



The Parent Leadership Project's *Parent Perspective*

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Early Intervention Information and Resources

April/May 2009

Planting the Seeds: Growing Parent Leaders

Parents Share Ideas with DPH

Each year, the Massachusetts Department of Public Health, Lead Agency for Early Intervention in Massachusetts, must submit an application for federal funding under Part C of IDEA (Individuals with Disabilities Education Act). As part of this application process, the Massachusetts DPH holds a Public Hearing to allow families, service providers and professionals serving young children and families to submit testimony about the proposed budget and other topics related to Part C in Massachusetts.

This year, DPH will submit its proposal for 23rd year funding under Part C. On February 27th, the DPH held a Public Hearing in Boston, and nearly 90 family members, EI staff and community providers attended.

Family members from across the state, including parents of children currently enrolled and those who have transitioned from Early Intervention, shared their stories at the hearing and spoke about the many ways in which Early Intervention has provided supports and services for them. Several parents also brought along their young children, helping to “put a face” on Early Intervention.



Parents from Early Intervention programs across the state brought along their infants and toddlers to support Early Intervention at the February Public Hearing.

Opportunity Knocks

**Massachusetts Early Intervention Consortium (MEIC) Conference:
*Celebrating 30 Years***



The Massachusetts Early Intervention Consortium (MEIC) is hosting its 30th Annual Conference this spring. On Wednesday, May 6th and Thursday, May 7th, 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, meet other parents and share their ideas with members of the PLP. On Wednesday evening of the conference, the EIPLP hosts a Parent Networking Dinner where parents at the conference can enjoy dinner while sharing their experiences and learning more about how families can become involved and make a difference in the EI system.

Workshop sessions this year include topics such as: “Legislative Advocacy in Early Intervention”, “PAC (Parent Advisory Council): Sharing Lessons Learned”, “Parents Can Dream New Dreams: The Emotional Impact of Parenting” and “Siblings Have Special Needs Too”. Other topic areas include addressing feeding issues in young children, coping with stress, and the unique needs of the premature infant.

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.

NCSEAM Family Survey Information



Families, these are difficult times for all of us. The Department of Public Health wants to thank you for continuing your support of the NCSEAM Family Survey. With the need to make many tough choices about how to save and spend limited resources, it is more important than ever that we are able to show the value of Early Intervention services for children and families. Please help DPH "make the case" by filling out and returning your Survey!

All 59 Massachusetts EI programs have received individual reports with analysis based on Surveys returned by families enrolled in their programs. If you would like to see what families said about how:

- 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

ask your Program Director to show you the results.

Family Survey Frequently Asked Questions

1. I just found out that my son is no longer eligible for EI. Why should I complete a Family Survey?

Your feedback on your EI experience, whether your child is still enrolled or you are commenting on past services is very helpful both to the individual Program and to the Department of Public Health. We use the information for quality assurance and system improvements.

2. I have two children in Early Intervention. Do I have to fill out two different Family Surveys?

No, please fill out one Survey. You may answer the questions thinking about your EI experience with both of your children.

Información Sobre La Encuesta Familiar NCSEAM



Familias, todos estamos pasando momentos difíciles. El Departamento de Salud Pública desea agradecerles por seguir apoyando la encuesta familiar de NCSEAM. Ante las presiones actuales para tomar medidas difíciles de ahorro y gastar una cantidad limitada de recursos, es más importante que nunca que sigamos mostrando el valor de los servicios de Intervención Temprana para los niños y sus familias. ¡Ayude al Departamento de Salud Pública a documentar esto completando y enviando su encuesta!

Todos los programas de IT han recibido informes individuales con análisis basados en las respuestas a las encuestas de las familias inscritas en sus programas. Si quiere saber lo que otros dijeron sobre la ayuda que han recibido de Intervención Temprana para:

- conocer sus derechos,
- comunicar eficazmente las necesidades de sus niños y
- promover su desarrollo y aprendizaje

pídale al director de su programa que le muestre los resultados.

Preguntas comunes sobre la encuesta familiar

1. Acabo de enterarme que mi hijo ya no reúne los requisitos para IT. ¿Para qué completar una encuesta familiar?

Sus comentarios sobre su experiencia de IT, ya sea si tiene un niño inscrito actualmente o sobre servicios pasados, es muy útil tanto para su programa como para el Departamento de Salud Pública. Usamos esta información para aseguramiento de calidad y mejora de sistemas.

