllis Sneirson

“Why doesn’t he attend one of the two wonderful schools in MA where all his needs could be attended to and he could be with children like himself?” was her response.

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Massachusetts Advocacy Center honors
Ruth Ann Rasbold and Cassandra Saunders

Ruth-Ann Rasbold, Director of the Early Intervention Training Center at the Federation was honored at the Hubie Jones Child Advocacy Award ceremony held at the Federal Reserve Bank on September 27, 2000. Ruth-Ann was recognized as a hero in advocacy for special education. Those who have had the opportunity to work with Ruth Ann, or to know her personally, know that she is a strong articulate woman, with a clear vision, whose advocacy and education efforts have touched the lives of thousands of children with disabilities in Massachusetts, and throughout the nation.

For the past 13 years, Ruth-Ann Rasbold has worked at the Federation in a variety of roles, facilitating collaboration between parents and professionals. In addition to her work with the Federation, she is involved in her local Parent Advisory Council, which struggles to maintain and improve special education supports and services, as well as community supports and accessibility. Ruth-Ann attributes her fire, passion, commitment and dedication to civil rights and equal opportunity to her two children, Megan, a sophomore at Newton North High School, and Max, a freshman. As a parent, Ruth-Ann has experienced and overcome countless barriers of discrimination faced by children with disabilities and their parents.

Cassandra Saunders, a student with cerebral palsy, now a senior at Sandwich High School, was also honored at the Hubie Jones Child Advocacy ceremony. Cassandra is the daughter of Federation staff member Toni Saunders. Cassandra has been in integrated school settings since preschool. As a result of her experiences in public school she has become a strong advocate for inclusion for children with disabilities. As a young woman with a disability, she has a personal determination to make a difference and to maintain a positive outlook on life and hope for the future. As a student spokesperson and Massachusetts Advocacy Center honors
Ruth Ann Rasbold and Cassandra Saunders

continued on page 13

Phyllis Sneirson

Violence Prevention

Parents’ PLACE—Parents Learning About Children’s Education—is the Massachusetts statewide Parent Information and Resource Center (PIRC), housed at the Federation. Parents’ PLACE provides information and training to support parents, educators, and others as they encourage and promote children’s healthy growth, development, and learning.

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Bulleti
For the second time this year, the Massachusetts Board of Education has issued new state regulations on special education. The Board, at its September meeting, passed emergency regulations to replace an earlier version of regulations that had taken effect on September 1, 2000. This was necessary because of the significant changes in state law passed this summer (see NewsLine, Summer 2000).

Under Massachusetts’s law, these emergency regulations are effective for up to 90 days. This allows the new regulations to be in effect even during a public comment period. The Board is scheduled to pass final regulations at its December meeting.

Among other things, the new regulations define parent consent and related services. The regulations also restore previous regulations that had been dropped by the Board and reestablished by the Legislature in the following areas:

- Student access to school facilities,
- Eligibility for related services,
- Timelines for the development of IEPs (Individualized Educational Programs) and the delivery of services,
- Transportation,
- Placement decisions,
- Parent involvement,
- Parent advisory councils,
- Communication with parents, and
- Approval and oversight of private day and residential schools.

New regulatory requirements are added which require:

- Annual parent training workshops
- Teacher training in certain areas
- Curriculum accommodations plans developed by school districts
- Sliding fees for Independent Educational Evaluations
- Preference for in-state programs, and
- Other administrative requirements.

While overall, the new regulations address many of the concerns identified by parents and advocates, the Federation remains concerned that the rights of students and their parents are being jeopardized in three ways:

1. Extended evaluations should require the writing of an IEP for as many services as are known to be necessary.
2. A new term, “students with very complex needs,” is introduced in the regulations, but not defined.
3. For these “students with very complex needs,” placement timelines can be extended under certain circumstances.

In addition to the emergency regulations, the Commissioner of Education has issued three Special Education Advisory Memos to school districts. The memos address

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“Changes to Massachusetts Special Education Law,” “Compliance Activities Required by the U.S. Office of Special Education Programs,” and “Guidance on Using a Sliding Fee Scale for Public Payment of Independent Educational Evaluations in Special Education.” Finally, the Department of Education has released a new Parent’s Rights Brochure which is available on their website, www.doe.mass.edu/sped.

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**STATE HOLDS MEETING TO ADDRESS U.S. DOE MONITORING REPORT**

On October 3, 2000, the Massachusetts Department of Education sponsored a public meeting to review the areas of non-compliance under IDEA-97 (the federal special education law), as identified by the U.S. Office of Special Education Programs (OSEP). Participants included members of the Statewide Advisory Council on Special Education (SAC) and others who served as members of the Statewide Steering Committee required by OSEP for the monitoring review. In addition, key staff from Mass DOE and the Education Committee in the Legislature were present. (Federation Executive Director, Richard Robison who is chairperson of the SAC, chaired this improvement planning meeting.)

Together, the group reviewed each of the 14 areas cited and suggested ways in which the state might improve its compliance with the law. The group generated a list of “Activities to Achieve Results”, some of which may be included in an improvement plan. The plan needs to be presented to OSEP in the near future. Topics discussed included:

- IEP development,
- Provision of psychological services when needed under an IEP,
- Availability of extended-school-year services,
- Lack of integration opportunities for children with disabilities served in separate educational environments,
- Opportunities for children to be involved in and progress in the general education curriculum,
- Lack of access to vocational education
- Parent participation in IEP and placement decisions,
- Development of statements of transition services,
- Involvement of non-educational agencies in transition planning,
- Invitation of students to plan their own transition services,
- Development of transition needs statements at age 14, and
- Overall supervision of local districts by the state, including monitoring services in charter schools.

