The Office of Special Education Programs (OSEP) held their annual 2013 IDEA Leadership Conference on July 29 – 31, in Washington, DC. State, agency and parent leaders, from Massachusetts and across the United States, including the Islands and Territories, attended this conference.

“The 2013 IDEA Leadership Conference supports better outcomes for infants, toddlers, children and youth with disabilities and their families by providing opportunities for key leaders and partners to interact with Department staff and OSEP-funded technical assistance providers.”

Families, Part B State Directors, Part C Coordinators, Section 619 Coordinators, Parent Center leaders, Part B and Part C Data Managers, State Advisory Panel members, and State Interagency Coordinating Council members attended to hear from experts in the field and to learn about evidence-based practices that support and improve results for infants, toddlers, children and youth with disabilities and their families.

Many of the presentations and workshops posted their PowerPoint, and in some cases webcast, presentations at http://leadership-2013.events.tadnet.org/.

This July I was invited to attend the 2013 IDEA* Leadership Conference in Washington, DC. I flew in early Sunday morning to make sure I could attend the ICC (Interagency Coordinating Council*) parent specific sessions held that day. One of the key discussions amongst fellow ICC members was how to increase parent involvement and develop the leadership skills of current participants. Best practices were shared and some great brainstorming took place among the representatives from all over the United States. That afternoon, we broke out into groups and worked on the federal legislation regarding the transition out of Part C (Early Intervention).

The attendees for the rest of the conference consisted of program directors in Parts B and C, ICC members, and assorted parent resource center staff and directors; many of whom were parents of children with special needs.

Monday morning started with a bang, including presentations by the Director of the Office of Special Education Programs and Arne Duncan, the Secretary of the Department of Education. They spoke of education reform and inclusion, among other things.

I took advantage of the opportunity and waited for Secretary Duncan outside of the ballroom with a picture of my daughter on the last day of school last year, and thanked him for his efforts working with the President and the importance of inclusion.

The next two days were intense! Early bird sessions started at 7:30, and the days typically ended around 5. There was such a huge offering of workshops available to many target audiences. Some highlights for me included a workshop on IDEA compliance on extracurricular activities and athletics, and working with EIFA (Early Intervention Family Alliance) board members to strategize on engaging all families whose children are enrolled in Early Intervention. (Cont’d –Page 3)
Dear Families,

This past October, Early Intervention programs distributed the NCSEAM Family Surveys. Service Coordinators give Surveys to all families whose children have been enrolled in EI for at least six months and who did not complete a Family Survey in March 2013. The Survey is distributed twice a year in October and March. Families are asked to complete one Survey per year.

The Survey was developed by the National Center for Special Education Accountability and Monitoring (NCSEAM) with input from states and is a tool to help EI programs and the Department of Public Health (DPH), Lead Agency for Part C Early Intervention services. It evaluates the effectiveness of EI in achieving positive outcomes for children and families. Your answers on the Survey measure your opinion about the extent to which:

- 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

If you received a Survey in October please complete it, in pencil, and return it in the self-addressed, stamped envelope provided.

Looking for help in understanding and completing the Survey? Call the EI Parent Leadership Project toll free at 877-353-4757, or check out the You Tube video that describes the process at: http://youtu.be/Gd5nnKOrkI0

Thank you for help. Your feedback is very important to your EI program and to DPH.

**Family Survey Frequently Asked Questions**

1. My son has been enrolled in EI since a year ago September. We’ve never received a Family Survey. What should I do?

Check with your Service Coordinator. He or she may have given you a Survey to fill out, but called it something different. Let your Service Coordinator know you want to share your important input with the EI program and DPH.

2. I love our EI services. Is it okay to say “very strongly agree” to all the questions?

You should answer all the questions on the Survey as thoughtfully and honestly as you can. If everything is “perfect,” and you want to fill in all the circles under "very strongly agree," of course you may. If there are areas where things could be a little better, your answers should reflect that.

Estimadas familias:

Este pasado mes de octubre, programas de Intervención Temprana distribuyeron a familias de NCSEAM. Los coordinadores de servicios distribuirán encuestas a todas las familias con hijos inscritos en IT durante al menos seis meses, que no completaron una encuesta en marzo de 2013. La encuesta se distribuye dos veces al año, en octubre y marzo. Pedimos a las familias que completen una encuesta por año.

