EIPLP is 25 Years Old!

The Early Intervention Parent Leadership Resources Project was founded in 1991. The first “The Parent Perspective” newsletter was published in the Winter 1992—93. The Early Intervention Parent Leadership Project (EIPLP) proudly celebrates our 25th year supporting parents, caregivers and families in Early Intervention. For fun, see the cover of our first newsletter below.

THE PARENT PERSPECTIVE

Welcome to the first issue of this publication, which should find its way to your mailbox approximately four times a year. The Parent Perspective is directed to parents of children who are or have been in Early Intervention. It came about because parents have the need and the right to know what is going on in the early intervention system statewide. The Department of Public Health’s support of this endeavor is further evidence of its commitment to parents.

We hope that you will reproduce any parts of this which would be useful to other parents in your program and are so bold as to suggest that the entire newsletter be included with your next program or PAC newsletter, if you wish. Please send along to us any comments or suggestions you have as to content or format for The Parent Perspective. It is, as we all are, just getting started and it has lots of room to grow.

PARENT LIAISONS: AN IDEA WHOSE TIME HAS COME

Some of you may have attended the parent meeting at last year’s M.E.I.C. Conference when Denise Izzo, Parent Liaison and Mary Kay Watts, PAC Chair, spoke about Denise’s position and how it has helped parents and the PAC at the New England Memorial Hospital EIP. Robin Foley, Worcester EIP Parent Liaison, share her experiences also. At that time, Robin and Denise were the only parents in paid positions of this type in Massachusetts. For many, the idea of a parent working in this capacity on an EI staff was a new one and parents returned home enthusiastic about the possibilities! This fall there are 10 Parent Liaison positions in programs across the state. Clearly, this is an exciting development for families and programs.

But how did all this begin? A little over two years ago, an alumni parent volunteered to answer the telephone at the Worcester EIP—just until a new secretary could be hired for the program. That parent was Robin Foley. Hearing Robin on the phone, Jimmilee Prouty, the Program Director, noted how positive it was to have new parents first contact with early intervention be through another parent. Soon Robin was working (and being paid for) 10 hours per week. She made intake appointments and talked with families about E.I. She attended staff meetings (especially when policy was being discussed) and became the liaison between the program staff and the PAC. Needless to say, her hours have been increased AND another parent has been hired to share some of the work!

THE PARENT PERSPECTIVE

Issue 1

Winter 1992-93
Ron Benham, Bureau Director, Family Health & Nutrition and Part C Early Intervention Director, reflects on his over 30 years implementing Early Intervention (EI) services in Massachusetts. In recognition of both 30 years of IDEA and 25 years of the EI Parent Leadership Project, we asked Mr. Benham to comment on the changes in the EI system, where he sees the system going and very importantly what family engagement means for the EI system.

What did the system look like when it started? What is different now?
First and foremost, twenty five years ago the system was much smaller in size. In the early '90's the number of children served was roughly 25% of the number we are serving in 2016. Medicaid reimbursement had been in place for several years but private insurance reimbursement was just beginning. We were also still in the planning stages for full implementation of the federal Part C (known then as Part H) section of the Individuals with Disabilities Education Act (IDEA). Fifth year status, at which time the system moved to a quasi-entitlement based upon child eligibility, was still two years away (1993).

Where is it going?
What a great question! In my mind’s eye, I believe the system will continue to grow but not at the rate(s) observed over the past twenty five years. As the system has matured it has certainly been driven to have larger numbers of policies and procedures to follow concurrent with the number of children and families served. Hopefully, the range or continuum of services (early care and education, child care, home visiting, family leave, etc.) for very young children will continue to grow and evolve with services more tailored to children and families’ individual circumstances and needs. I see this as a progressive development with the on-going and evidenced/scientific understanding and importance of early childhood on later life success.

Why is family involvement/engagement so important to you and to the system?
This is both the easiest and hardest of the questions to answer. The easiest part is the simple fact that parent/families are the greatest teachers of their young children. The obvious importance of attachment and bonding in the early years is incredibly critical to other developmental milestones. The love and support of the developing young child during the period of critical brain development is also crucial to later academic success and social/emotional development. The hardest part to answer is how do we collectively continuing supporting families through this process while their lives, and the lives of their children, have become much more challenging in terms of work/life balance. For me, this is a very important systemic challenge.

We are very proud of the fact that in Massachusetts, we have engaged families at many levels to ensure that we are meeting their needs and that policies and programs are meaningful and relevant. EIPLP is a great example of our system’s commitment to include families as partners in all the work we do. We celebrate the growth and development of families, rely on them to share their unique perspectives and enjoy watching them become leaders both within the Early Intervention system and across the multiple systems of care where their children receive services as they get older.