The Mass DOE must now translate all of this information into specific goals and formulate a plan to ensure that the state comes into compliance with federal law in a reasonable time frame. If you have any comments concerning the implementation of IDEA in Massachusetts, please contact Richard Robison at the Federation (robison@fcsn.org), or the Office of Special Services at Mass DOE. The Federation will keep you posted on the development of the plan.
While the changes are confusing, let us not be distracted from the substance of the matter. One of the most exciting aspects of the revisions to both federal and state special education laws is the renewed emphasis on all students gaining access to the general curriculum. As many have already discovered, the new IEP forms implement the requirements in IDEA that students’ goals and objectives support their progress in the general curriculum. Subject by subject, the team must determine the student’s present level of performance, the impact of a student’s disability on their progress, their specific instructional needs and identification of the necessary supports and services which will enable them to make effective progress.

At the risk of overexposure, I would like to share with Newsline readers the academic successes witnessed within my own family over the past year. As a high school student, my daughter who has Down syndrome is very much a part of the general education environment with support from special education. Topics covered in Early British Literature found her engaged in a study of Beowulf, Chaucer’s Canterbury Tales, King Arthur, Shakespeare, David Copperfield and other classics. American History included exposure to the Declaration of Independence, political developments of the 1800’s, US expansion, the Progressive Era (early 1900’s), World Wars I & II, and on through the civil rights movement of the 1960’s. Science included Biology from the parts of the microscope, to measuring in metrics. Topics included evolution, fossils & geological formations, dissecting a pig, to understanding genes and cells. Math focused more on money skills and the fundamentals (which was appropriate for her). She completed over a dozen book reports of various types, such as: a biography of Emily Dickinson, two of C.S. Lewis’ Chronicles of Narnia, The Wizard of Oz, A Winter’s Tale by Shakespeare and others.

As I look back at the year’s accomplishments, there are a couple of thoughts that come to mind. First of all, it is clear she is receiving a high quality education. In her situation, it would be easy to imagine that most of this was well beyond her. That would be true if it had been presented without accommodations. But in fact, the accommodations and support did enable her to truly engage in the educational process. Second, she was able, in most cases, to relate these lessons to her daily life circumstances. For example, on a trip to the Grand Canyon last summer, she recalled much of what she had learned about the rock formations and the evolution of the Canyon.

I am intrigued by much of the discussion that is emerging at the present time within special education circles, among parents and professionals alike. I have heard people ask, “Well, exactly what is the general curriculum?” or, “She’s not a candidate for that!” The OSEP monitoring report identified this issue as one of the primary issues our state needs to address within special education. Administrators admitted to the federal monitors, without hesitation, that “they don’t teach general education subjects at their school,” or “they have no content specialists”.

Someone has challenged my wife and myself about our thoughts on this by saying, “but when is she going to learn functional skills or life-skills?” Our goal is for our daughter (and our son) to become as independent as possible. What this implies is being prepared for and holding a job that will provide the resources necessary to become independent. Presently, students with significant disabilities experience unemployment rates that exceed 70%. The most functional skills I can imagine in our times, in our economy, are the literacy skills and awareness that comes from a high quality education. We will not neglect the practice of those skills, but for the first time we are no longer being asked to choose between special ed or curriculum, job skills or academics. The new IEP is structuring a change that is long overdue.

Richard Robison
Procedural Safeguards are one of the principles of the federal special education law, known as IDEA (Individuals with Disabilities Education Act). Parents and their children with disabilities have specific rights in the special education process and procedural safeguards protect these rights. These safeguards ensure that families are aware of their rights, that information is shared in a timely manner, and that students receive appropriate services. Parents also have the right to disagree with the school’s proposals and can offer their own.

In order to be informed about decisions regarding your child’s special education services and your right to participate, parents must receive Written Notice from the school district when their child is referred to special education for the first time or being reevaluated, about IEP (Individualized Education Program) meetings, or when the school proposes any change in a child’s services. This notice must include an explanation of all the procedural safeguards (only partly discussed here) and must:

- Explain why the school will or will not provide specific services for your child,
- State any other options that were considered and why those will or will not be utilized,
- Explain what evaluations, tests or other factors the school used to make the decision.

Providing written notice is a two-way street. Parents must give written notice to the school if they plan to remove their child from public school and enroll the child in a private school at the public school’s expense. Notice must be given at least 10 business days prior to changing their child’s placement. Notice must also be given when parents plan to go to a hearing (see below).

Parental Consent
As mentioned above, the school must notify the parents about any action they propose or refuse to take in regard to providing a free and appropriate public education to their child with a disability. Once they are informed, parents must give their consent before the school can proceed. Parents may withhold their permission if they feel it is not in their child’s best interest. Parents may also decide to consent to some evaluations, but not all, or to only some of the services listed on the IEP.

If parents do not respond to the school’s request to evaluate a child or to the offer of services through an IEP the school may act without parent’s permission if they can prove they tried to reach the parents many times without success.

The Right to Inspect and Review Records
Parents can request to review their child’s records and the school must make these materials available within 2 days. There are two types of student records: the transcript and the temporary record, which includes major information about your child’s special education eligibility, IEPs, standardized test results, evaluations and comments.

The school cannot release your child’s records to anyone without your consent. When they ask your permission to release records they must tell you which records, why and to whom.

You and your child have the right to add relevant material to the record. You may also request that information be changed or removed by speaking with the school principal.

Families are encouraged to work in partnership with their school district to resolve any disagreements about special education services and placement for their child. However, if the parents and school are unable to agree and the parents feel the school system is not complying with the law, the procedural safeguards provide a way for parents to file a Complaint, to request Mediation or a Due Process Hearing. These are handled through the Massachusetts Department of Education (DOE). To file a complaint, call the DOE at 781-338-3737. To request mediation or a due process hearing call 781-338-6400.

During mediation or a hearing, your child has the right to stay in his or her current school placement until your dispute is resolved; this is called “stay-put”. There are some exceptions: if the student carries or possesses weapons, is involved in any drug-related activity, or if the current placement is likely to result in injury to the child or others, the student’s educational placement can be changed.

