



## 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)

**Early Intervention Information and Resources**

**February/March 2009**

*Planting the Seeds: Growing Parent Leaders*

**Working for Change:  
Massachusetts Parents Travel to Washington D.C.**

Massachusetts families are involved at all levels of the Early Intervention system, from local involvement with their own EI programs to participating in national-level policy making. Kimber O'Connell and Joanne Williams, co-chairs of the Massachusetts ICC (Interagency Coordinating Council), along with Jennifer DerBogossian, ICC Regional Parent Representative, traveled to Washington DC to join parents and representatives from every state, island and territory of the United States at the National Early Childhood Conference.

Each year, the Federal Office of Special Education Programs (OSEP) in collaboration with the National Early Childhood Technical Assistance Center (NECTAC) hosts a National Early Childhood Conference. This year's conference, "Building Partnerships for Effective Change", was held Dec. 7-10th at the Renaissance Washington DC Hotel. Kimber O'Connell, ICC Co-Chair, says, "The greatest benefit of attending is getting to meet other parents from across the nation to compare notes on how Early Intervention works. We get to see what parents can do to support Early Intervention and how to effect change through legislation."

The conference's information sessions encourage family members and professionals to share the latest research on Early Inter-



*Joanne Williams, Margaret Mahoney, Kimber O'Connell and Jennifer DerBogossian at the OSEP Conference.*

vention and to network across states. For parents, this experience can also give an appreciation for the "behind the scenes" work that goes on regarding policies and decision-making at the federal level.

Despite the economic challenges that face the state and federal governments, Kimber says the tone at OSEP was one of optimism. "There was a lot of energy, and it seems everyone is hopeful."

**Opportunity Knocks**

### **Visions of Community 2009**



On Saturday, March 14, the Federation for Children with Special Needs will host the 2009 *Visions of Community* Conference at the Seaport World Trade Center in Boston. This statewide conference offers families and professionals the opportunity to network, gather information and share resources. The conference features more than 30 session choices, with topics including health care for children with special needs, special education, literacy, autism and many more. Many of the sessions are translated into Portuguese, Spanish and Cantonese.

Registration for the full-day conference is \$70 if registered by the early-bird deadline of February 13. The registration fee includes a continental breakfast and lunch. A limited

number of scholarships are available for families. Parents can call 617-236-7210 x198 or email [conf2009@fcsn.org](mailto:conf2009@fcsn.org) for more information about scholarship opportunities. Child care is available for children ages 3-14.

The Federation has made arrangements for free round-trip bus transportation to and from the Seaport World Trade Center from various sites across the state. Transportation will be available from Holyoke, Lawrence, Worcester and Hyannis and is available on a first-come, first-served basis. Families MUST pre-register for the transportation by calling 1-800-331-0688 x196.

For more information or to register for the conference, visit the Federation for Children with Special Needs website at [www.fcsn.org](http://www.fcsn.org) or call 1-800-331-0688.

## NCSEAM Family Survey Information



Families, results are in for our first full year of implementation of the NCSEAM Family Survey. The Department of Public Health would like to thank all of you who completed and returned a Family Survey. Getting your input on the three important questions is the best way for DPH as Lead Agency for Part C Early Intervention services to demonstrate that this program really works. The Family Survey measures how well:

- Early Intervention services help families know their rights
- Early Intervention services help families effectively communicate their children's needs
- Early Intervention services help families help their children develop and learn

2239 Family Surveys were returned from December 15, 2007 through December 1, 2008. This was a large enough number to ensure statistical validity, and the results indicated improvement over last year. Your responses show that Early Intervention services helped you to:

Know your rights - **77.6%**

Effectively communicate your children's needs - **74.6%**

Help your child develop and learn - **85.6%**

Individual reports will be sent to EI programs so that they can use the results to evaluate their services and find ways to continue to make improvements.

### Family Survey Frequently Asked Questions

1. I returned my Survey, am I done now?

*For 2008, yes and we thank you. If your child is still enrolled in EI in 2009, you'll be receiving another Survey. Please keep up the good work!*

2. I answered the Survey questions, but there are other things I'd like to say about EI services. How can I let DPH and my program know what's on my mind?