IDEA—Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities.

Infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B.
Dear Families,

Thank you for completing a NCSEAM Family Survey last year. In 2015, 3930 Surveys were received and analyzed giving us a return rate of 35%. This is a great rate as 20% or more is a lot for a survey. In Early Intervention, our families receiving EI services are always looking for ways to help their programs and the EI system...and this rate shows it! We appreciate your commitment to making services better for your own and other children by sharing your experience through the NCSEAM Family Survey.

Information gathered through the Family Survey helps to evaluate how effective Early Intervention services are for families. Your feedback is very important and is used to continuously improve our Massachusetts Early Intervention system. Please keep it up!

In 2015 we learned that:
- 86.2% feel that Early Intervention services helps your family know your rights
- 83.4% say that Early Intervention services helps your family effectively communicate your children’s needs
- 92.4% feel that Early Intervention services helps your family help your children develop and learn

The next Family Survey distribution will be in March 2016. Families whose children have been enrolled in Early Intervention for at least six months and who did not fill out a Survey in October 2015 will receive one from their Service Coordinator. Please remember families complete only one Survey each calendar year. Look for yours and take a few minutes to complete it using a pencil and return it in the self-addressed, stamped envelope provided.

Please continue to share your thoughts and feelings about the impact of Early Intervention services on your child/ren and family.

Family Survey Frequently Asked Questions

1. Do families who don’t speak or read English have to complete this Survey?

   Yes, the second most common language families’ speak at home is Spanish. The Survey is available in Spanish, Portuguese, Vietnamese and Haitian Creole. Service Coordinators give families the Survey in the language in which they are most comfortable.

2. What does DPH do with the information from the Family Survey?

   In a required Annual Performance Report, DPH reports to the Office of Special Education Programs (OSEP) on both child and family outcomes. Outcomes are the results children and families experience from participating in Early Intervention (EI). In Massachusetts we measure family and child Outcomes using different tools. Family Outcomes are measured by the NCSEAM Family Survey.

   In addition, the Department looks for trends and emerging issues that families indicate on their Surveys. We work with EI Programs to improve practices and make changes as needed.

Información sobre la encuesta familiar de NCSEAM

Estimadas familias:

Gracias por completar la encuesta de NCSEAM a las familias el año pasado. En 2015, se recibieron y analizaron 3930 encuestas. La tasa de respuesta fue del 35%. Este es un porcentaje excelente, ya que una tasa de respuesta del 20% a una encuesta se considera un valor muy alto. Las familias que reciben servicios de Intervención Temprana siempre buscan maneras de ayudar a sus programas y al sistema de IT... ¡y esta gran tasa de retorno lo comprueba! Agradecemos el compromiso que han demostrado con la mejora de los servicios para sus hijos y los de otras familias, compartiendo sus experiencias a través de la encuesta de NCSEAM.

La información de la encuesta nos ayuda a evaluar la eficacia de los servicios de Intervención Temprana para las familias. Sus comentarios son muy importantes. Los usamos para mejorar continuamente el sistema de Intervención Temprana de Massachusetts. ¡Por favor sigan participando!
En 2015 aprendimos que:
El **86,2%** de las familias opinan que los servicios de Intervención Temprana las ayudan a conocer sus derechos.
El **83,4%** de las familias dicen que los servicios de Intervención Temprana las ayudan a comunicar eficazmente las necesidades de sus niños.
El **92,4%** de las familias opinan que los servicios de Intervención Temprana las ayudan a promover el desarrollo y el aprendizaje de sus niños.

La próxima encuesta a familias se distribuirá en marzo de 2016. Las familias con niños inscritos al menos hace **seis** meses en un programa de Intervención Temprana que no completaron una encuesta en octubre de 2015, recibirán una de su coordinador de servicios. Por favor recuerden que las familias completan sólo una **encuesta** por año calendario.

Estén atentos a su encuesta y tómense unos minutos para completarla con **lápiz** y enviarla en el sobre provisto con franqueo y dirección de destino.

Por favor continúen compartiendo sus opiniones y sentimientos acerca del impacto de los servicios de Intervención Temprana en sus niños y sus familias.