You may see entire the Parents’ Rights Brochure at www.doe.mass.edu/sped or www.fcsn.org
Since I was new to the entire educational process, I probably would have accepted the school’s decision; however, through the intervention of one of the very few advocates available at the time, I decided not to accept the principal’s recommendation. Indeed, without the advocate’s help and guidance, my son’s entire education would have taken an entirely different route and he might not have been prepared to attend a first rate university, where he received his Bachelor of Science and later earned a Master’s degree in Political Science.

My experience was not unusual and thirty years later, many parents still experience feelings of isolation and vulnerability when they first approach school administrators in regard to placement and services for their children with special needs. There is no doubt that the presence and support of another person can help relieve some of the anxiety associated with this process.

When I was negotiating a placement for my son, there were few advocates, and most did not provide free or low-cost services to parents. There was some training available through private advocacy organizations such as the Federation and the Massachusetts Advocacy Center but these opportunities were limited by funding issues.

Due to the increasing demand for trained advocates with knowledge of the special education laws, it became obvious that a system that would provide advocacy training had to be established within the Commonwealth. The Massachusetts Developmental Disability Council awarded money to the Federation to develop and implement training. This training would ensure that parents of children with special needs knew the special education law, knew their rights, and would be able to negotiate appropriate services for their children. Attorneys Robert Crabtree and Lawrence Kotin were the first directors of this project and along with Federation staff, designed a course that would train parents to become knowledgeable and skilled advocates. In compensation for the training, these parents had to be willing to make a sustained commitment to represent parents of children with special needs regarding special education issues. In fact, this course provided the foundation for all the training programs offered by the Federation over the past 20 years.

Initially, two training programs were held each year - one taught advocacy on behalf of others, the other concentrated on self-advocacy. Over time, these programs evolved into one course. As a result, the Federation has a solid framework for recruiting, training, and supervising advocates whom we call “parent consultants”. There are now a significant number of parent consultants available to assist parents in their quest for a free and appropriate public education for their children with special needs. We estimate that close to 800 parents and professionals have participated in this consultant training. To meet the increasing demand, this advocacy training is now offered three times a year, once in Boston, once in Worcester and again in Northampton.

The early participants viewed their advocacy efforts as an informal way to help other parents. Many provided their services at no cost. Today, more and more participants take the consultant training as a first step in a long-term career change where their primary focus is to empower parents to share their experiences and help other parents in need.

The Federation is indeed gratified that the parent consultant training has become so popular and successful and that there have been so many benefits. Many children’s lives have been changed because they received a better education. Parents no longer have to feel isolated and alone. These dedicated parents and advocates have helped change the philosophy of school administrators with regard to integrated placements and supports within the general school curriculum.

As we look to the future, the frequency, duration and content of the training may change to meet the changing needs and issues that periodically emerge within the Commonwealth. However, the Federation’s commitment to helping parents remains constant.

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**SAVE the DATE for...**

**“Maximizing Our Children’s Future”**

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

Saturday • March 17th, 2001 • 8:00am–4:15pm

**FEATURED KEYNOTE SPEAKER:**

Dr. Tom Hehir

*Former Director of Office of Special Education Programs*

*United States Department of Education, Washington DC*

Sponsored By:

Family TIES, Federation for Children with Special Needs, Massachusetts Families Organizing for Change, Parent Professional Advocacy League (PAL)
MEET KATIE:
Katie, 20 years old, is a senior at South High Community School in Worcester. An SSI recipient, Katie lives with her mother, father, and older brother. She is excited about graduation and is looking forward to her prom. Katie’s vision for the future includes moving into her own apartment, getting married, learning more about computers, and working in an office. Last September, Katie got a job at an insurance company. With help from a job coach (a person who helps her learn the job), Katie organizes, alphabetizes, and files a variety of documents. Katie and her parents were afraid that she would lose her SSI benefits, particularly her Medicaid coverage.

Can Katie continue to receive SSI and work without losing her benefits?
Yes! The Social Security Administration allows SSI recipients to work, and also encourages them to take advantage of special programs to maximize their income.

When should I worry about losing Medicaid?
Medicaid coverage can continue even if Katie’s earnings become too high for an SSI cash payment. She would have to make more than $24,373 a year in order to lose Medicaid coverage.

What happens to Katie’s SSI check when she starts working?
Generally, when an SSI recipient starts to work, their SSI check is less. The higher the income, the lower the SSI checks. However, “exclusions” and “work incentives” can reduce the amount of income that is counted and allow the person to continue to receive higher SSI cash benefits. Up to $85 a month can be “deducted” from wages. After that, the SSI check is reduced $1 for every $2 earned.

APPLYING THE EARNED AND GENERAL INCOME EXCLUSIONS:
Katie receives $430 from SSI. Her income from work is $900 a month.

1. Subtract $85 from total wages ($900 MINUS $85 = $815)
2. Divide the result by two: $815/2 = $407.50
3. Subtract that from SSI amount ($430 MINUS $407.50= $22.50)

Although Katie’s SSI check was reduced to $22.50 a month, she still has her entire paycheck. As a result, her total monthly income went from $430 to $922.50. More importantly for Katie and her family, she continues to be fully covered by Medicaid.

Are there any Work Incentives specifically for students?
The Student Earned Income Exclusion (SEIE) allows students less than 22 years of age to exclude up to $400 a month from their earned income, until they reach a maximum of $1,620 a year.

How did Katie apply for the Student Earned Income Exclusion?
Katie’s family called the local Social Security Office and asked for the person in charge of “Work Incentives”. They explained that they wanted to report that Katie was working and also apply for the Student Earned Income Exclusion. Her family made an appointment, and was asked to bring:

1. A letter from the school stating that Katie was regularly attending school
2. A letter from her parents stating the date Katie began to work, how many hours per week she was working, and her wages
3. Pay stubs

How do you calculate the Student Earned Income Exclusion?
Using Katie as an example:

1. Subtract $400 (SEIE) from $900 (Katie’s monthly wages) = $500
2. Apply the general and earned income exclusions ($500-$85 = $415)
3. Divide $415 by two = $207.50 (countable income)
4. Subtract $207.50 from $430 (former SSI amount)= $222.50 (new SSI amount)

How did the Student Earned Income Exclusion maximize Katie’s income?
Before she started working, Katie received only $430 from SSI. After she started working and applied only the general and earned income exclusions, she was receiving $922.50. After applying Student Earned Income Exclusion, Katie is receiving $1,122.50 a month, and she is fully covered by Medicaid. Katie is proud to have a good job and to be able to pay for all her graduation expenses herself.