2. Tengo dos niños en Intervención Temprana. ¿Tengo que completar dos encuestas familiares diferentes?

No, por favor complete sólo una encuesta. Puede contestar las preguntas pensando en su experiencia con ambos niños.

Parent Leaders in the Community:**Getting Involved in the System:
Why Parents become Leaders!**

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.

Whether you are new to the Early Intervention system or have been receiving services for awhile, you are likely to have heard the term “family involvement”. The Massachusetts Early Intervention system supports family involvement at all levels, encouraging families to take on leadership roles within their own programs and beyond. But maybe you're thinking, “Why do parents get involved? What can parents really do?” The answers are as different and varied as the families in Early Intervention, but there are many common themes. So, here are our TOP FIVE reasons why families choose to get involved:

1. Families need and want to connect with other families.

For many parents, the journey into Early Intervention may be a confusing one. They may have concerns about their child's development, or they may already have a diagnosis but are just beginning to understand what that means for their child. They may suddenly have a whole new language to learn – IFSP, Service Coordinator, Program Director. Families consistently report that they receive the most information from other families. Finding out about resources and supports is one reason why families choose to get involved in their Early Intervention PAC (Parent Advisory Council) or to become Parent Contacts. Experienced parents can also share what they've learned along their journey, making it possible for other families to more quickly meet their child and family's needs.

2. Families want to learn new skills. Learning to navigate the many systems that provide services for their child, such as Early Intervention, state agencies and the medical system, can be challenging. Attending workshops, conferences or other events can help families understand these systems and develop skills to advocate for young children.

3. Families want to use their skills and talents to say “Thank You” to Early Intervention. When parents share their skills and talents with Early Intervention, they help the programs understand what families can “bring to the table.” Early Intervention supports children and families during the earliest parts of their journey. The skills learned in these early years travel with a family as they move forward, and many parents want to say “Thank you” to the providers and pro-

grams that have helped them to support their child's learning and development. Speaking on behalf of other families in EI is one way to give back.

4. Parents want to effect change and to have their voices heard. Each family in Early Intervention has a story to tell about their experience. The voices of parents help to shape the Early Intervention system, and by getting involved, parents can be sure that their voices are heard. As parents develop leadership skills and move beyond their own EI programs, they create a constituency of families that supports and advocates for Early Intervention services. By creating a large group of families working towards a common goal, families in Early Intervention can help develop the policies that affect children and families to make big things happen!

5. Parents have big dreams, too! Many parents of children in Early Intervention dream about changing or supporting systems to be more responsive to the needs of families. Maybe parents have a great idea for a new activity for their EI program to consider, so they apply for a Hausslein Parent Leadership Award. Perhaps parents want to be sure that federal laws and regulations continue to meet the needs of children in Early Intervention, so they write to and visit their Senators and Representatives in Washington, D.C. Whatever their dreams, parents who get involved in Early Intervention learn that they can “lead the way” for other families.

These are only some of the reasons that parents choose to get involved in the Early Intervention system. We'd love to hear more about what inspired YOU to get involved!

Share your stories of family involvement with the Early Intervention Parent Leadership Project by calling 1-877-353-4757, emailing us at eiplp@yahoo.com, or meeting us at the MEIC conference in May! We'll compile a “Top Ten” list to publish in the next issue of the *Parent Perspective*.



Padres líderes en la comunidad

Participación activa en el sistema: Por qué se convierten los padres en líderes

¿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.

Ya sea si usted es nuevo en la Intervención Temprana (IT) o si ha estado recibiendo servicios por un tiempo, es probable que haya oído hablar de la “participación familiar”. El sistema de Intervención Temprana de Massachusetts apoya la participación familiar a todos los niveles alentando las familias a asumir papeles de liderazgo en sus propios programas y en general. Tal vez se pregunte por qué participan los padres. ¿Qué es lo que realmente pueden hacer?” Las respuestas son tan diferentes y variadas como las familias que reciben Intervención Temprana, pero tienen muchos temas en común. Estas son nuestras CINCO RAZONES PRINCIPALES por las que las familias deciden participar:

1. Las familias necesitan y desean relacionarse con otras familias. Para muchos padres, el comienzo con la Intervención Temprana es confuso. Pueden tener inquietudes sobre el desarrollo de su hijo o tal vez les hayan dado un diagnóstico pero recién están empezando a comprender lo que significa para su niño. De pronto tienen que aprender siglas y nombres nuevos, como IFSP, Coordinador de Servicios o Director del Programa. Las familias informan con gran frecuencia que reciben la mayoría de la información de otras familias. Una de las razones por las que deciden participar en el Consejo Asesor de Padres (PAC) de su programa de Intervención Temprana es averiguar sobre recursos y apoyos. Los padres que ya han hecho este recorrido pueden compartir lo aprendido en el camino y ayudar a otras familias a empezar a responder más rápidamente a las necesidades de su niño y a las propias.