**Preguntas comunes sobre la encuesta a las familias**

1. ¿Las familias que no hablan ni leen inglés también tienen que completar esta encuesta?
   **Sí. El segundo idioma más común que las familias hablan en el hogar es el español. La encuesta está disponible en español, portugués, vietnamita y haitiano criollo. Los coordinadores de servicios les dan la encuesta a las familias en el idioma en que se sientan más cómodas.**

2. ¿Qué hace el Departamento de Salud Pública con la información de la encuesta a las familias?
   **En un informe de rendimiento anual obligatorio, el Departamento de Salud Pública informa los resultados, tanto para los niños como las familias, a la Oficina de Programas de Educación Especial (Office of Special Education Programs, OSEP). El término “resultados para las familias” se refiere a los beneficios que los niños y las familias obtienen al participar en la Intervención Temprana. En Massachusetts, medimos estos resultados con diferentes herramientas. Los resultados para las familias se miden con la encuesta a las familias de NCSEAM.**

**Información sobre la encuesta familiar de NCSEAM (continuado)**

**Remember March is NCSEAM Family Survey Month! Please ask your Service Coordinator if you are due to complete one. Your feedback makes the Massachusetts EI System better!**

**Massachusetts Early Intervention Consortium (MEIC) Conference Coming in May!**

On Monday, May 9 and Tuesday, May 10th, the Massachusetts Early Intervention Consortium will host its 37th MEIC Conference at a new location and on new days! This traditionally Wednesday and Thursday conference is moving to Monday and Tuesday during the 2nd week of May.

This year’s conference will be held at the Sheraton Framingham Hotel & Conference Center in Framingham, Massachusetts. Loretta LaRoche, speaker, author and international stress management and humor consultant, will kick off the conference with her Keynote, sure to capture attention and engage the audience sharing her humor in reframing stressful situations.

Workshops at this year’s conference include “Let’s Go For a Walk,” “Feeding Picky Eaters: Beyond the Chicken Nugget!,” “Understanding the ‘F’ in the IFSP (presented by your very own EI Parent Leadership Project),” and many more. To view the brochure and learn more, visit [web.percs.info/](http://web.percs.info/).

Are you a Parent Contact for your EI Program? Please reach out to Liz Cox at [liz.cox@state.ma.us](mailto:liz.cox@state.ma.us) or 877-353-4757 about how you can attend the conference this year!
**Parent Perspective**

| This has been the second year that my daughter and I have attended the MEIC Conference. Every year I get excited to attend because I know it’s a two day "respite" for both of us. When I say respite, I mean my daughter gets two days off from her intense therapy program, six times a week. She has an opportunity to meet and play with her fellow Early Intervention buddies as well as splash in the pool. For me it's an overnight in a hotel where we get to enjoy an amazing family dinner with other families whose children are enrolled in EI. There are always heart-filled conversations with other families who have been through the hard road of having a child with special needs. We hear each others stories, give each other advice, wipe away each others tears and give each other hugs of strength and support. It is at the family dinner that we realize how amazing our little ones are and how they each give us the strength to carry them toward their next milestones.

As a parent of a child who has Cerebral Palsy, attending the two days of workshops and presentations, I got many amazing ideas on how to help me meet my daughter's needs that I could then implement at home. Two of the workshops I was able to attend this year, were iPad Apps for children with special needs and Yoga for children with special needs. These two amazing workshops provided me with pamphlets and information that I was able to adapt and use at home to meet my daughter's individual needs.

The MEIC Conference is an amazing conference for both parents and professionals. It has been the most family oriented conference I've attended thus far. Each presenter was welcoming and flexible with parents who had children with them. The Parent Leadership Project has a wonderful family room just for families to come together. There are snacks, waters, tissues and a comfortable space for families who need a little private time away from the large group. We have become part of this larger EI family at the conference and they have welcomed us all as their own. My family feels privileged to have attended the MEIC Conference two years in a row. We are looking forward to our attendance next year.

**HELP us meet our goal of “500 likes!”**

Receive our Newsletters, Events & Opportunities more quickly! Email us at eiplp@live.com and ask to be added to our email list!

| Este ha sido el segundo año en que mi hija y yo asistimos a la Conferencia de MEIC. Siempre me entusiasmo porque sé que será un respiro para las dos, mi hija tendrá un descanso dos días de su intenso programa de terapia seis veces a la semana. Podrá reunirse y jugar con sus compañeros Intervención Temprana y divertirse en la piscina. Para mí será una noche de hotel en la que podremos disfrutar de una maravillosa cena familiar con otras familias de niños en IT. Siempre hay conversaciones sentidas con otras familias que han transitado el arduo camino de tener un niño con necesidades especiales. Compartimos historias, nos damos consejos, limpiamos las lágrimas y damos abrazos de fuerza y apoyo. Es en la cena de la familia que nos damos cuenta de lo increíble que son nuestros pequeños y cómo nos dan fuerza para llevarlos hacia sus próximos hitos.

