



*The Parent Leadership Project's*

# *Parent Perspective*

(877) 35-EI-PLP ♦ [www.eiplp.org](http://www.eiplp.org) ♦ [eiplp@yahoo.com](mailto:eiplp@yahoo.com)

**iContiene articulos en Español!**

***Parent Leadership is for Everyone: Engaging Diverse Families as Leaders* February/March/April 2011**

## **Summer Time is Around the Corner**

**S**pring is here and summer is fast approaching! What will you and your family be doing this summer to stay cool, have fun and make memories?

As you begin to think about what will be on the schedule this summer, there are many programs and activities available for kids...think about carving out time for old-fashioned typical summertime activities... like laying in the grass and cloud watching or star gazing, going fishing, catching fireflies or bringing books or crayons outside on a blanket in the park.

Many times when our children have special needs, we get caught up in the therapies and activities that target their specific needs. Our world becomes focused and it is sometimes difficult to "see the tree for the forest." My personal experience had always been to have an ulterior motive in every activity for which I signed my son up. More recently, I have started really thinking about how activities of all kinds could meet his need to have fun, learn and grow, and meet my need to provide him with activities that supported his occupational, physical and vision therapy goals.

There are many great resources in Massachusetts. Be sure to check out the following websites for summer camps, activities and programs:

Federation of Children with Special Needs Summer Fun 2011 [www.fcsn.org/2011\\_camp\\_handout.pdf](http://www.fcsn.org/2011_camp_handout.pdf)

Sped Child & Teen  
[www.spedchildmass.com/camps\\_2011](http://www.spedchildmass.com/camps_2011)

Boston Central [www.bostoncentral.com](http://www.bostoncentral.com)

Summer Programs Guide MassResources.org  
[www.massresources.org/pages.cfm?contentID=76&pageID=26&Subpages=yes](http://www.massresources.org/pages.cfm?contentID=76&pageID=26&Subpages=yes).



No access to the Internet? Your local Recreation Department should have a listing of what they'll be offering this summer... libraries, museums and local colleges will also have resources available...

Opportunities fill up fast, so be sure to start planning now! The PLP wishes you and your family, a wonderful summer filled with fun, relaxation and adventure!

## **Universal Design**

**Happy  
20th  
Birthday**



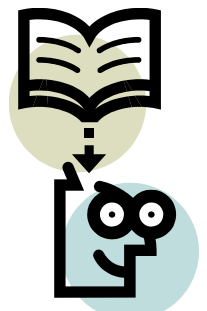
**EI  
Parent  
Leadership  
Project**

**E**ntering Early Intervention (EI), most families hear terms that they've never heard before or maybe haven't entirely understood. One such term is Universal Design. Families may not know what it means the first time they hear it, but once it is explained, a whole new thought process opens up.

What is Universal Design? Universal Design (UD) is defined by the Universal Design Alliance as "a user-friendly approach to design in the living environment where people of any culture, age, size, weight, race, gender and ability can experience an environment that promotes their health, safety and welfare

today and in the future." Although UD is a newer term, its concept has been around for years.

While basically a simple idea, Universal Design hugely impacts all children and adults by promoting a better and more fulfilling quality of life. Philosophically UD is the answer...rather than adapting something for one person when needed, create a universal design setting that will meet the needs of all potential participants.



(Continued on page 6)

## NCSEAM Family Survey Update

March 2011

### Dear Families:

We are now in the midst of our March 2011 **NCSEAM Family Survey** distribution. If you did not complete a **Survey** in October 2010 and your child has been enrolled in EI for at least six months, you should receive a **Survey** from your EI Service Coordinator. If you haven't please ask your Service Coordinator if you should be getting one.

If you do have a **Survey**, please complete it, **in pencil**, and return it in the stamped, self-addressed envelope provided. The Department of Public Health and your EI program need your input about the EI services your child and family receives. We use your feedback to continuously improve the Early Intervention system in Massachusetts. In addition, DPH uses the information you provide to report to the federal government about outcomes for families who receive EI services. All **Surveys** that come back over the next few months will be counted, so don't worry that it might be too late.

Thank you for your help with this important activity.

### Family Survey Frequently Asked Questions

**1.** Who will know what we say on our **Family Survey**? I don't want private information about my family to be shared broadly.

