



The Parent Leadership Project's *Parent Perspective*

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Early Intervention Information and Resources

February 2010

Partnering for Real Results: Parent Leaders in Action

Public Hearings for Early Intervention: Share Your Parent Perspective



The Massachusetts Department of Public Health, in cooperation with the Massachusetts Interagency Coordinating Council (ICC), will hold a Public Hearing on the Commonwealth's 24th Year Part C Application for funding under Part C of the Individuals with Disabilities Education Act (IDEA) Early Intervention Program.

The hearings will be held at the following locations:

February 25, 2010—1:30-3:30pm

Western Region Public Health Office
23 Service Center Rd.
Northampton MA

March 1, 2010—10am-1pm

Department of Public Health
250 Washington St. Public Health Council Room, 2nd Floor
Boston, MA

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 come and speak on the issues.

Written comments may be sent to:
Massachusetts Department of Public Health
Attn: Ron Benham
Early Intervention Services
250 Washington St., 5th Floor
Boston MA 02108-4619

For more information about the Public Hearings, please visit the Early Intervention Parent Leadership Project website at www.eiplp.org or call 1-877-353-4757.

Opportunity Knocks

Visions of Community: 2010



On Saturday, March 13, the Federation for Children with Special Needs will host the 2010 *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 dozens of break-out sessions on topics such as Adaptive Recreation, Transition, Health Care and Special Education. Many of the sessions are presented or interpreted into Portuguese, Spanish and Cantonese.

Registration for the full-day conference is \$75 if registered by the early-bird deadline of February 12. After February 12, conference registration is \$90. Continental breakfast and lunch are included in the conference fee. A limited number of partial scholarships are available for families. Parents can call 617-236-7210 x198 (English), 197 (Portuguese), or 199

(Spanish) or email voc2010@fcsn.org for more information. Child care is available for children ages 3-14 and must be requested at the time of registration.

The Federation has made arrangements for free round-trip bus transportation to and from the Seaport World Trade Center from various locations across the state. Transportation is available on a first-come, first-served basis. Families MUST pre-register for the conference and indicate their interest in transportation on the registration form. A staff member will contact families with further information.

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

NCSEAM Family Survey Information February 2010



Dear Families:

Thank you for continuing to fill out and return the NCSEAM Family Survey. Final numbers and analysis for 2009 show improvement over last year's results.

2270 Surveys, almost 15% of those sent to EI programs were returned.

Here's what you had to say about your EI services:

Families who report that early intervention services helped them know their rights 78.6%

Families who report that early intervention services helped them effectively communicate their children's needs 75.1%

Families who report that early intervention services helped them help their child develop and learn 86.3%

Please Remember - Going forward, Surveys will be distributed to families in a new way! Families whose children have been enrolled in EI for at least **six** months will receive NCSEAM Surveys in **March and October** only. We are counting on you to look for, fill out and return your Surveys and hope that the total number returned will increase under this new method.

As always if you have questions about the Family Survey, you may bring them to your Service Coordinator, Program Director or the Early Intervention Parent Leadership Project.

Family Survey Frequently Asked Questions

1. I'm still not sure why we have to do this. I tell my EI provider what I think about our services.

Just as DPH oversees EI services in Massachusetts, the Federal Office of Special Education Programs (OSEP) oversees DPH. It is a federal requirement that we measure the value of EI services for children and families. This Survey allows DPH to collect family outcomes and report them to OSEP.

2. I keep hearing that word "outcomes". What does it mean?
"Outcomes" are the results children and families experience from participation in Early Intervention. Knowing these results helps DPH, families and EI programs understand if the EI system is meeting children and family needs and how to improve services.

Actualización sobre la encuesta familiar de NCSEAM Febrero de 2010



Estimadas familias:

Gracias por seguir completando y enviando la encuesta familiar del Centro Nacional de Supervisión de la Educación Especial (*National Center for Special Education Accountability Monitoring*,

NCSEAM). Los números finales y el análisis de 2009 muestran mejores resultados que el año anterior. Recibimos **2270** encuestas, casi el 15% de las enviadas a programas de Intervención Temprana (IT).