This article is from Opening Doors, a collaborative project of the Institute for Community Inclusion, the Federation for Children with Special Needs, and the Disability Law Center. The purpose of the project is to increase the use of SSI work incentives. For more information, or for your local Social Security Office, call:

The Social Security Administration
(800) 772-1213

If you have questions related to SSI and SSI work incentives, or suggested topics for future newsletters, please contact: Elena Varney, Institute for Community Inclusion, Children’s Hospital, 300 Longwood Avenue, Boston, MA 02115; (617) 355-8022
CONOZCA A KATIE:

Katie tiene 20 años y está cursando último grado en la escuela pública South High Community School en Worcester. Ella recibe SSI. Katie vive con su mamá, su papá y su hermano mayor. Ella está muy alegre porque dentro de poco se va a graduar y ya está lista para la fiesta de graduación este año. La visión que Katie tiene para el futuro incluye mudarse a su propio apartamento, casarse, aprender más sobre computadores y trabajar en una oficina. El pasado mes de septiembre Katie encontró un trabajo en una Compañía de Seguros. Con la ayuda de un capacitador laboral (una persona que la ayuda a ella a aprender lo necesario para realizar el trabajo), Katie organiza alfabéticamente y archiva una gran variedad de documentos. Katie y sus padres tenían el temor de que ella iba a perder los beneficios del SSI, especialmente la cobertura médica.

¿Puede Katie seguir recibiendo SSI y trabajar sin perder sus beneficios?

Sí! La Administración del Seguro Social permite trabajar a aquellos que reciben SSI, y al mismo tiempo les invita a aprovechar los programas especiales para incrementar sus ingresos.

¿Cuándo me debo preocupar de perder Medicaid?

La cobertura de Medicaid puede continuar aún si los ingresos de Katie son muy altos para un pago de SSI en efectivo. Katie tendría que ganar más de $24,373 al año para perder la cobertura de Medicaid.

¿Qué pasa con el cheque del SSI de Katie cuando ella comienza a trabajar?

Generalmente cuando alguien que recibe SSI comienza a trabajar, el cheque del SSI baja un poco. Entre más dinero gane la persona, más pequeño es el cheque. Sin embargo, “exclusiones” e “incentivos de trabajo” pueden reducir la cantidad que se cuenta y permitir a la persona continuar recibiendo beneficios más altos en efectivo del SSI. Hasta $85 puede ser “deducido” del sueldo en un mes. Después de eso, el cheque del SSI es reducido en $1 por cada $2 ganados.

APLICANDO LAS EXCLUSIONES DE INGRESOS GANADOS E INGRESOS GENERALES

Katie recibe $430 del SSI. Su salario mensual de trabajo es $900.

1. Substraiga $85 del total del sueldo ($900 MENOS $85 = 815)
2. Divida en resultado entre dos: $815/2 = $407.50
3. Substraiga aquella cifra de la cantidad del SSI ($407.50 MENOS $430 = $22.50)

A pesar de que el cheque del SSI de Katie ha sido reducido a $22.50 al mes, ella todavía tiene su cheque completo. Como resultado del proceso, su ingreso total mensual fue de $430 a $922.50. Más importante para Katie y su familia es que ella continúa recibiendo de manera completa los servicios de Medicare.

¿Existen Algunos Incentivos de Trabajo Específicamente para Estudiantes?

La Exclusión de Ingreso Ganado para Estudiantes (SEIE) permite a estudiantes menores de 22 años excluir hasta $400 de sus ingresos mensuales hasta que alcancen un máximo de $1,620 al año.

¿Cómo aplicó Katie para La Exclusión de Ingreso Ganado para Estudiantes?

La familia de Katie llamó a la oficina del Seguro Social y preguntaron por la persona encargada de los “Incentivos de Trabajo”. Ellos explicaron que querían informar que Katie estaba trabajando y querían aplicar para La Exclusión de Ingreso Ganado para Estudiantes. Su familia hizo una cita, y le pidieron que llevara:
1. Una carta de la escuela afirmando que Katie estaba asistiendo regularmente.
2. Una carta de los padres constatando que Katie había comenzado a trabajar, el número de horas de trabajo y el salario que recibía.
3. Recibos de pago

¿Cómo calcular La Exclusión de Ingreso Ganado para Estudiantes?

Usando a Katie como ejemplo:

1. Substraiga $400 (SEIE) de $900 (Salario mensual de Katie) = $500
2. Aplique las exclusiones de ingreso general e ingreso ganado ($500-$85 = $415)
3. Divida $415 en dos = $207.50 (ingreso contable)
4. Substraiga $207.50 de $430 (Cantidad inicial del SSI) = $222.50 (Cantidad del SSI)

¿De qué manera La Exclusión de Ingreso Ganado para Estudiantes aumenta los ingresos de Katie?

Antes de que empezara a trabajar, Katie sólo recibía $430 del SSI. Después de que comenzó a trabajar y aplicó sólo para la exclusión de ingreso general e ingreso ganado, ella recibía $922.50. Después de aplicar para La Exclusión de Ingreso Ganado para Estudiantes Katie está recibiendo $1,122.50 al mes, y a la vez está siendo cubierta completamente por Medicaid. Katie se siente orgullosa de tener un buen trabajo y ser capaz de cubrir todos los gastos de su graduación por sí misma.