***What you put on the Family Survey is completely anonymous. Your responses go into a large database with no personally identifying information. The information is combined and analyzed to provide state-wide information. Your EI program gets a report based on what families say, but no names are ever asked for or shared.***

**2.** I might have gotten a **Survey** from my EI program, but I'm not really sure and I can't find it anyway. What should I do?

***Talk to your Service Coordinator. Each EI program has a list of families who should complete the Survey. She/he can tell you if they gave you a Survey. If yours is lost they can give you another. Just be sure to only complete one Survey!***

**3.** I've heard the words Family Outcomes before? What does that mean?

***Outcomes are the results children and families experience from participating in Early Intervention (EI). In Massachusetts we measure both family and child Outcomes using different tools. Family Outcomes are measured by the NCSEAM Family Survey.***

## Novedades de la encuesta familiar de NCSEAM

Marzo de 2011

### Estimadas familias:

Estamos distribuyendo nuestras **encuestas familiares de NCSEAM** de marzo de 2011. Si usted no completó una **encuesta** en octubre de 2010 y su niño lleva al menos seis meses inscrito en Intervención Temprana (IT), su Coordinador de Servicios de IT debería darle una. Si no ha recibido una encuesta, pregunte a su coordinador si le corresponde recibir una.

Si tiene una **encuesta**, por favor complétela, **a lápiz**, y envíela en el sobre provisto con franqueo y dirección de destino. El Departamento de Salud Pública y su programa de la IT necesitan saber su opinión sobre los servicios de IT que su niño y familia reciben. Utilizamos esta información para mejorar continuamente el sistema de Intervención Temprana en Massachusetts. Además, el Departamento de Salud Pública usa la información que usted da para informar al gobierno federal de los resultados para las familias que reciben servicios de IT. Todas las **encuestas** que lleguen durante los próximos meses se contarán. No es demasiado tarde.

Gracias por su ayuda con esta importante actividad.

### Preguntas comunes sobre la encuesta familiar

**1.** ¿Quién se entera de lo que decimos en nuestra

**encuesta familiar?** No quiero que la información privada de mi familia se divulgue ampliamente.

***Lo que se pone en la encuesta familiar es totalmente anónimo. Sus respuestas van a una gran base de datos sin información de identificación personal. La información se combina y analiza para dar información a nivel estatal. Su programa de IT recibe un informe basado en lo que las familias han dicho, pero no se preguntan ni comparten nombres.***

**2.** Es posible que yo haya recibido una **encuesta** de mi programa de IT, pero no estoy seguro y, además, no puedo encontrarla. ¿Qué debo hacer?

***Hable con su coordinador de servicios. Cada programa de IT tiene una lista de familias que deben completar la encuesta. Su coordinador puede decirle si le dieron una encuesta. Si la suya se perdió, pueden darle otra. ¡Pero asegúrese de completar sólo una encuesta!***

**3.** He oído las palabras "resultados para las familias" antes. ¿Qué significan?

***Son los resultados que los niños y las familias obtienen por participar en Intervención Temprana. En Massachusetts medimos los resultados tanto de la familia como del niño con diferentes herramientas. Los resultados para las familias se miden a través de la Encuesta Familiar de NCSEAM.***

*Parent Leadership is for Everyone:*

## Why Blog?

By Jennifer Chabott, West Regional ICC Parent Representative

**I** didn't know much about blogging when I got started. I pretty much just jumped in and figured it out as I went. You can too. Really! But first ask yourself why? I have thought about this a lot since being asked to share my experience with blogging. The how just happens. I feel that the "why" is most important factor when deciding to begin a blog.

**Why do I do it?** For me it began at the six month mark after receiving our son's diagnosis and I felt like I had a lot on my mind. Things I needed to sort, things I wanted to remember, and things I wanted to share. My first post:

### Zero to Six Months Gone By . . . .

Six months ago we were first told of the possibility that Christopher fell into the PSDS/Autism Spectrum. Since that time a lot has been learned. A lot has been done and accomplished and still there is so much more to do. This blog has been created now for me to keep track of all this hard work that so many including Christopher is doing. And hopefully the team working with him now and in the future will find this to be a helpful tool. This blog may also serve as a place for family and friends to visit and check in on all the good things happening for Christopher.

Thank you for visiting . . . come back again soon and often. Please keep in mind this is my first real blog . . .so I am kinda of learning as I go.