Esto fue lo que ustedes dijeron sobre sus servicios de IT:

Familias que informan que los servicios de IT les ayudaron a conocer sus derechos
78,6%

Familias que informan que los servicios de IT les ayudaron a

comunicar eficazmente las necesidades de sus niños
75,1%

Familias que informan que los servicios de IT les sirvieron para ayudar a sus niños a desarrollarse y aprender
86,3%

Por favor recuerden que de ahora en adelante las encuestas se distribuirán a las familias de una manera nueva. Las familias con niños inscritos en IT durante al menos **seis** meses recibirán las encuestas de NCSEAM solamente en **marzo y octubre**. Contamos con que ustedes estén pendientes a la llegada de las encuestas, las completen y las envíen de vuelta. Esperamos que con este nuevo método, el número total de encuestas recibidas aumente.

Como siempre, si tienen preguntas sobre la encuesta familiar, pueden dirigirlas a su coordinador de servicios, al director del

(Continued on page 6)

Parent Leaders in the Community:**Growing Parent Leaders:
Finding Your Own Voice****By Jennifer O'Leary, Metrowest ICC Parent Rep**

This past December, I had the honor of representing Massachusetts parents and our State ICC (Interagency Coordinating Council) at the National Early Childhood Conference in Washington, D.C. This conference occurs each year and is sponsored by the Office of Special Education Programs (OSEP) and the National Early Childhood Technical Assistance Center (NECTAC). I had the pleasure of attending this conference with ICC Tri-chair Joanne Williams and ICC Northeast Parent Rep Jenn DerBogossian who both serve on the ICC.

The conference is designed for participants from all states in the Early Intervention system at all levels, such as State Early Intervention Directors and Staff, ICC members (including families and EI Program Directors), and other professionals in the area of Early Intervention.

The Massachusetts Department of Public Health has long been a supporter of parents attending this conference to enhance their understanding of Early Intervention and bring what they learn back to the state to share with the ICC and other families. Each year, there are meetings that all participants attend, as well as smaller meetings that are designed for specific groups. This year, the all day meeting for ICC Representatives was by far the most informational and helpful for me in my role as a Parent Leader on the ICC.

At the all day ICC Session, I participated in two discussion groups. The topics were "Parent Leadership on an ICC" and "How to Work on a State ICC". I came away with a lot of great information that I felt I could begin work on immediately. In these discussions, I learned that Parent Leadership can be achieved in different ways. Some ICC's use more experienced parents as mentors for newer parents on an ICC. This helps the newer parents learn how their ICC works, what their general role is, who the other members of the ICC are, and any "insider" information they might need to know. This enables the new parents on the ICC to participate more quickly and to have an impact on ICC discussions.

I also learned about Nebraska's Family Leadership Team (FLT) model. The FLT is an official subcommittee of the ICC and is made up of all the parent representatives on the ICC. The FLT has advisors to keep them updated on Early Intervention and trends in the state. They meet to discuss the ICC meeting agenda and formulate positions and opinions on those topics that they feel should be expressed at the meeting. The FLT gives the parents an opportunity to talk informally about the issues and determine where parents need more information, such as inner state workings and federal regulations. This idea was brought back to the parents on our State

ICC and we are currently working to implement a Family Leadership Team to increase parent participation on the ICC.

Another great session I attended was just for families. It was the Early Intervention Family Alliance (EIFA) parent meeting. EIFA is a national parent organization dedicated to improving outcomes for infants and toddlers with disabilities and their families. EIFA has advocated at the national level for Early Intervention and drafted a policy letter for President Obama when he was elected president. They also recently supported a national call-in day to the White House to ask for increased funding for Early Intervention in the FY2011 budget.



The two hour meeting was full of parent networking, resource sharing, and discussions among parents from across the country who are passionate about the importance of Early Intervention for our children. EIFA is trying to make its national voice stronger by increasing parent membership. You can go to www.eifamilyalliance.org to get more information or to join on-line. If your child is currently enrolled in Early Intervention, your membership is free! Once you "graduate" from EI, the membership fee is only \$25 per year. Professionals and organizations can also join EIFA. As state funding issues for Early Intervention continue, EIFA will play an important role in advocacy on a national level for increased federal funding.

OSEP was a wonderful experience for me both personally and professionally. What I learned there has really helped me to find my own voice.