Este artículo proviene de “Opening Doors” (Abriendo Puertas), un proyecto de colaboración del Instituto para la Inclusión de la Comunidad, la Federación para Niños con Necesidades Especiales, y el Centro de la Ley de Discapacidad. El propósito de este proyecto es incrementar el uso de incentivos para el trabajo del SSI. Para mayor información acerca de PASS, o para su Oficina del Seguro Social local, llame al:

Administración del Seguro Social
(800) 772-1213

Si usted tiene alguna pregunta relacionada con el SSI o los incentivos de trabajo del SSI, o sugerencias para temas en el futuro, por favor llame a Elena Varney, Instituto para la Inclusión de La Comunidad, Children’s Hospital, 300 Longwood Avenue, Boston, MA 02115; (617) 355-8082.
APRESENTANDO KATIE: Katie, 20 anos de idade, cursa o último ano na South High Community School em Worcester. Ela é beneficiária do SSI (Renda de Seguridade Social) e mora com a mãe, o pai e o irmão mais velho. Ela está super animada a respeito de sua graduação e ansiosa pelo baile de formatura deste ano. A perspectiva de Katie para o futuro inclui: mudar-se para o seu próprio apartamento, casar-se, aprender computação e trabalhar num escritório. Setembro passado ela conseguiu um emprego numa agência de seguros. Com a ajuda de um orientador profissional (job coach) – uma pessoa que a ajuda no aprendizado do trabalho –, Katie organiza, ordena e arquiva uma série de documentos. Katie e seus pais temiam que ela pudesse vir a perder os benefícios do SSI, particularmente o direito ao sistema de saúde financiado pelo governo (Medicaid).

Katie pode continuar a receber o SSI e trabalhar sem perder os seus benefícios? Sim! O “Social Security Administration” de fato permite que os beneficiários do SSI trabalhem e, também, encoraja-os a aproveitar dos programas especiais para que aumentem a sua renda.

Quando devo me preocupar com a perda do Medicaid? A cobertura do Medicaid pode continuar, mesmo que o ordenado de Katie torne-se alto demais para receber um pagamento do SSI. Ela teria de ganhar mais de $24.373 por ano para perder a cobertura do Medicaid.

O que acontece com o cheque SSI de Katie quando ela começar a trabalhar? Geralmente, quando um beneficiário do SSI começa a trabalhar, o pagamento é reduzido. Quanto mais alta a renda, mais baixo o valor do cheque. Contudo, “exclusões” e “incentivos de trabalho” (“exclusions” e “work incentives”) podem diminuir o total da renda considerada, permitindo, assim, que se receba maiores benefícios em dinheiro do SSI. Até $85 dólares por mês, no máximo, podem ser “deduzidos” do ordenado. A partir daí, o cheque do SSI é reduzido em $1 dólar para cada $2 recebidos.

APLICANDO AS EXCLUSÕES DE RENDAS SALARIAL E SUPLEMENTAR: Katie recebe $430 de SSI. Seu salário é de $900 por mês.

1. Subtraia $85 do valor do salário ($900 menos $85 = $815)
2. Divida o resultado por 2: $815/2 = $407,50
3. Subtraia este valor do montante do SSI ($430 menos $407,50 = $22,50)

Como o Student Earned Income Exclusion maximizou a renda de Katie? Antes de começar a trabalhar, Katie recebia apenas $430 de SSI. Quando começou a trabalhar e aplicou só no programa de exclusões de rendas salarial e suplementar, ela recebia $922,50. Depois de aplicar no programa Student Earned Income Exclusion, Katie está recebendo $1.122,50 por mês, e continua inteiramente coberta pelo Medicaid. Katie está orgulhosa de ter um bom emprego e ser capaz de pagar por todas as despesas de sua gradução por si própria.

Este artigo é uma realização do Opening Doors (Abrindo Portas), um projeto em colaboração com o Institute for Community Inclusion, a Federation for Children with Special Needs, a Disability Law Center. A proposta do projeto é aumentar o uso do “work incentives” do SSI. Para maiores informações sobre o PASS, ou para o seu escritório local do Social Security, telefone: (800) 772-1213

Caso você tenha alguma questão relacionada ao SSI e ao “SSI work incentives”, ou queira sugerir temas para os próximos informativos, por favor contacte: Elena Varney, Institute for Community Inclusion, Children’s Hospital, 300 Longwood Ave, Boston, MA, 02115 – (617) 355-8022.
“Opportunity-to-learn” requirements are a key component of standards-based education reform. Standards-based education reform is the term used to describe nationwide efforts to improve education by first setting standards. Standards are seen as a way to raise student achievement by specifying what students should be learning and what teachers should be teaching. Schools are judged based on each student’s achievement, with large-scale assessments focused on educational results. However, standards and assessments can bring about meaningful educational change only if combined with requirements that ensure that all students have access to the kind of learning opportunities they need to reach the standards.

Opportunity-to-learn requirements address strategies, services, and supports designed to ensure that all students have a fair chance to learn the knowledge and skills set forth in the state standards. Opportunity-to-learn requirements can include:

- Curriculum modified to achieve standards
- Instructional materials and methods
- Class size and structure
- Individual assistance
- Supportive services
- Teacher training
- Professional development
- Adequate funding
- Teacher self-assessments and peer reviews

Schools must address these requirements to ensure equity and excellence for all students and to close the achievement gap between students with and without disabilities.

Opportunity-to-learn requirements and students’ rights to quality education can be derived from most state constitutions and state education reform statutes. The highest courts of many states have said that the education clauses of their state constitutions define a constitutional right to education. These constitutional requirements have often been raised when a state’s school finance system has been challenged in court. However, the constitutional right to a quality education is not limited to school finance. For example, in Kentucky, successful state constitutional litigation led the legislature to enact a detailed standards-based education reform law.

With the Individuals with Disabilities Education Act Amendments of 1997 (IDEA), Congress emphasized the provision of high quality education. Students with disabilities must be provided an opportunity to be involved and progress in the general curriculum, and must be provided with appropriate accommodations, modifications, and services consistent with their individual needs, to facilitate their involvement and progress. The Individualized Education Program (IEP) must specify the special education instruction, related services, and supplementary aids and services necessary to provide the student the opportunity, as appropriate, to learn what all other students are expected to learn.