**So do you have a why?** Now you need to set yourself some goals.

**Like how often do you want to post?** I found that in the beginning while I was learning it was great to make an effort to post at least one event, thought, picture, or whatever it took to get me on a roll. Some posts are short; others long, some with photos, some even with spelling errors. It doesn't need to be perfect – you just have to keep at it. After a month I had the instant satisfaction of 32 posts to revisit and recall whenever I wished. It became an online journal slash scrap book. And I was hooked. I started sharing the site address with friends and family for them to follow along on our journey too.

**What time of day is going to work best for you?** Put it on your daily planner. For me it's before the kids wake or after they have gone to bed. Interested in beginning your own blog? There are many Blog sites, I

myself have found that Blogger has been easy to use and the service is free. Google the term "Blogspot" and it will direct you to your first step into the blog world.

I have been blogging now for a year and a half, and I can tell you there is nothing to fear. Again it's your blog, so if you are worried about sharing too much information, then don't. Some bloggers use only nicknames for their children. There are the obvious rules like never post your address, phone number and such. You can adjust the settings as you wish, having your blog be only viewed by people that you invite to it. I now have several blogs, some are open to anyone and others are closed for more personal thoughts that I am working on and only wish to share with trusted friends. Either way it's up to you. I find that I not only gain from venting and sharing but over time I began to follow other blogs and now I have small network of followers that comment on posts. It's nice to have the feedback and to know that I am not alone in my thoughts and challenges as we journey on.

Our Blog Living With Autism:

<http://chabott.blogspot.com/> or feel free to email me if you have questions about getting started: [chabott@hotmail.com](mailto:chabott@hotmail.com)

### **Share your story with other families and new EI staff through Digital Stories!**

Digital stories are condensed 3—5 minute videos made up of photos, music and your voice sharing an experience.

Currently used in trainings –  
Early Intervention Training Center (EITC) orientation for new EI staff and for the EIPLP

Your experiences with EI in the following areas are important to us:

- IFSP development
- Family-professional partnerships
- Having providers come into your home and community settings
- Positive transitions out of EI

If you have a great story or idea for a story you would like to share and would like to participate in this opportunity please contact:

**Faith Bombardier at 1-877-353-4757**

*El liderazgo de padres es para todos:*

## ¿Por qué un blog?

Por Jennifer Chabott, representante de padres de la Región Oeste en el Consejo Coordinador entre Agencias

**C**uando empecé, no sabía mucho sobre los blogs. Simplemente me metí en el asunto y fui resolviendo las cosas sobre la marcha. Usted también puede hacerlo. ¡De verdad! Pero primero debe preguntarse, ¿por qué? Desde que me pidieron que compartiera mi experiencia con los blogs, he pensado mucho en esto. El "cómo se hace", la forma de llevarlo a cabo, viene luego. Pero creo que el "por qué" es el factor más importante cuando se decide iniciar un blog.

**¿Por qué lo hago?** Para mí comenzó a los seis meses de haber recibido el diagnóstico de mi hijo. Sentía que cargaba demasiado en la mente: cosas que necesitaba ordenar, otras que quería recordar y algunas que quería compartir. Mi primer entrada en el blog:

### Han pasado cero a seis meses. . . .

Hace seis meses nos informaron por primera que era posible que Christopher tuviera un trastorno generalizado del desarrollo del espectro autista. Desde ese entonces hemos aprendido, hecho y logrado mucho, pero aún queda mucho más por hacer. Mi propósito con este blog es llevar un registro del duro esfuerzo que hacen tantos niños como Christopher. Y espero que los miembros del equipo que trabaje con él, ahora y en el futuro, encuentren que es una herramienta útil. Este blog también puede servir para que la familia y los amigos visiten y se mantengan al tanto de todas las cosas buenas que le están sucediendo a Christopher.

Gracias por visitar. Vuelvan pronto y a menudo. Y por favor recuerden que éste es mi primer blog real. Estoy aprendiendo sobre la marcha.