2. Las familias desean aprender habilidades nuevas. Aprender a navegar tantos sistemas que dan servicios a su niño, como Intervención Temprana, agencias estatales y el sistema médico, puede ser un reto. Asistir a talleres, conferencias y otras actividades puede ayudar a las familias a entender estos sistemas y desarrollar habilidades para abogar a favor de los niños pequeños.

3. Las familias desean usar sus habilidades y talentos para darle las gracias a la Intervención Temprana. Al compartir sus habilidades y talentos con los servicios de Intervención Temprana, los padres ayudan a que los programas entiendan las necesidades de sus familias. Intervención Temprana apoya a los niños y sus familias durante la infancia temprana. Las habilidades aprendidas durante estos años siguen acompañando a las familias, y muchos padres ansían dar las gracias a los proveedo-

res y programas que los ayudaron a respaldar el aprendizaje y el desarrollo de sus hijos. Hablar en representación de otras familias del programa es una manera de retribuir.

4. Los padres desean lograr el cambio y que sus voces sean oídas. Cada familia tiene una historia para contar acerca de su experiencia de Intervención Temprana. Las voces de los padres ayudan a moldear el sistema de Intervención Temprana y, al participar, aseguran que sus opiniones se oigan. Al desarrollar la capacidad de liderazgo y trascender sus propios programas de IT, los padres crean una comunidad de familias que apoya y aboga a favor de estos y otros servicios para la primera infancia. Al unir a muchas familias en torno a un objetivo común, los que se han beneficiado de la IT pueden ayudar a desarrollar políticas que ayudan a los niños y las familias a lograr cosas grandes.

5. ¡Los padres tienen sueños grandes también! Muchos padres de niños en IT desean lograr cambios y ayudar a que los sistemas respondan mejor a las necesidades de sus familias. Por ejemplo, tienen una gran idea sobre una posible actividad nueva para su programa y solicitan la distinción “Haussein Parent Leadership Award”. Por ejemplo, quieren asegurar que las leyes y regulaciones federales sigan respondiendo a las necesidades de los niños en IT y escriben y visitan a sus senadores y representantes en Washington, D. C. Sean cuales sean sus sueños, los padres que participan activamente en su sistema de Intervención Temprana se dan cuenta de que pueden facilitarles las cosas a otras familias.

Estas son sólo algunas de las razones que llevan a las familias a participar en su sistema de Intervención Temprana. ¡Nos encantaría saber que lo(a) inspiró a USTED a participar!

¡Comparta sus experiencias de participación familiar con el Proyecto Padres Líderes de IT llamando al 1-877-353-4757, escribiendo a eiplp@yahoo.com o viniendo a la conferencia de MEIC en mayo! Haremos una compilación de diez relatos interesantes para publicar en el próximo número de *Parent Perspective*.



WORKSHOPS & CONFERENCES



Turning Three — April 9 from 6-8pm at Dimock Early Intervention Program. This workshop, presented by the Federation for Children with Special Needs, highlights the differences between Early Intervention and publicly funded preschool for children with disabilities. Discussion includes eligi-

tivity, the Team process for decision making and parents' role in the transition process. For more information, contact the Federation at 1-800-331-0688 or visit www.fcsn.org.

Central MA Family Support Resource Fair, "A Road Map for Success" — April 22 from 10am to 3pm at Worcester Technical High School. This is a drop-in event with over 75 vendor agencies represented. On "Little Kid Lane", representatives will be present from Early Intervention, Child Care Resource and Referral Agencies, WIC and other community agencies providing services to this age group. Information on schools, medical needs and much more will also be available.

Moving Beyond Early Intervention: The Turning Three Transition Conference — May 2 from 9am to 2:30pm at the MassMutual Learning and Conference Center in Chicopee. Experienced parents and professionals will share the essentials of a smooth transition from Early Intervention. Participants will develop an action plan and learn how to help their child say "good-bye" to EI and "hello" to school. For more information, call 413-533-7140 or email criterionheritagepac@yahoo.com

Massachusetts Early Intervention Consortium (MEIC) Conference — May 6 and 7 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.