Under the IDEA Amendments of 1997, the IEP must include, for example, a statement of:

- The child’s present level of educational performance, including how the student’s disability affects involvement and progress in the general curriculum
- Measurable annual goals, including benchmarks or short-term objectives, that will enable the child to be involved and progress in the general curriculum
- Special education and related services, and supplementary aids and services the student needs to be involved and progress in the general curriculum and reach other IEP goals
- Program modifications and supports for school personnel (teacher, aides, etc.) that are necessary to ensure that the student advances appropriately toward attaining the IEP goals
- Modifications in the administration of state or districtwide assessments of student achievement. 1

Special education evaluations, re-evaluations, IEP reviews, and parent progress reports must now address the student’s progress in the general curriculum. These new requirements in IDEA help to ensure that IEP teams continually address the services, strategies, and supports necessary for the student to have an opportunity to learn and attain the standards. Students with disabilities have parallel rights under Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, which prohibit discrimination on the basis of disability. These laws can also be used to require schools to provide the specialized instruction and supplementary aids and services a student needs to benefit from the general curriculum and standards.

Ed. Note: This article has been adapted from Every Single Student, a PEER publication of the Federation for Children with Special Needs. Information in this Fact Sheet is based on the PEER Information Brief, “Opportunity to Learn and Education Reform: Ensuring Access to Effective Education for All Students,” by Kathleen B. Boundy, J.D., Center for Law and Education. Boston. If you would like to read more about “Opportunity to Learn,” visit the Federation online at www.fcsn.org/peer, or call Carolyn Romano at the Federation at 617-236-7210.

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1. For Specific IEP content, see section 1414 of IDEA.

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Making the Most of a 10 Minute Office Visit

Last year, Family TIES had the opportunity to host a series of “Information Exchange” workshops across the state. In the West, Dr. Brian Dempsey shared these tips about how to make your office visit more productive.

- Organize yourself before the appointment. Write down your questions and concerns so you will remember to ask.

- If you have paperwork to be filled out, (school physical, nursing orders, etc.) understand that the doctor cannot do that during a ten-minute visit. Be prepared to leave the papers and give the doctor a few days to complete them.

- Realize that a ten-minute visit means ten minutes. Don’t schedule this type of visit if you have major issues or a subject that needs more time to discuss.

- If you need a longer appointment, try to book later in the day, perhaps the doctor’s last appointment.

- When you have an appointment for one of your children, do not take along the rest “just for the doctor to take a quick look at.” Make separate appointments for each child.

- Be prepared to answer the doctor’s questions precisely. “Since Tuesday” is much more helpful than, “oh, a few days, I guess…”

- Write down answers to your questions as you go over them with your doctor. This will save you both time instead of having to call him back because you forgot was said.

- If you make your appointment for 10am, be there on time, otherwise your appointment will be rushed and you will leave feeling like you didn’t get the answers you needed.

Most importantly remember that your relationship with your child’s physician is a partnership. If you work together as a team your child will always benefit.

For more information on parent-professional relationships, or on upcoming workshops, call your Family TIES Coordinator at 1-800-905-TIES.

Did you know...

- On October 17th, the President signed the Children’s Health Act into law. The new law includes provisions for research grants and new centers for autism, Fragile X Syndrome, diabetes, asthma, hearing loss, and epilepsy. It also includes a new center on Birth defects and Developmental Disabilities at the Center for Disease Control as well as provisions for a new study on the effects of PKU.

- The Children’s Health Insurance Program (CHIP) expands MassHealth eligibility to all children living in families with incomes up to 200% of the poverty level. CHIP was created with Federal Funds as part of a national children’s health insurance initiative.

- Children who are NOT eligible for CHIP or other MassHealth benefits may be eligible for the Children’s Medical Security Plan (CMSP). Every uninsured child and teen in Massachusetts can get health care coverage at little or no cost. Children aged 18 and younger can enroll in a program with either full coverage or only primary and preventive care. The type of coverage depends on the family’s income. Immigration status does not affect the child’s eligibility.

To determine whether a child is eligible for MassHealth/Medicaid under these new expanded guidelines, call MassHealth at 1-800-841-2900.

To determine eligibility for CMSP, call 1-800-909-2677 (voice/MA only) or 800-497-4648 (TTY/MA only).

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

NewsLine
Editor: Beth Dvoretsky
Layout & Design: Nummi Nummerdor
Advertising: Brooke Heraty
Contributors: Sandy Blanes, Kathy Cruz, Brooke Heraty, Rachael Herrup-Morse, Gisel Pimentel, Ruth Ann Rasbold, Richard Robison, Diana Rocha, Carolyn Romano, Polly Sherman, Phyllis Snerison, Joanne Spencer, Eileen Souza, Elena Varney, Laurie Ventola, Donna Welles

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

The Federation for Children with Special Needs, Inc.
Our Mission: To provide information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

Board of Directors: Dan Heffernan, President; Peter Brennan, Treasurer; Miryam Wiley, Clerk Ed DeNoble, Linda Downer, Jack Foley, Robin Foley, W. Iliam Henderson, Anne Howard, Sara Miranda, Deborah Smith-Pressley, Kim Yoshida

Executive Director: Richard J. Robison
Dear Friend,

The year 2000 has been a historic year for Special Education in Massachusetts. As you know, the State legislature passed 50 significant changes to Chapter 766, including the roll back of the “Maximum Feasible Benefit” standard, after years of parent advocacy to preserve it. Fortunately, many of the other changes have maintained or improved requirements under the law. Though we are disappointed, we have won many important battles. Our advocacy efforts are strong because of you who have done so much to maintain the rights of children with special needs.

It has required a huge effort to keep up with the changes that have taken place. Hopefully you have found our website and the articles in our quarterly publication, NewsLine, helpful in staying on top of the issues. We have regularly updated the latest developments and made sure the most recent documents were available to all. This spring, we had as many as 1,500 visits per day to our site. Our current circulation of NewsLine has increased to over 21,000 readers. Eighty percent of our readers are parents, but organizations, institutions, and professionals across Massachusetts and the United States also subscribe. Our parent calls, more complex than ever, have nearly doubled this year. We have offered twice as many workshops as in previous years and have seen at least a 30% increase in attendance per session. To say our staff and volunteers have been working hard on your behalf is an understatement!