Como madre de una niña con parálisis cerebral, los dos días de talleres y presentaciones me dieron muchas ideas increíbles sobre cómo responder a las necesidades de mi hija que podré poner en práctica en casa. Dos de los talleres es a los que pude asistir este año, fueron sobre aplicaciones de iPad y yoga para niños con necesidades especiales. Estos dos talleres excelentes me dieron folletos e información que he podido adaptar y usar en mi casa para satisfacer las necesidades de mi hija.

La Conferencia de MEIC es increíble tanto para los padres como para los profesionales. Fue la más orientada hacia las familias de las que asistí hasta el momento. Los presentadores fueron acogedores y flexibles con los padres que habían venido con sus hijos. El Proyecto Padres Líderes tiene una sala familiar maravillosa sólo para que las familias que se reúnan. Hay bocadillos, agua, pañuelos de papel y un espacio cómodo para las familias que necesitan tiempo en privado lejos del grupo. En la conferencia hemos pasado a formar parte de esta familia más amplia de IT que nos han acogido como uno más. Nos sentimos privilegiados de haber asistido a la Conferencia de MEIC dos años seguidos. ¡Ahora esperamos con entusiasmo nuestra tercera en mayo de 2013! |
Digital Story Opportunities

Digital stories are three to five minute videos made up of photos, narration and music that give viewers information based on a specific highlighted topic. The Early Intervention Parent Leadership Project (EIPLP) has been teaming with the Early Intervention Training Center (EITC) to produce parent and staff stories about their early intervention experiences.

It’s a great opportunity to share your story...so gather your photos and give us a call at 877-353-4757 or email us at eiplp@live.com.

To view stories that we’ve helped families create, visit http://eiplp.org/digital-stories/

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Why does my EI Provider want to know so much about my family?

By Jean Nigro, Director of the Early Intervention Training Center

Early Intervention is a unique service delivery system and a relatively young field having been established under federal law 99-457 only since the mid-1980s. For years those of us who worked in this field knew that what we were doing was effective, but the research to support our work was not available. It is only in the past few years that we have the evidence to support a relationship-based service delivery model that is designed to support parent and caregiver competence and confidence in fostering the optimum development of infants and toddlers.

Because we now know that children learn best in the context of everyday activities, families are being asked to describe their daily routines and activities, in terms of what interests and engages their child; what is going well; and, what challenges they face. Sharing this information helps to identify difficulties that providers may problem-solve with families. Moreover, providers and parents can determine the routines in which to embed interventions and learning opportunities. For example, if a child loves her bath time, it may be a natural opportunity to encourage the learning and use of more words, improving balance, reaching for and grasping toys, etc.

Because family routines are the context for delivering services, early intervention providers must learn as much as they can from families about the way they engage and interact at home, with friends and extended family and in their communities. Currently the Early Intervention Training Center (EITC) is offering several professional development initiatives for Early Intervention providers to support them in using a more consistent and comprehensive approach to gathering information from families.

Information is usually gathered through conversations with the family. Observations, check lists and interviews can also assist the provider to get useful information. Parents need to know the purpose of this information, how it will be used and where it will be kept. As a parent or family member you can expect that your early intervention provider will be using these strategies to gather information, not only about your child, but about your entire family and your way of life. It may seem strange to be sharing information which by itself may not seem to be important, but the process of gathering family information fosters the relationship that develops over time with the provider and family members. And, the techniques used will yield valuable information that will result in better outcomes for you and your child.


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Massachusetts Early Intervention Training Center

Watch the Early Intervention Training Center calendar for up-to-date opportunities...providers, families and caregivers are all welcome to participate in the online courses available! www.eitrainingcenter.org

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EIPLP

The Early Intervention Parent Leadership Project (EIPLP) wants to know how best to stay in touch with you. To hear about opportunities, resources, conferences and up to date information...did you know you can...

“Like” us on FaceBook
“Follow” us on Twitter
Receive Electronic Newsletters and Emails

If you’d like to be added to our email list to receive electronic newsletters and emails, email us at eiplp@live.com or call us at 877-353-4757!
FAMILIES ARE OUR STRENGTH. That’s the primary meaning behind the acronym in our name: Together In Enhancing Support.

The Early Intervention Parent Leadership Project and Family TIES of Massachusetts are programs overseen by the Office of Family Initiatives at the Massachusetts Department of Public Health. Our collective aim is to support families of children with special needs. As parents too, we truly understand the challenges that families face as they unfold the challenges and delights of their developing child.