**¿Tiene usted un "por qué"?** Entonces ahora tiene que fijarse algunas metas. **Por ejemplo, ¿con qué frecuencia publicar?** Cuando estaba aprendiendo, para mí fue importante publicar por lo menos un evento, pensamiento, foto o lo que fuera para tomar impulso. Algunas entradas eran cortas, otras largas, algunas con fotos, algunas incluso con errores de ortografía. No tiene que estar perfecto, lo importante es perseverar. Al cabo de un mes tuve la satisfacción de poder releer y recordar instantáneamente en todo momento 32 entradas diferentes. El blog se convirtió en un diario o álbum en línea. Y me enganché. Empecé a compartir la dirección del sitio con amigos y familiares para que pudieran seguir nuestras novedades.

**¿Qué hora del día será la más conveniente para**

**usted?** Escríbalo en su agenda diaria. Para mí el horario ideal es después de que los niños se hayan ido a la cama o antes de que se despierten. ¿Le interesaría comenzar su propio blog? Hay muchos sitios para blogs. Blogger me resultó fácil de usar y es gratuito. Busque en Google el término "Blogspot" y lo dirigirá a sus primeros pasos en el mundo de los blogs.

Llevo un año y medio blogueando y puedo garantizarles que no hay nada que temer. Recuerde además que el blog es de usted, así que si no quiere compartir demasiada información personal, no lo haga. Algunos bloggers se refirieron a sus hijos sólo por apodos. Hay reglas obvias, como nunca publicar la dirección, el número de teléfono y cosas por el estilo. Además, puede ajustar la configuración como usted quiera, por ejemplo, dando acceso sólo a personas que usted invita. Yo tengo varios blogs. Algunos son públicos y otros, que tienen pensamientos más personales que sólo quiero compartir con amigos de confianza, son por invitación. Usted decide. Además de permitirme descargarme e intercambiar información, con el tiempo empecé a seguir los blogs de otros y ahora tengo pequeña red de seguidores que comentan cuando publico algo nuevo. Es bueno oír otras opiniones y saber que no estoy solo ante mis pensamientos y desafíos.

Nuestro blog, Viviendo con Autismo:

<http://chabott.blogspot.com/> No dude en escribirme por correo electrónico si tiene preguntas sobre cómo comenzar su propio blog: [chabott@hotmail.com](mailto:chabott@hotmail.com)



## Celebrating 20 years of Parent Leadership!

**EIPLP wants to hear from you! Please  
send us a sentence or two of what you  
learned from the PLP  
or email us then & now photos...  
...we'd love to hear from you!  
[eiplp@yahoo.com](mailto:eiplp@yahoo.com)**

**We will be collecting your stories  
for the coming year in honor  
of the Project's Birthday.**

## Thank You!

The EIPLP would like to extend their gratitude to:

**Thom Child & Family Services  
Criterion Child Enrichment  
Cape Cod Child Development**

**For their support and contribution to the EIPLP MEIC Conference Parent Dinner, celebrating 20 years of Parent Leadership**

## Family TIES of Massachusetts Update

Spring has finally arrived, and our thoughts race away from winter's cold temperatures and mountains of snow. Now, it's time to think of being outdoors, planting gardens, and enjoying playgrounds and other recreational opportunities. You may wonder, what are the options for our family and our child with special needs?

Remember, our children are CHILDREN FIRST. Fun is waiting just around the corner! Ask your child what might be fun, and look for cues when those eyebrows jump – is there some interest in playing in water (not necessarily swimming), squishing sand through toes while building sand castles, playing with balls of all sizes, horseback riding? These are activities that interest most children. The challenge for parents of children with special needs is to make time for and find opportunities to have fun.

When thinking about recreation, consider your child's interests, strengths, motivators, and local opportunities. Consider if an activity makes sense for your child, what benefits might come from participating, do you need to research some aspect of the activity, what challenges might you have to address, and most important: who wants this more, my child or me?

As you consider options, remember to check in with the Massachusetts Department of Conservation and Recreation. Its "Universal Access Program" offers inclusive activities all around the state. Check their website: [www.mass.gov/dcr](http://www.mass.gov/dcr) and key in the this term to learn more about year-round outdoor activities for everyone. Make play a priority for your family!

Family TIES staff can help families to identify community-based opportunities for recreation. Our website also includes a Topic Sheet on this subject; check the home page for the link. Feel free to call our toll-free line, 800-905-TIES (8437) or visit our website to find direct contact information for your Regional Coordinator: [www.massfamilyties.org](http://www.massfamilyties.org).