Even though our work has dramatically increased, our funding has remained the same. The special education advocacy work of the Federation is not supported through any specific grant. It is only made possible by your donations. Last year we were pleased that nearly 300 individuals and families responded with generous contributions, totaling just under $35,000.

As we look ahead we know that 2001 will be equally as important as we continue our advocacy efforts. New contributions to the Federation’s Fall Campaign Fund, and increases in the amounts contributed by previous donors – of any amount – will encourage us all.

Thank you in advance and best wishes on a successful school year.

Sincerely,

Richard J. Robison
Executive Director

Daniel T.S. Heffernan
President

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advocate, she has testified at the statehouse, advocating for maintaining maximum feasible benefits under the Massachusetts special education law, Chapter 766.

Cassandra has developed a special interest in technology and will attend Massachusetts Communication College after graduation in June 2001. Her passion for music has inspired her to write songs and she has recently cut a demo tape entitled “Angel for Life”.

The Federation joins the family and friends of Ruth-Ann Rasbold and Cassandra Saunders in congratulating the advocacy efforts of both these exemplary people.
The Federation Travels to Brazil

by Sandy Blanes, Portuguese Outreach Specialist

When I was hired by the Federation to coordinate programs for Portuguese-speaking families, I never imagined my outreach efforts would extend all the way to Brazil. The U.S. Department of Education (U.S.D.O.E.) became aware of our work with the Portuguese community when they read the Federation’s Annual Report. As a result, Judy Heumann, the Assistant Secretary to the U.S.D.O.E., invited me to be part of a presentation she and others were giving at the 5-day Rio International Congress for Rehabilitation. The D.O.E. in Brazil invited the Special Education Directors from all 37 Brazilian states, teachers, other professionals and parents to attend this conference and share their dreams and hopes for inclusion in their country as well as to learn about inclusion efforts in other countries.

Judy Heumann, Delia Pompa from the Office of Bilingual Education and others presented a course entitled “Inclusion in Public Schools.” They gave an overview of the History of Special Education in the US and I shared my expertise and gave the “parent perspective” about inclusion and the importance of parent participation in inclusion in local public schools. In addition to being able to present in Portuguese, to the relief of those wearing headphones for translations all day long, I had also sacrificed one of my suitcase allotments to bring in packets of materials about the Federation and the Parent’s Place instead of additional clothing. I had plenty of room for gifts and souvenirs as conference attendees gratefully took all 70 pounds of materials. Our packets now sit on the desks of Special Education Directors in all the Brazilian states. Our outreach to Brazil continues as I still receive additional e-mail requests for more information.

We have a ways to go to achieve accessibility and accommodations here in the states, but you are instantly thrown back about 30 years as you try to negotiate and the streets and access the shops, restaurants, and tourist sights in Brazil. Judy’s husband, after hitting a hole in a ramp with his wheelchair, was thrown face down in the middle of the street and hurt his hand. He also made an unforgettable “climb” up the Sugar Loaf mountain, an inaccessible site. He jumped from his wheelchair into the tram, supported by his crutches, as there was no way to wheel the chair onto the tram and secure it. His determination to get to the top was a lesson in courage for the many tourists who shared the tram ride with him.

The opportunity to attend this Congress was exciting because the Federation is now involved in inclusion efforts at an international level. This opportunity also had great personal meaning for me, and was a homecoming of sorts, as I had lived in Brazil for 16 years. I first went there as a young mom with three children, only to return here when my eighth child, Nelly, was born with special health needs and needed medical attention that I could only get for her in the states. Nelly has since passed away. I was still mourning her when I began working at the Federation and to this day, I am thankful for how special my co-workers made me feel. Usually the child gets all the special treatment, but at the Federation they realize that everyone has special needs.

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.

NOVEMBER 2000
11/29, Fair Haven, 6:30–8:30pm, IEP 2000

DECEMBER 2000
12/6, Salem, 6–8pm, Basic Rights
12/7, Bedford, 7–9pm, Access to the General Curriculum
12/7, Holyoke, 7–9pm, IEP 2000

JANUARY 2000
1/3, Quincy (snow date 1/10), 9:30–11:30am, Basic Rights
1/8, Franklin (snow date 1/29), 7–9pm, Basic Rights
1/9, North Easton (snow date 1/10), 7–9pm, Basic Rights
1/9, Southboro (snow date 1/18), 7–9:30pm, Transition
1/10, Natick (snow date 1/17), 7–9pm, Basic Rights
1/16, New Bedford, 6:30–8:30pm, Basic Rights
1/17, Topsfield, 7–9pm, Basic Rights
1/18, Holden, 7–9pm, IEP 2000
1/22, Milford, 7–9pm, IEP 2000
1/23, Acton (snow date 1/30), 7–9pm, Basic Rights
1/24, Boston, 6–8pm, IEP 2000
1/29, Wayland (snow date 1/30), 7:30–9:30pm, Basic Rights

FEBRUARY 2000
2/1, Wakefield (snow date 2/8), 7–9pm, Transition IEP Development (14-22)
2/1, Hanover (snow date 2/8), 7–9pm, Communication
2/6, Whitman (snow date 2/13), 7–9pm, Basic Rights
2/7, West Boylston, 7–9pm, Transition
2/12, Georgetown, 7–9pm, Basic Rights
2/13, Reading (snow date 2/14), 7–9pm, Transition
2/15, Bedford (snow date 3/1), 7–9pm, MCAS
2/26, Wayland (snow date 2/27), 7:30–9:30pm, IEP 2000

MARCH 2000
3/8, Cambridge, 7–9pm, IEP 2000
3/13, Northbridge, 7–9pm, Basic Rights
3/14, Methuen, 7–9pm, Basic Rights
3/22, Concord, 7–9pm, Basic Rights

APRIL 2000
4/3, Saugus, 7–9pm, Basic Rights

WORKSHOP DESCRIPTIONS

Access to the General Curriculum: This parent friendly workshop on diverse learning styles and access to the general curriculum for all students. The training includes discussion and examples of modifications of content, delivery of instruction and performance criteria that allow students with disabilities to more fully participate and have success in the general curriculum.