*You can share additional information, concerns and ideas directly with your Service Coordinator or Program Director. Families can also call the EI Parent Leadership Project toll-free line at 1-877-353-4757. A staff member, who is the parent of a child who received EI services, will be glad to get your input and can direct you on if you have concerns that need to be addressed.*

## Información Sobre La Encuesta Familiar NCSEAM



Familias: después de cumplirse nuestro primer año completo de llevar a cabo la encuesta familiar del Centro Nacional de Supervisión de la Educación Especial (*National Center for Special Education Accountability Monitoring, NCSEAM*), han llegado

los resultados. El Departamento de Salud Pública desea agradecer a todos los que completaron y enviaron una encuesta familiar. Para el Departamento de Salud Pública, como agencia principal de la Parte C de los servicios de Intervención Temprana, las respuestas de ustedes a las tres importantes preguntas de la encuesta son la mejor manera de demostrar que este programa realmente funciona. La encuesta familiar mide cuán bien los servicios de Intervención Temprana ayudan a las familias a:

- Conocer sus derechos
- Comunicar eficazmente las necesidades de sus niños
- Promover el desarrollo de sus niños y ayudarles a aprender

Entre el 15 de diciembre de 2007 y el 1 de diciembre de 2008 se recibieron **2239** encuestas familiares. Este número fue suficientemente grande como para asegurar la validez estadística de la encuesta, y los resultados indican que se lograron mejoras durante el último año. Sus respuestas muestran que los servicios Intervención Temprana les ayudaron a:

Conocer sus derechos: **77,6 %**

Comunicar eficazmente las necesidades de sus niños: **74,6 %**

Promover el desarrollo y el aprendizaje de sus niños: **85,6 %**  
Los informes individuales se enviarán a los programas de IT con el fin de que puedan usar los resultados para evaluar sus servicios y encontrar maneras de seguir mejorando.

### Preguntas comunes sobre la encuesta familiar

1. Ya envié mi encuesta, ¿tengo que hacer algo más?

*Para 2008 eso es todo, y le damos las gracias. Si su niño seguirá inscrito en el programa de Intervención Temprana durante 2009, usted recibirá otra encuesta. ¡Buen trabajo! Siga así.*

2. Contesté las preguntas de la encuesta, pero me gustaría comentar otras cosas sobre los servicios de Intervención Temprana. ¿Cómo puedo decirles lo que pienso al Departamento de Salud Pública y a mi programa de IT?

*Puede comunicar información adicional, inquietudes y sugerencias hablando directamente con su coordinador de servicios o con el director de su programa. Las familias también pueden llamar sin cargo al número telefónico del Proyecto Padres Líderes de IT: 1-877-353-4757. Un miembro del personal, formado por padres o madres de niños que han recibido servicios de Intervención Temprana, con gusto escuchará sus comentarios y lo(a) conectará con los recursos apropiados según sea necesario.*

**Parent Leaders in the Community:****MEIC Conference:  
Food, Fun and Families!**

*What does Parent Leadership mean? How can parents and families take on leadership roles in their Early Intervention programs and in their own communities? What are some of the ways that parents and families build connections and grow the skills that support them to become leaders? In this and following issues of the newsletter, we'll be exploring these questions and highlighting the process of grassroots leadership development.*

Each year, the Massachusetts Early Intervention Consortium (MEIC) hosts a statewide conference for families and Early Intervention providers to come together for learning and networking. This year's MEIC Conference will be held on Wednesday, May 6 and Thursday, May 7 at the Best Western Royal Plaza Hotel in Marlboro and will mark the 30<sup>th</sup> year of the event.

Through generous funding from the Department of Public Health, Lead Agency for Part C, the Early Intervention Parent Leadership Project sponsors one Parent Contact from each EI program across the state to attend this conference. The funding covers the cost of the Parent Contacts' registration fee and overnight stay at the hotel (double occupancy). Continental breakfast and lunches are included in the registration fee. On Wednesday evening, the Parent Leadership Project hosts a Parent Networking Dinner, an opportunity for the families attending the conference to share ideas and learn more about parent leadership.