Navigating the Maze — May 19 from 9am to 3:30pm at the Summit View Meeting House in Holyoke. This day-long conference offers families and professionals the opportunity to learn about public benefits and programs available to support children with special needs. Programs from the Mass. Departments of Public Health, Mental Retardation/Developmental Services, Mental Health and Children & Families will be discussed. Registration is free for families, \$10 for professionals. For more information or to register, please contact Karen Cassidy at 413-783-5500.

Spring Accessible Recreation Fair — June 6 from 10am to 3pm at Artesani Park in Brighton. Sign up for a wide array of summer opportunities, such as kayaking, sailing and hiking in the Boston area and beyond. This event is free and open to the public. Refreshments provided. Pre-register by calling 617-626-1294.

Basic Rights — April 14 from 6-8pm at UCP-Berkshires in Pittsfield. This workshop provides families with an introduction to their rights and responsibilities under state and federal special education laws. Participants will learn how to effectively partner with the school, make decisions and monitor their child's educational progress. For more information or to register, contact the Federation for Children with Special Needs at 1-800-331-0688 or visit their website at www.fcsn.org.

Taking Care of Our Children Taking Care of Ourselves



Presented by:
The New England Regional Seminar for Families of
Children with Visual Impairments, Ages 0-7

Saturday, May 2, 2009
8:15am to 3pm
Perkins School for the Blind
Watertown MA

This is an opportunity for parents of young children with visual impairments or deafblindness and other family members and professionals throughout New England to share common concerns and to learn from one another. Sessions will include information on topics such as communication strategies, social skills and IEP development. Families will also be able to participate in parent-to-parent support groups for families of children with similar visual conditions. Childcare and lunch will be provided.

For more information contact :
Tom Miller at PreschoolProgam@Perkins.org
or visit the Perkins website at
www.perkins.org

Calling All Parents! Involvement in the CEIS Process



The Massachusetts Department of Public Health is inviting parents to participate in the Certification for Early Intervention Specialists (CEIS) Review Process. A group of stakeholders, including EI staff, EI family members and others involved in Early Intervention will meet to discuss how the new competencies recommended in February 2009 can best be met by Early Intervention professionals in their portfolio process.

The review process will begin in June 2009 and is expected to be completed in fall of 2010. Members of the stakeholders group will be required to attend meetings, complete work outside of meetings and provide notification to their constituents about the public comment period.

Families interested in becoming involved in this process need to submit an application. More information about the CEIS process and the application can be found on the PLP website at www.eiplp.org.

Family TIES of Massachusetts: *Together In Enhancing Support*

Family TIES of Massachusetts is a network for families of children with special needs. Our staff is made up of parents of children with a variety of disabilities and chronic conditions. Just like you, we are parents who have faced challenges like a new diagnosis, uncertainty around medical situations, and concerns about our child's development.

When it comes to parent-to-parent support, we offer and receive supportive listening, empathy, and sound advice each and every time we have contact with another parent. These are the core elements of our Parent-to-Parent Program. The Parent-to-Parent Program brings together parents facing similar challenges in raising their children with special needs. Parents can request matches based on a variety of circumstances, including diagnosis or particular issues facing a family. Support Parents

volunteer their time to speak on the phone with other families in need of support. These volunteer parents are provided with training in listening, sharing concerns and offering information and support with respect for confidentiality and cultural and individual differences.

To learn more about Parent-to-Parent, call our toll-free line 800-905-TIES (8437). You can also download the Match Request form from our website and send the completed form to begin the match process.

Visit our website, www.massfamilyties.org, for more information about the Parent-to-Parent Program, and so much more about resources.



Resources for Families

911 Disability Indicator Form



*"This is the 911 operator.
What is your emergency?"*

No one wants to have to call the emergency services number, but accidents, illnesses and other emergencies

can happen, and it's important for families to be prepared. Letting your local emergency services personnel know that you have a young child with special health care needs can support them in providing appropriate response and assistance when you call from your home.

When a call is made to 911 from your home phone, the enhanced 911 system automatically displays your name, address and telephone number. The 911 Disability Indicator Form allows the emergency services dispatcher to also see codes that will identify that you have a person with a special need in your home. These codes help the dispatcher to better communicate with the caller and to provide important information to the first responders (police, fire, ambulance).