## WORKSHOPS & CONFERENCES

### Early Intervention Training Center (EITC)

**Building a Community**—This workshop, offered by the Early Intervention Training Center, provides an overview of the Massachusetts Early Intervention system. The orientation series is presented by a team of three facilitators, including EITC staff or consultant, a parent, and DPH staff. Parents are welcome to attend. For more information, visit [www.eitrainingcenter.org](http://www.eitrainingcenter.org).

**Federation for Children with Special Needs Trainings**  
[www.fcsn.org](http://www.fcsn.org)  
800-331-0688

**Turning Three**—This workshop, presented by the Federation for Children with Special Needs, highlights the difference between Early Intervention and publicly funded pre-school for children with disabilities. Discussion includes eligibility, the Team process for decision making and parents' role in the transition process. This workshop is held at various locations throughout the State. Contact the Federation for Children with Special Needs for more information.

**Basic Rights**—This workshop provides families with an introduction to their rights and responsibilities under state and federal special education laws. For more information about dates and locations, contact the Federation for Children with Special Needs.

Family TIES of Massachusetts is a parent-led network for families of children with special needs. We recognize that parents are an importance source of knowledge and strength to other parents. Our staff provides information and referral services, facilitates emotional support through our Parent-to-Parent Program, and offers free trainings. To reach us for any reason, please call our toll-free line or visit our website for staff contacts: 800-905-TIES (8437) or [www.massfamilyties.org](http://www.massfamilyties.org).

## Universal Design Continued

Broadly, UD is apparent in our day-to-day lives at a physical level...wider doors, flat entrances, levered door handles for ease of opening, closed captioning, etc.

A great example are curb cuts...while they were initially created for wheelchairs, parents with strollers, kids on skateboards, scooters and roller skates, and delivery persons use curb cuts more frequently.

Universal Design is also seen in educational settings. UD adds a dimension to the learning environment that enhances the learning experience for all students, not just those with special needs. In the classroom, UD can be as simple as reading the test questions aloud or increasing the font size on classroom materials and as complex as computer-based



learning programs. It encompasses the needs of all children at all levels – including physical, learning styles and abilities.

Design for All (DfA) is a term that is used in designing products, services and systems for all without having to make adaptations for those who may need them making the use of them barrier free. Some examples of DfA are flexible straws, automatic doors, Velcro and electric toothbrushes...

For more information about Universal Design check out these websites:

[www.udlcenter.org](http://www.udlcenter.org)

[www.adaptenv.org](http://www.adaptenv.org)

## Federation for Children with Special Needs Update

On March 12, 2011, the Federation for Children with Special Needs hosted their annual Visions of Community conference at the Boston World Trade Center. Keynote speakers **Marianne Leone** an actor, screenwriter, essayist and author of *Knowing Jesse - A Mother's Story of Grief, Grace, and Everyday Bliss* and **Dr. Mitchell D. Chester**, Commissioner, Massachusetts Department of Elementary and Secondary Education, captured the audience with their words of wisdom, compassion and insight.

Dr. William Henderson, for many years the principal of the Patrick O'Hearn School in Boston, where he created an institution that welcomed children of all abilities and fostered inclusion. Upon his retirement the school was renamed The Dr. William Henderson Inclusion Elementary School in his honor. along with Rich Robinson, Executive Director of the Federation, presented the **2011 Community Partnership Awards**. This recognition celebrated the contributions and commitment of: Bedel A. Omar, founder of the Somalia Development Center in Springfield; Carrie McGee, founder of Whole Children; Gail Steele, Director of Theater

at the Mount; Garret Colson, Advocate; Tere Ramos, Parent Leader; and, Christopher Gieling, Inclusive Special Education Teacher.

The assortment of workshops offered at this conference was outstanding. The Parent Leadership Project was pleased to present the Family Involvement in the 21st Century: Utilizing Technology workshop—also being presented at the MEIC conference on May 4.



*The Federation is a center for parents and parent organizations to work together on behalf of children with special needs and their families. Organized in 1975 as a coalition of parent groups representing children with a variety of disabilities, the Federation offers workshops and training, advocacy and resources to parents of children with special needs and the professionals who serve them.*

What will you be up to this summer?

...email us at [eiplp@yahoo.com](mailto:eiplp@yahoo.com)

...we'd love to hear from you!

### Parent Perspective Newsletter Survey

Do you find this newsletter informative?