Jessica DiMario, the mother of a child enrolled in EI, attended last year's MEIC Conference as the Parent Contact for the Professional Center for Child Development EI Program. Like many families, Jessica faced some obstacles to attending the two-day conference. "I was not going to attend at first, because I didn't think that I would have child care. I was worried about leaving my son, Adam, for the night because he had breathing issues in the past and had trips to the hospital in an ambulance," Jessica said. With some support, Jessica was able to make a plan for caring for her son during the conference. She was excited about attending because "it was an opportunity for me to learn more about Early Intervention, to learn from other parents and most important of all, how I can help my family and my child."

The two days of the MEIC Conference are filled with opportunities for learning and networking. Workshop topics include information on early childhood development, transitioning from Early Intervention, and developing advocacy skills. Sessions are co-presented by parents and professionals. Jessica was able to share her experience of having a child with special needs during a session on feeding and nutrition.

Partnering with her son's nutritionist from the EI program, Jessica talked about concerns she had with her son's feeding: "I really loved being able to talk about and share all of Adam's feeding issues and our struggle to get him to eat." For Jessica, this partnership was her favorite part of the conference.

In addition to the informal networking at lunches, between sessions and in the Family Hospitality Room, Wednesday evening's Parent Networking Dinner provides families with a chance to relax, enjoy a good meal, and share their stories with each other. Jessica says, "The parent dinner was great! Everyone talked about their kids and the challenges that they have encountered and how they made it through." The Parent Dinner also gave her a chance to learn more about the Early Intervention Parent Leadership Project and ways to become more involved in the EI system.

This year's conference promises to be an interesting and exciting two days, and Jessica encourages families of children enrolled in EI to consider attending. "The conference was a great learning experience with a lot of information about state programs that I never knew existed. I really look forward to going again this year!"

In February, the EI Parent Leadership Project will be sending out information about the 2009 MEIC Conference to Parent Contacts. If you are interested in becoming a Parent Contact or have other questions about the MEIC Conference, please contact the Parent Leadership Project at 1-877-353-4757 or by email at [eiplp@yahoo.com](mailto:eiplp@yahoo.com). More information about the conference will be available soon on the Project website [www.eiplp.org](http://www.eiplp.org).



**SAVE THE DATE!**

30th Annual MEIC Conference  
May 6&7, 2009  
Best Western Royal Plaza Hotel, Marlboro

Look for more information on the Project website at  
[www.eiplp.org](http://www.eiplp.org)

## Padres Líderes en la Comunidad

### Conferencia MEIC: Familias, Comida y Diversión

***¿Que significa ser un padre líder? ¿Cómo pueden asumir papeles de liderazgo los padres y las familias en sus programas de Intervención Temprana y en sus propias comunidades? ¿Cómo pueden relacionarse y desarrollar habilidades que los ayuden a convertirse en líderes? En este número del boletín y en los próximos exploraremos estos temas y examinaremos el proceso de desarrollo de líderes desde las bases.***

Cada año, el Consorcio de Intervención Temprana de Massachusetts (*Massachusetts Early Intervention Consortium* o MEIC) patrocina una conferencia estatal para que las familias y los proveedores de Intervención Temprana (IT) se reúnan para aprender y hacer contactos. La conferencia de MEIC de este año tendrá lugar el miércoles 6 y el jueves 7 de mayo en el Best Western Royal Plaza Hotel de Marlboro, y marcará el 30° aniversario de este evento.

Mediante una generosa subvención del Departamento de Salud Pública, Agencia Principal de la Parte C, el Proyecto Padres Líderes del programa de Intervención Temprana auspicia la participación de un padre de contacto de cada programa de IT para que asista a la conferencia. El subsidio cubre el costo de la tarifa de inscripción del padre de contacto y su alojamiento en el hotel por una noche en habitación doble. La tarifa de inscripción cubre desayuno continental y almuerzo. El miércoles por la noche, el Proyecto Padres Líderes organiza una cena para que los padres hagan contactos y para dar a las familias la oportunidad de compartir ideas y aprender más sobre el liderazgo de los padres.