Promoción de padres líderes: Cómo encontrar su propia voz

Por Jennifer O'Leary, representante de padres de la región Metrowest en el ICC

Este último mes de diciembre tuve el honor de representar a los padres y el Concejo Coordinador entre Agencias (Interagency Coordinating Council, ICC) de nuestro estado en la conferencia sobre la primera infancia (National Early Childhood Conference) celebrada en Washington, D.C. Esta conferencia se lleva a cabo cada año y es patrocinada por la Oficina de Programas de Educación Especial (Office of Special Education Programs, OSEP) y el Centro Nacional de Asistencia Técnica para la Primera Infancia (National Early Childhood Technical Assistance Center, NECTAC). Tuve el placer de asistir acompañada por Joanne Williams, que preside tres comités del ICC, y Jenn Der-Bogossian, representante de padres de la región noreste en el ICC.

La conferencia está destinada a personas de todo el país que participan en el sistema de Intervención Temprana a todo nivel, como directores y personal de programas estatales, miembros del ICC (desde familias hasta directores) y otros profesionales de IT.

El Departamento de Salud Pública de Massachusetts lleva mucho tiempo promoviendo la participación de los padres en esta conferencia para que comprendan mejor el sistema de Intervención Temprana y traigan de vuelta lo aprendido a nuestro estado y lo compartan con el ICC y las otras familias. Cada año, hay reuniones generales para todos los participantes así como reuniones más pequeñas para grupos específicos. Este año, la reunión de un día entero para representantes del ICC fue por lejos la más informativa y útil para mí por mi función de padre líder en el concejo.

Tuve la oportunidad de participar en dos grupos de conversación. Los temas tratados fueron "El liderazgo de los padres en un ICC" y "Cómo trabajar en un ICC estatal". Aprendí mucha información valiosa que me pareció que podría empezar a poner en práctica inmediatamente. En estas charlas, me di cuenta de que el liderazgo de padres puede lograrse de diferentes maneras. En algunos concejos, los padres con más experiencia sirven de mentores a los padres más novicios. Esto les ayuda a aprender cómo funciona el ICC, cuál es su función general, quiénes son los demás miembros y cualquier otra información interna que necesitan. De esta manera pueden empezar a participar más rápidamente e influir en las deliberaciones.

También me enteré del modelo del Equipo de Liderazgo Familiar (Family Leadership Team, FLT) de Nebraska. Se trata de un subcomité oficial del ICC integrado por todos los padres que actúan como representantes en el mismo. Tienen asesores para mantenerse informados sobre la intervención temprana y las tendencias en el estado. Se reúnen para hablar del orden del día de las reuniones del ICC y formular posiciones y opiniones que

a su juicio deberían expresarse. El FLT permite que los padres hablen informalmente sobre diferentes asuntos y determinen qué necesitan saber, como cuestiones internas a nivel estatal y regulaciones federales. Les hemos presentado esta idea a los padres de nuestro ICC de Massachusetts y ahora estamos en tratativas de iniciar un Equipo de Liderazgo Familiar para aumentar la participación parental en nuestro concejo.

Otra sesión excelente a la que asistí fue una exclusivamente para familias de la Alianza Familiar para la Intervención Temprana (Early Intervention Family Alliance, EIFA). EIFA es una organización nacional de padres dedicada a lograr mejores resultados para los bebés y niños pequeños con discapacidades y sus familias. EIFA ha abogado a favor de la Intervención Temprana a nivel nacional y le redactó una carta de recomendaciones al Presidente Obama cuando fue elegido. Recientemente, también patrocinó una jornada nacional de llamadas telefónicas a la Casa Blanca para pedir más fondos para la Intervención Temprana en el presupuesto del año fiscal 2011.

La reunión de dos horas les dio a estos padres de todo el país, que sienten apasionadamente que la intervención temprana es fundamental para sus niños, la oportunidad de relacionarse, compartir recursos y conversar. EIFA está tratando de fortalecer su voz a nivel nacional aumentando el número de padres miembros. Para inscribirse o para obtener más información visite la página web www.eifamilyalliance.org. Si su niño recibe actualmente servicios de Intervención Temprana, la inscripción es gratuita. Una vez que usted se "gradúa" de IT, la cuota es de sólo \$25 por año. Los profesionales y las organizaciones también pueden unirse a EIFA. Si las dificultades para seguir financiando la Intervención Temprana en nuestro estado continúan, EIFA jugará un papel importante abogando a nivel nacional a favor de más fondos federales.