Would you like to see format changes? Please

**complete our survey** by visiting

[www.eiplp.org/perspective.html](http://www.eiplp.org/perspective.html)

**Spotlight on DPH**

**The Pediatric Palliative Care Network (PPCN)**

By Jennifer Bates, Director of Pediatric Palliative Care Program



**T**he Pediatric Palliative Care Network (PPCN) is a state-funded program administered by the MA Department of Public Health, Children & Youth with Special Health Care Needs. The PPCN serves the unmet physical, emotional, social and spiritual needs of children with life-limiting illnesses in Massachusetts.

Families caring for children with life-limiting illnesses face many difficult challenges. The goal of the Pediatric Palliative Care Network is to improve the quality of life of the entire family through its support and services.

*Parents receiving services said: "It is so helpful to know there is a nurse to call 24/7" and "To have a nurse make a home visit can be helpful especially in the winter when the weather is bad."*

The DPH contracts with a statewide network of 11 hospices, skilled in all aspects of pediatric palliative care. Palliative care services include but are not limited to: pain and symptom management; assessment and case management; spiritual care; social services and counseling for the patient and other family members such as siblings

who are well; volunteer support; complementary therapies; respite care; emergency services; and bereavement care for family members in the event of death.

In order for a child to receive palliative care, a doctor must diagnose that the child has a life-limiting illness and the family must reside Massachusetts. The PPCN cares for families beginning in the prenatal period (when a diagnosis has been made during pregnancy) through the 19<sup>th</sup> birthday. Unlike hospice care, palliative care is not prognosis dependent. In fact, many children with life-limiting illnesses live a long time.

Anyone can make a referral to PPCN: family members, physicians, or other healthcare professionals. The services of the Pediatric Palliative Care Network are provided at no cost to eligible children and their families, providing these services are not already covered by the child's health insurance or available from any other sources.

**To learn more about The Pediatric Palliative Care Network, contact:**

DPH Community Support Line at 1-800-882-1435.

Interpreter services are available.

TTY (617)624-5992 [www.mass.gov/ppcn](http://www.mass.gov/ppcn)

A	R	C	C	Z	U	E	I	L	P	L	S	Q
F	C	Q	U	S	R	O	D	T	Q	L	D	A
E	A	D	N	I	Q	O	E	E	P	B	Z	X
R	Y	G	N	N	M	Z	A	O	L	D	S	I
P	Q	A	E	F	A	V	F	M	P	C	P	F
A	P	W	U	S	D	E	W	H	P	L	E	S
S	O	D	D	X	R	O	Y	R	U	E	D	P
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G	K	A	H	H	I	T	I	W	C	A	P	E
M	E	I	R	K	M	N	O	Y	K	C	H	A

**ACROYNMS DEMYSTIFIED...**

Try to find these commonly used acronyms.

**ECC** - Department of Early Education & Care

**PE** - Physical Education

**NCLB** - No Child Left Behind

**CTF** - Children's Trust Fund

**HMO** - Health Maintenance Organization

**LD** - Learning Disability

**NICU** - Neonatal Intensive Care Unit

**PAC** - Parent Advisory Council

**SPAN** - Special Needs Advocacy Network

**SPED** - Special Education

# THE PARENT LEADERSHIP PROJECT

The Parent Leadership Project was created to support parents whose children receive Early Intervention services. The Project's main goal is to promote lifetime advocacy, leadership skills and the development of an informed parent constituency, which will encourage Early Intervention services to be increasingly family-centered. The Project is a parent driven endeavor, which continually seeks family involvement and input regarding the needs of families enrolled in Early Intervention and is implemented by parents whose own children have received EI services. The Project staff consists of a Statewide Director, a Communications Coordinator, an EI Program Focused Monitoring Parent Coordinator, Education Coordinator and Collaboration & Outreach Coordinator. Please feel free to contact any of them with your thoughts, suggestions, and concerns.

## **EI Parent Leadership Project Team**

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Find us on Facebook: *Early Intervention Parent Leadership Project*



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[eiplp@yahoo.com](mailto:eiplp@yahoo.com). Thanks!



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Northampton MA 01060

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**NEXT DEADLINE:** We welcome your input and suggestions for resources and articles. The next deadline is **June 10, 2011**. Please call our toll-free number (877) 353-4757 or email the newsletter editor at [kris.levine@state.ma.us](mailto:kris.levine@state.ma.us).

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