Families of children with special health care needs or disabilities are encouraged to fill out a 911 Disability Indicator Form and file it with the Disability Coordinator in their community. The Disability Coordinator is usually located at the local Police or Fire Department. Information designated on the disability indicator form is confidential and will only be seen at the dispatcher's location when an emergency call is placed from your home address.

The 911 Disability Indicator Form is available for download at the Family TIES of Massachusetts website at www.massfamilyties.org under the "Information and Resources" section or by calling Family TIES at 1-800-905-8437. Families can also contact their local Police or Fire Departments to find out if they have copies of the Disability Indicator Forms in their offices.

Look for more information about Emergency Planning in upcoming issues of the Parent Perspective.

Working Together — Central Region

The **Criterion-Middlesex Early Intervention Program** in Framingham held a variety of events for families over the past several months. A “Meet and Greet” for all of the families of children with Down syndrome enrolled in the program was a great success. The children attended with parents, siblings, grandparents and friends! More Meet and Greet events are being planned for this spring. During the winter, the program held its annual “Transition Night” when representatives from schools in the nine towns served by the EI program are invited to meet with EI families and discuss their integrated preschool programs. On May 12, the program will be hosting a “Spring Fling” Open House. This is an opportunity for all of the children and families to have some fun, get to know each other, and enjoy the spring weather!

Kennedy Donovan Center, South Central Early Intervention has moved to a new location. The building includes classrooms for both preschool and early intervention groups. The new accessible outdoor play space was funded by a grant from the CVS Foundation. This past summer, the program started a new collaboration with the Family Resource Center. The Family Resource center is funded through a grant from the Community Partnerships for Children. This collaboration provides a community play space and programming two days a week and several Saturdays a month. The program is free to all families enrolled in EI and those whose children up to age 5 are on an IEP.

This spring, KDC South Central will be participating in a number of community events. The Community Baby Shower, a free area event open to women who are expecting or have new babies, will be held on May 14th at Notre Dame Hall in Southbridge. New moms and moms-to-be will have the opportunity to participate in raffles and workshops and gather resource information. On June 20, KDC will also participate in Community Connections Kite Day in Southbridge MA.

The staff of the **Thom Marlboro Area Early Intervention Program** has been busy developing many innovative groups for infants, toddlers and their families. Our Food Explorers Group emphasizes providing children with positive experiences around food and increasing exposure to different types of food. The 8 week session works on expanding tolerance to new foods leading to an increase in a child’s intake under the supervision of our Occupational Therapy feeding specialists. The Learning, Listening and Language Through Play group is a community integrated group which specializes in working with children with hearing loss. Staff involved in the group include a Teacher of the Deaf, Speech and Language Pathologist and Developmental Specialists. Several other groups, including, Jump Jiggle and Jive for Juniors, Sensory Explorations and Playful Parenting are being planned for the spring.

Thom Marlboro EIP will be participating in the Family Fun and Resource Fair sponsored by the Assabet Valley Family Network and the Community Partnerships for Children. This is a free event for children from birth through 5 years of age in the Metro West area and will be held on Saturday, April 4th at the Kane Elementary School in Marlboro.

The **Central Regional Consultation Program (CRCP)** is planning a busy spring season for families! In April, the CRCP is co-sponsoring “Exploring Positive Guidance”, a dinner and workshop event for families. A second dinner and workshop event, “Emotions Coaching” will be held on May 21 in Auburn and is co-sponsored by the CRCP, Child Care Connection and the Thom Western Regional Consultation Program. The program is also excited to be participating in the Central Mass Family Resource Fair on April 22 at Worcester Technical High School. The “Road Map for Success” will give families the opportunity to learn about the many services and supports available to them in their communities. Information on state resources, the school system, medical needs and assistive devices, along with many others, will be available and representatives from many agencies will be present to speak with family members.

Beginning April 16th, the program will be offering “Songs in Sign Language” in collaboration with Child Care Resources. The workshop is designed to teach popular children’s songs and finger plays in sign language. Participants will learn to sign 12 popular children’s songs and finger plays that can be used with individuals or groups, as well as with varying ages and abilities. The workshop is appropriate for beginners and for those with some sign language experience. For more information about any of these events, contact Joan Rafferty at 978-632-4432.



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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NEXT DEADLINE: We welcome your input and suggestions for resources and articles. The next deadline is **May 15**. Please call our toll-free number (877) 353-4757 or the email the newsletter editor at Brenda.allair@state.ma.us.

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