Family TIES staff works with families, to explore your concerns in raising a child with special needs. In offering information and resources, we hope to improve everyday life as you learn about your child’s diagnosis, possible support services, and address everyday activities like childcare, dance programs, and integrated sports and recreation.

Our Let’s Get Organized workshop helps parents to embrace their role as expert, as primary caregiver and advocate for your child. Participants discuss techniques to increase confidence and competence in sharing the unique gifts and challenges of their child with the medical and educational teams who support the child.

Our Parent-to-Parent Program offers the opportunity for parents to talk with someone who is intimately aware of the emotional roller coaster of caring for the wide variety of needs we address on a daily basis. Staff can also help find local support groups and even national networks that focus their efforts on the same condition as their child. This helps us all to remember, we are not alone in our journey as parents.

Looking for someone to just listen? Someone to help find answers and resources? A place to turn when you’re just not sure where to go next? Call us. We are here for you.

To speak with a Regional Coordinator familiar with local community resources or to discuss our Parent-to-Parent Program, please call our toll-free line: 800-905-TIES (8437) or visit our website, www.massfamilyties.org.

Family TIES is a statewide parent-to-parent information and support network for families of children with disabilities, special healthcare needs, or chronic illnesses, and their providers. We are a proud Alliance Member of Parent to Parent USA, a national organization that provides technical assistance to parent-to-parent programs across the country. Family TIES of Massachusetts is a project of the Federation for Children with Special Needs, with funding from and in collaboration with the Massachusetts Department of Public Health, Division for Children & Youth with Special Health Needs.

FEDERATION FOR CHILDREN WITH SPECIAL NEEDS

Turning Three—Provides information about the required process for transitioning a child from Early Intervention (IE) to special education. Discussion includes EI transition planning, special education eligibility, the Team process and the parent’s role in planning, making decisions and monitoring their child’s progress.

Basic Rights—Provides families with the foundation knowledge needed to understand other special education workshop topics. This workshop introduces participants to the federal and state special education laws, special education process, parent and student rights and how to resolve differences with the school.

The Early Intervention Partnerships Program (EIPP) through the Department of Public Health, within the Division for Pregnancy, Infancy and Early Childhood is a home visiting program that has been in existence for over 10 years. EIPP serves women with identified maternal or infant risk factors across the state. The purpose of EIPP is early identification of maternal and infant risk; and linkage of families to services to prevent or reduce poor health and/or developmental outcomes. EIPP is coordinated by an existing Early Intervention Program. There are seven sites in Massachusetts that serve families during the perinatal period. They offer the necessary supports to promote maternal health and optimal post-pregnancy outcomes as well as a focus on infant growth and development through the first year of life.

Using a maternal child health (MCH) team that includes a maternal child health nurse, social worker, and community health worker, EIPP seeks to:
• improve access and use of health care services;
• improve nutrition, physical activity and breastfeeding initiation and duration rates;
• ensure safe and healthy social, emotional and physical environments; and
• strengthen the local perinatal and early childhood systems through collaboration with community resources and active engagement of families.

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www.fcsn.org
THE PARENT LEADERSHIP PROJECT

The EI Parent Leadership Project (EIPLP) strives to develop an informed parent constituency, promote leadership and lifelong advocacy skills for parents and family members, facilitate family participation to ensure that Early Intervention Services are family-centered and support EI programs to identify, train and mentor families to take on roles across the EI and Early Childhood system. 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 Director, a Media Coordinator, a Statewide Monitoring Coordinator and a Statewide Training and Technical Assistance Coordinator. Please feel free to contact any of them with your thoughts, suggestions, and concerns.

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Want information “hot off the press?”
E-mail your name and e-mail address to:
eiplp@live.com
We’ll add you to our email list!

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To receive the Parent Perspective Newsletter, a free publication, published three times a year by the Parent Leadership Project, call us toll-free at (877) 353-4757 and ask to be added to the EIPLP mailing list or email eiplp@live.com

NEXT DEADLINE: We welcome your input, suggestions for resources and articles. The next deadline is May 15, 2016. Please call our toll-free number (877) 353-4757 or email the newsletter editor at kris.levine@state.ma.us.

The Parent Perspective newsletter is produced three times a year by the Early Intervention Parent Leadership Project, through funding from the Massachusetts Department of Public Health. If you would like to be removed from this mailing list, please contact eiplp@live.com.

The Parent E-Perspective newsletter is produced more often and available electronically. If you would like to be added to this mailing list, email us at eiplp@live.com or visit our FB page and click on Join My List.

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