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: These updated training workshops include a walk through of the new IEP with emphasis on IDEA 97, access to the general curriculum, writing curriculum based measurable annual goals, and the states new special education regulations.

Transition IEP Development (14-22): The IEP 2000 for Students 14 and Older Workshops emphasize Transition to adults living planning.

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.
Access in Action: A Profile

Jessica is a volunteer guide with Outdoor Explorations. She helps to run programs for people with and without disabilities, ranging from environmental service projects in urban parks and gardens to three-day adventure trips kayaking off the coast of Maine. The fact that Jessica has a cognitive disability helps give her a unique perspective about the impact of Outdoor Explorations (OE). She has come to be a powerful role model for people in the OE community.

In 1991, Carolyn Bess started OE, hoping to create community experiences where people of all abilities could learn together by participating in environmental awareness projects or through outdoor experiences. In Jessica’s case, Carolyn’s vision has been more than realized. Prior to joining the OE team, Jessica had little guide experience. She enjoyed outdoor activities, but was not aware of any program that would allow her to get involved in a leadership role. When asked if she had prior experience or opportunities in environmental and community leadership, she replied simply, “Not really.” This has since changed, and both she and OE have benefited as a result of her participation.

Jessica participated in OE events for 2 years prior to becoming a guide. Her enthusiasm and her empathetic and compassionate nature caught the attention of the other OE guides. They asked Jessica if she was interested in applying to be a volunteer. Jessica’s response was immediate, “I said I would. I wanted to stick with the program because I liked it a lot and I liked helping people with disabilities.”

On the first day of volunteer training, Jessica was apprehensive, but realized the same trust and camaraderie that she felt as a participant in past OE programs was still there. Jessica registered at the table, picked up her volunteer manual and found a seat. She was concerned that a person like her – with a cognitive disability – would not be a good volunteer leader. However, she quickly realized the diversity of the others in attendance. Two had guide dogs while three others used wheelchairs. With the support of OE’s program staff, Jessica’s confidence grew. She successfully completed the Volunteer Leadership Training and became an Outdoor Explorations guide – ready to help lead her first program.

That was three years ago. Since that time, Jessica has proved to be an invaluable part of the OE family. She has helped supervise numerous Skill Clinics along with several more complex and involved Adventure Trips. OE has become a stronger and more inclusive organization because of Jessica’s involvement. She sums up the effects of OE’s inclusive programming, “It helps to see how people who use wheelchairs and people who are blind get around in life.” And for people who have disabilities? “Well,” she muses, “I think it helps people who have disabilities get out in general instead of just staying at home. It helps them to have friends also.” She continued enthusiastically, “I’ve made some friends through OE. I get to see them each time I go back. It’s awesome.” We think so too.

PAL News

The Annual Advisory Board Meeting for the Parent/Professional Advocacy League (PAL) was held on October 5. This year’s theme, “Meeting the Challenge,” was an opportunity for the PAL network to celebrate the successes of the past year. Worcester Communities of Care helped sponsor this year’s event and we extend our many thanks to all those who made it possible.

Ross Greene gave a keynote address about explosive/noncompliant children and adolescents. There was a presentation entitled, “Update on Special Education Laws and Regulations,” by Cindy Nicholls, the Education Specialist at Worcester Communities of Care. Jesse Davis and Edan Healey were part of a youth panel discussion about “What Works/What Doesn’t.” After an evening meal, awards were presented to the hard-working family advocates in the PAL network. Special Community awards were given to Alice Dembner of the Boston Globe, Senator Therese Murray, Tim Sindefal of the Disability Law Center, John Willett, a parent, and Cheryl Califano, parent and advocate. Each of these individuals has made a significant contribution to helping to improve the lives of children and adolescents with emotional and behavioral disabilities.

In other news, PAL was awarded a challenge match grant from the Boston Foundation to help promote a Massachusetts Agenda for Children’s Mental Health. The Foundation will match each dollar contributed to our organization, to a maximum of $15,000.

Hyperbaric Oxygen Chamber Coming to Massachusetts!

American Hyperbarics, Inc. will be bringing their mobile hyperbaric oxygen chamber to the Hopkinton, MA area in January 2001. Should hyperbaric oxygenation prove to be successful, patients may have an improvement in cognitive, motor, sensory function and behavior. For more information contact:

Linda Gobeille 508-435-9829
(Massachusetts parent)
Keisha Gulledge of American Hyperbarics 334-673-1490
Website: www.americanhyperbarics.com
Family TIES (Together In Enhancing Support) is a statewide information and support network for families of children with disabilities, special health care needs or chronic illnesses. This project is supported by the Massachusetts Department of Public Health (DPH) and operates in collaboration with the Federation. Family TIES is staffed by a network director, a statewide coordinator of family support and by parent coordinators, based in each of the six DPH Regional Offices.

Family TIES is hiring Northeast and Southeast Regional Parent Coordinators. The parents who applies for this position must be the parent of a child with special needs or health issues.

Responsibilities include providing resource and referral information to families and professionals. The Parent Coordinator will also provide parent-to-parent matching. This position is for 20 hours a week with benefits. Applicants must have computer skills and must be able to travel in state.

Apply to: Polly Sherman, Family TIES Network Director
Southeast Regional DPH Office
109 Rhode Island Road
Lakeville, MA 02347
Phone: 508-947-1231
FAX: 617-727-9296
E-mail: polly.sherman@state.ma.us

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2. Ask for matching gifts forms for all the members of your team.
3. Review the requirements of your matching gifts program carefully—each program has its own policies.

Correction. The phone number for the Massachusetts Department of Education, Office of Program Quality Assurance was incorrectly listed in the last issue. The number is (781) 388-3737.