Jessica DiMario, madre de un niño inscrito en el programa de IT, asistió a la conferencia de MEIC del año pasado como padre de contacto del Centro Profesional de Desarrollo Infantil (*Professional Center for Child Development*), uno de los programas de IT. Como muchas familias, Jessica enfrentaba obstáculos para asistir a la conferencia de dos días. “Al principio, pensé que no iba a poder ir, porque no sabía que ofrecían servicios de guardería infantil. La idea de dejar a mi hijo Adam solo durante una noche me intranquilizaba”, cuenta Jessica, “porque había tenido dificultades respiratorias y lo habían tenido que transportar en ambulancia al hospital”. Con un poco de apoyo, Jessica pudo hacer arreglos para el cuidado de su hijo durante la conferencia. La posibilidad de asistir la entusiasmaba mucho “porque era una gran oportunidad para informarme mejor sobre los servicios de Intervención Temprana, conocer las experiencias de otros padres y, lo que es más importante, aprender cómo puedo ayudar a mi familia y a mi hijo”.

Durante los dos días de la conferencia hay muchas oportunidades para aprender y hacer contactos. Los temas de los talleres incluyen información sobre el desarrollo durante la primera infancia, la transición después de la Intervención Temprana, y

cómo desarrollar la capacidad para abogar a favor de nuestros hijos. Las sesiones son presentadas conjuntamente por padres y profesionales. Jessica pudo compartir su experiencia de tener un hijo con necesidades especiales en una sesión sobre alimentación y nutrición. Con la nutricionista del programa de IT que atiende a su niño, Jessica habló sobre sus preocupaciones de alimentación: “Me encantó tener la posibilidad de hablar sobre las dificultades de alimentación de Adam y lo difícil que es lograr que coma”. Para Jessica, la posibilidad de ofrecer esta presentación conjunta fue la parte favorita de la conferencia.

Además de la posibilidad informal de hacer contactos en los almuerzos, entre sesiones y en la Sala de Hospitalidad Familiar, la cena del miércoles a la noche (*Parent Networking Dinner*) permite que las familias se relajen, disfruten de una buena comida y compartan sus historias. Jessica cuenta que para ella, “¡La cena para padres fue fabulosa!” Todos hablaron de sus hijos, las dificultades que enfrentaron y cómo las superaron”. La cena para padres también le dio la oportunidad de aprender más sobre el Proyecto Padres Líderes y cómo participar más en el sistema de Intervención Temprana.

La conferencia de este año promete dos días interesantes y estimulantes, y Jessica alienta a las familias de niños inscritos en Intervención Temprana a que consideren asistir. “La conferencia fue una gran experiencia de aprendizaje, con mucha información sobre programas estatales que yo ni sabía que existían. ¡Me entusiasma mucho la idea de volver a ir este año!”

En febrero, el Proyecto Padres Líderes de IT enviará información sobre la Conferencia de MEIC de 2009 a los padres de contacto. Si está interesado(a) a ser un padre de contacto o tiene otras preguntas sobre la Conferencia de MEIC, por favor comuníquese con el Proyecto Padres Líderes llamando al 1-877-353-4757 o enviando correo electrónico a [eiplp@yahoo.com](mailto:eiplp@yahoo.com). Pronto se anunciará más información sobre la conferencia en el sitio web del Proyecto Padres Líderes: <http://www.eiplp.org/>.



## Opportunity Knocks

### Public Hearing Notice

The Massachusetts Department of Public Health, in cooperation with the Massachusetts Interagency Coordinating Council, will hold a public hearing on the Commonwealth's application for 23rd year funding under Part C of Individuals with Disabilities Education Act (IDEA). Part C of IDEA is the federal law that provides funds to assist states in providing Early Intervention services for infants and toddlers with disabilities.

This hearing is being held for the specific purpose of discussing the Department of Public Health's proposed budget for 23rd year funding under Part C of the Individuals with Disabilities Education Act (IDEA) known in Massachusetts as the Early Intervention Program For Infants and Toddlers with Disabilities.