OSEP fue una experiencia maravillosa para mí personal y profesionalmente. Lo que aprendí realmente me ha ayudado a encontrar mi propia voz.



WORKSHOPS & CONFERENCES

Visions of Community Conference 2010 — Saturday, March 13, 2010 at the Seaport/World Trade Center Boston. This conference features dozens of break-out sessions (many presented in or translated into Spanish, Portuguese and Cantonese) with topical strands and information covering Early Childhood, Special Education, Health Care for Children with Special Needs, Social/Recreational Opportunities and more. For more information, visit the Federation for Children with Special Needs website at www.fcsn.org.

Taking Care of Our Children, Taking Care of Ourselves Conference — May 1 at Perkins School for the Blind in Wauvertown. This year's 27th annual conference is presented by The New England Regional Seminar for Families of Children with Visual Impairments, Ages 0-7. Parents of young children (ages 0-7) with visual impairments or deafblindness and other family members and professionals throughout New England are encouraged to come and participate in this opportunity to share common concerns and to learn from one another. For more information, visit the Perkins website at www.perkins.org.

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. The workshop is held at



various locations throughout the state. For more information, contact the Federation for Children with Special Needs at 1-800-331-0688 or visit www.fcsn.org.

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, visit the Federation for Children with Special Needs website at www.fcsn.org or call 1-800-331-0688.

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 the website at www.eitrainingcenter.org or contact Eileen McDonal at 508-751-6309.

Save the Date!

Massachusetts Early Intervention Consortium (MEIC) Conference — April 13 and 14 at the Best Western Royal Plaza Hotel in Marlboro. This conference brings together Early Intervention staff, early childhood providers and families of children who are receiving Early Intervention services to learn about child development and the Massachusetts EI system. For more information, please contact the Early Intervention Parent Leadership Project at 1-877-353-4757 or visit www.eiplp.org.

MEIC Conference: Parents, Providers, Community



The Massachusetts Early Intervention Consortium (MEIC) is hosting its 31st Annual Conference this spring. On Tuesday, April 13th and Wednesday, April 14th, families, Early Intervention providers and other members of the early childhood community will gather for two days of learning, sharing and networking. The conference will be held at the Best Western Royal Plaza Hotel in Marlborough.

For families of children in Early Intervention, the MEIC conference is an opportunity to learn more about issues in early childhood development, the Massachusetts Early Intervention system, and ways to get involved. The Early Intervention Parent Leadership Project (EIPLP), through generous support

from the Massachusetts Department of Public Health, sponsors one Parent Contact from each EI program to attend this event. The EIPLP also provides a Hospitality Room during the conference, where families can relax, grab a snack, and share their ideas with members of the PLP. On Wednesday evening of the conference, the EIPLP hosts a Parent Networking Dinner. Parents attending the conference can enjoy dinner while sharing their experiences and learning more about opportunities for family involvement.

For more information about the MEIC Conference, contact the Early Intervention Parent Leadership Project at 1-877-353-4757. The conference brochure is also available on the web at www.eiplp.org.

Actualización sobre la encuesta familiar de NCSEAM (cont'd)

(Continued from page 2)

programa o al Proyecto Padres Líderes de Intervención Temprana.

Preguntas comunes sobre la encuesta familiar

Todavía no estoy segura de por qué tenemos que hacer esto. Puedo decirle lo que pienso de los servicios a mi proveedor de IT.

Así como el Departamento de Salud Pública supervisa los servicios de IT en Massachusetts, la Oficina Federal de Programas de Educación Especial (Office of Special Education Programs, OSEP) supervisa al Departamento de Salud Pública. Medir el valor de servicios de IT para los niños y las familias es un requisito federal. Esta encuesta permite que el

Departamento de Salud Pública reúna información sobre los resultados para las familias y los informe a OSEP.

Todo el tiempo oigo la palabra "resultados". ¿Qué significa? *Los "resultados" son los beneficios para los niños y las familias de participar en el programa de Intervención Temprana. Conocer estos resultados ayuda al Departamento de Salud Pública, las familias y los programas a comprender si el sistema de IT está satisfaciendo las necesidades de los niños y las familias, y cómo mejorar los servicios.*

Opportunity Knocks

Reviewers Needed: Massachusetts Early Intervention Operational Standards



The Standards committee of the Inter-agency Coordinating Council (ICC) is currently reviewing the Early Intervention Operational Standards. These operational standards are developed to describe requirements of all community Early Intervention programs in Massachusetts and are used as criteria by the Massachusetts Department of

Public Health, Lead Agency for Early Intervention, for ongoing monitoring, contract performance review and program certification.