During the hearing the Department welcomes testimony regarding the proposed budget, eligibility (and possible changes in eligibility based upon funding levels for State Fiscal Year 2010), Transition Policy and any other aspects of the grant.

#### Who Should Testify?

Members of families with young children, professionals who serve young children and families, and officials from any state

agencies with responsibilities for services to children and families are encouraged to speak on the issues.

Written comments may be sent until March 27, 2009 and should be addressed to:

Massachusetts Department of Public Health  
Early Intervention Services  
250 Washington St., 5th Floor  
Boston MA 02108-4619

Attn: Ron Benham, Acting Director, Bureau of Family Health & Nutrition



**Stay Tuned for More Information!**

Updated Information about the  
**Public Hearing,**  
Including date, time and location  
will be available on the  
**EI Parent Leadership Project website**  
[www.eiplp.org](http://www.eiplp.org)  
or by calling 1-877-353-4757

## WORKSHOPS & CONFERENCES

**Building a Community, Part 1**— March 12 at Tewksbury Hospital from 9am to 4pm. This workshop, offered by the Early Intervention Training Center, provides providers and families with an overview of the Massachusetts EI system. For more information or to register, visit the website at [www.eitrainingcenter.org](http://www.eitrainingcenter.org) or contact Eileen McDonal at 508-751-6309.

**Basic Rights** — March 16 at John F. Ryan School Library in Tewksbury from 7-9pm. This training, offered by the Federation for Children with Special Needs, provides families with an introduction to their rights and responsibilities under state and federal special education laws. For more information, please contact the Federation at 1-800-331-0688.

**Community Resources for People with Autism 19th Annual Conference** — April 7 from 8:30am to 3:30pm at The Log Cabin and Meetinghouse in Holyoke. This conference brings together families and professionals to learn how to best support children with autism at home, school and in the community. Registration is required and a limited number of

scholarships are available to families. For more information, visit the website at [www.communityresourcesforautism.org](http://www.communityresourcesforautism.org)

**Turning Three** — April 9 at Dimock Early Intervention Program in Roxbury from 6-8pm. This workshop highlights the differences between Early Intervention and publicly funded preschool for children with disabilities. The parents' role in the transition process is also discussed. For more information, please contact the Federation for Children with Special Needs at 1-800-331-0688.

**SAVE THE DATE! 26th Annual New England Regional Seminar for Children with Visual Impairments and Their Families** — May 2 at Perkins School for the Blind in Watertown. This conference for families of young children (birth to age 7) with visual impairments offers information on a wide variety of topics. More information will be available on the Perkins website at [www.perkins.org](http://www.perkins.org).





## Working Together — Boston Region

Over the fall and early winter, **Boston EI for Children and Families** has run two parent groups using the Incredible Years curriculum. These 12-week sessions, facilitated by Boston EI social workers, are designed to enhance children's social and emotional competence and promote positive parenting.

In October, working with the Street Law Clinic, Boston EI sponsored an Immigration Clinic for Spanish-speaking families in the program. Boston EI also works collaboratively with the Joseph Smith Community Health Center onsite to meet families with young children receiving their care at the health center. This helps to raise awareness of Early Intervention and break down barriers and fears that might prevent families from accessing EI services.

**Harbor Area Early Intervention**, North Suffolk Mental Health Association, has moved to a new state of the art early childhood facility! The new address is 130 Condor Street, East Boston. Phone, fax and email is all unchanged from the prior location. As of December 2008 construction of a new build-out was completed allowing sufficient space for staff, families and program operation. This new space was constructed using a "green" approach, and has lots of natural light, energy efficient systems and furnaces which allow for fresh air to be circulated. The program has also been approved to add 3 infant expansion slots to our Harbor Area Child Care in partnership with DCF (Department of Children and Families) and EEC (Department of Early Education and Care), and will now service 15 children and families through this therapeutic program. The program is excited about being now able to better meet the needs of the catchment and community. The program plans to host an Open House during the Spring of 2009, and will continue fundraising efforts to support the project.

The staff at **Thom Boston Metro Early Intervention Program** were very busy this holiday season. Staff worked closely with the Salvation Army and Cradles to Crayons to deliver toys and household items as well as clothing for families in need. It was wonderful to see the generosity of companies who sponsor families in Boston.

In addition to spreading holiday cheer, Thom Boston Metro EI has begun some innovative groups for children and their caregivers. Our swim group, run by a motor therapist at a local pool, is continuing through the winter months because of popular demand. Parents enjoy playing in the pool with their little ones. It is a fun and different way of providing therapy to children with motor delays. The program has also begun Family Yoga classes for any EI family with a toddler over the age of 18 months. This group will promote relaxation and well being for families that attend.

The ongoing Spanish Parent support group has now transitioned from cake decorating to learning how to knit! This has been hugely popular as a way for Spanish speaking parents to meet

other families and explore their common excitement and challenges with parenting!

In addition, the program continues to run a very well attended community story hour at the Roslindale public library. Two music therapists sing, play the guitar, and read stories to a packed audience of up to 75 adults and children. As the winter runs its course, it is evident that there is a tremendous need for activities in the community suitable for young children. We hope to run similar groups at other area libraries in the future.

**Children's Community Early Intervention Program** has been offering a Family Expressive Arts Group one Saturday a month for the families of children enrolled in the program as well as children in the community. The group reads a children's story together, and then the children participate in expressive arts activities based on a theme inspired by the book, including songs, creative arts projects, movement and sensory play. Parents and children are given the opportunity to play together in a potentially new way, and parents are given suggestions for carrying over expressive arts play at the home. The children are engaged, interested and exposed to new ways of playing and learning, and all participants have left reporting a positive experience. During January, the group will be inspired, by Eric Carle's children's classic, *Brown Bear, Brown Bear What Do You See?*.

In November, **Bay Cove EI** collaborated with the Department of Public Health in filming a training video intended for use in promoting awareness of careers in Early Intervention at various local colleges and Universities. The video will feature two EI staff members, Gretchen Allinson and Anne Coleman as they make home visits and lead toddlers' therapeutic playgroups.

In addition to providing valuable services to children and their families, Bay Cove EI serves as a training site for many interns from a variety of schools and disciplines. This fall the program has provided field placements for graduate students in Speech Language Pathology from Emerson, Expressive Therapies from Lesley University, and Birth to Three from Wheelock, and undergraduates from Brandeis and Salem State, and Boston College. Orientation to Early Intervention is also provided to a large class of undergraduate students from Lesley University, as well as Family Practice and Pediatric Residents from Boston Medical Center.



# 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

Darla Gundler  
800-445-1255 Ext. 1157  
Darla.gundler@state.ma.us

Faith Piaggi  
413-586-7525 Ext. 1119  
Faith.piaggi@state.ma.us

## Contact Us:

Toll-Free: 877-35-EI-PLP  
Email: [eiplp@yahoo.com](mailto:eiplp@yahoo.com)  
On the web: [www.eiplp.org](http://www.eiplp.org)

Brenda Allair  
413-586-7525 Ext. 1162  
Brenda.allair@state.ma.us

Jada Carlson  
978-851-7261 Ext. 4058  
Jada.carlson@state.ma.us



23 Service Center  
Northampton MA 01060

## IN THIS ISSUE

*Resources for Families . . . . . p.6*

*Training Opportunities . . . . . p.5*

*Public Hearing . . . . . p.5*

*Working Together . . . . . p.7*

*Parent Leader Spotlight . . p.3,4*  
*English and Español*

**To receive the *Parent Perspective Newsletter*, a free publication, published six times a year by the Parent Leadership Project, call us toll-free at (877) 353-4757 and ask to be added to the PLP mailing list or email [eiplp@yahoo.com](mailto:eiplp@yahoo.com)**

**NEXT DEADLINE:** We welcome your input and suggestions for resources and articles. The next deadline is **March 13**. Please call our toll-free number (877) 353-4757 or the email the newsletter editor at [Brenda.allair@state.ma.us](mailto:Brenda.allair@state.ma.us).

The *Parent Perspective* newsletter is produced six times a year by the Early Intervention Parent Leadership Project, through funding from the Massachusetts Department of Public Health.