The Operational Standards document is reviewed every three years. Feedback is needed from all who are interested in Massachusetts Early Intervention, including parents of children who have been or are currently enrolled in EI, as well as staff. The Standards are divided into 13 sections and all sections

will be reviewed. Please see the EI Parent Leadership Project website at www.eiplp.org to find the schedule of sections to be reviewed and the comment form. Each section of the Standards can be found at <http://www.eiplp.org/icc.html> and can be downloaded and printed individually. If you are unable to download or do not have internet access please call the EI Parent Leadership Project toll-free line at 1-877-353-4757 to receive a hard copy of the sections you are interested in and a review form.

All feedback will be considered when reviewing the document. The review is expected to be completed in September 2010. After the review is complete the committee will then present all changes to the ICC to be voted on as a recommendation for acceptance by the Department of Public Health.

Spotlight on DPH Programs

“SSI Plus....”

An Important Benefit for Eligible Children with Special Health Care Needs

If you have a child with a disability, a chronic illness, or blindness, you know that obtaining accurate, up to date information about public benefit programs can be a challenge.

Many families do not know that they may qualify for a monthly cash benefit from SSI (Supplemental Security Income) along with automatic eligibility for a MassHealth card for a child who meets the criteria for the SSI program. SSI is a federal program of the Social Security Administration (SSA) which was the first government program to provide cash payments for children with disabilities. Eligibility for a child to qualify for SSI is based on the parents’ and child’s income and resources (assets) along with the child meeting certain criteria for a disability determination and specified citizenship or legal immigrant status.

The general definition for a child (birth to 18 years of age) to be considered disabled, according to SSA regulations is:

The child has a medically determinable physical or mental impairment (or combination of impairments) that results in marked and severe functional limitations, and the disability is expected to last at least one year or is expected to result in death.

To begin an SSI application, the parent or guardian can call a local Social Security office, or call the national SSA Teleservice Line at 1-800-772-1213. The date of the telephone interview serves as a “protected filing date” for the application. A “protected filing” means that once a child is determined to be SSI eligible, both the cash benefit and the MassHealth eligibility will begin starting on the first of the month following the date of the call. This is very important since the SSI application proc-

ess may go on for a few months before the final determination is made.

Some Massachusetts families are told about the CommonHealth Program, which is the “buy-in” MassHealth program for individuals with disabilities/chronic illness who are over the income limits for MassHealth Standard.

However, families who think they may be income and resource eligible for SSI should first check whether they qualify for the federal SSI benefit which brings the automatic eligibility for MassHealth along with the monthly SSI check, at no monthly premium cost to the family.

Even if a family’s countable income qualifies them for only a small SSI check (as low as \$1.00), the child will still become automatically eligible for a MassHealth card. If the child is covered by a parent’s employer-sponsored health insurance, then MassHealth will be the second payer for the child’s medical care. The MassHealth agency may also provide premium assistance for the family’s primary health insurance. To find out more about the **MassHealth Standard/CommonHealth Premium Assistance (MS/CPA) Program**, call 1-800-862-4840.

To learn more about SSI eligibility, application process and appeals on SSI Denials, contact the **DPH Community Support Line at 1-800-882-1435** to speak with a **Resource Specialist**. The Community Support Line also provides information on CommonHealth, Kaileigh Mulligan Home Care Program and other public benefits and services for children with disabilities, chronic illness and other special health care needs.



Quote of the Month:

“If your actions inspire others to dream more, learn more, do more and become more, you are a leader.”

John Quincy Adams



What inspires you? Tell us your favorite quote or share a song that’s meaningful to you. We’ll include your favorites in future issues and highlight them at the upcoming MEIC conference! Email us at eiplp@yahoo.com or call 1-877-353-4757.



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.

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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

NEXT DEADLINE: We welcome your input and suggestions for resources and articles. The next deadline is **March 12**. Please call our toll-free number (877) 353-4757 or the email the newsletter editor at 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.