La encuesta, preparada por el Centro Nacional de Supervisión de la Educación Especial (National Center for Special Education Accountability and Monitoring, NCSEAM) con aportes de los estados, es una herramienta para ayudar a los programas de IT y al Departamento de Salud Pública, la agencia principal a cargo de la Parte C de los servicios de IT. Evalúa la efectividad de la IT para lograr resultados positivos para los niños y sus familias. Las respuestas miden la opinión de los padres con respecto al grado en que los servicios de IT ayudan a las familias a:

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

Si recibe una encuesta en octubre, por favor completéela con lápiz y envíe en el sobre provisto con franqueo y dirección de destino.

¿Necesita ayuda para comprender y completar la encuesta? Llame sin cargo al Proyecto Padres Líderes al 877-353-4757 o vea el video de YouTube que explica el proceso: http://youtu.be/Gd5nnKOrkI0

Gracias por su ayuda. Sus comentarios son muy importantes para su programa del IT y para el Departamento de Salud Pública.
For meals and evenings we were on our own, and it was
great to be able to spend some down time with so many
knowledgeable people from all over country. We were able
to take full advantage of the incredible culture that Wash-
ington, DC has to offer, while making contacts and friends
on a national level.

I walked away from this conference feeling inspired and
empowered. There was such an amazing network of par-
ents and professionals there, and everyone I met was ask-
ing how things were going and if there was a way that they
could help. I was able to participate on at a national level,
in ways I wouldn't have imagined possible; my feedback as
a parent was always respected and appreciated; and it was
awesome to feel like a productive member of such an im-
portant organization.

*The Individuals with Disabilities Education Act (IDEA), is a
United States federal law that governs how states and pub-
lic agencies provide early intervention, special education,
and related services to children with disabilities. To learn
more http://idea.ed.gov/

*Interagency Coordinating Council (ICC) is a federally man-
dated statewide inter-agency group that advises and as-
sists the Department of Public Health on Early Intervention.
To learn more http://www.eiplp.org/icc.html

*Early Intervention Family Alliance (EIFA) is a national
group of family leaders dedicated to improving outcomes
for infants and toddlers with disabilities and their families.
To learn more http://eifamilyalliance.org/

"Your Voice Counts!"

Liz’s Perspective (continued)

En julio me invitaron a asistir a la Conferencia de Lideraz-
go IDEA 2013 en Washington D. C. Tomé un vuelo tem-
prano el domingo por la mañana para poder asistir ese
mismo día a las sesiones específicas para padres del Con-
sejo Coordinador entre Agencias. Uno de los temas clave
que se trataron fue cómo aumentar la participación de los
padres y cómo desarrollar la capacidad de liderazgo de los
que ya participan. Muchos compartieron información sobre
las mejores prácticas y hubo un intercambio fructífero ent-
tre representantes de todo Estados Unidos. Por la tarde,
nos dividimos en grupos y tratamos la legislación federal
sobre el proceso de transición para salir de la Parte C
(Intervención Temprana).

Los asistentes al resto de la conferencia eran directores de
programas de las partes B y C, integrantes del Consejo
Coordinador entre Agencias y miembros y directores diver-
sos del centro de recursos para padres, muchos de ellos
con hijos con necesidades especiales.

El lunes empezó a toda marcha, con presentaciones del
director de la Oficina de Programas de Educación Especial
y de Arne Duncan, el ministro de educación. Entre otras
cosas, hablaron de la reforma a la educación y la inclusión.
Aproveché la ocasión para esperar al ministro Duncan en
la puerta de la sala con una foto de mi hija el último día de
clases del año pasado y le di las gracias por la labor que
realizaba con el presidente y por promover la importancia
de la inclusión.

Los dos días siguientes fueron intensos. Las sesiones co-
menzaban a las 7:30 de la mañana y las jornadas termina-
ban alrededor de las cinco de la tarde. Había una gran va-
riedad de talleres para muchos públicos diferentes.

"Su opinión es importante!"

Liz’s Perspectiva acerca de la Conferencia de Liderazgo IDEA 2013
Por Liz Cox, Representante de Padres ICC
Algunos de los más destacados, para mí, fueron uno sobre el cumplimiento con las actividades extracurriculares y de atletismo de la Ley IDEA, y otro sobre desarrollo de estrategias, junto con los miembros de la junta directiva de EIFA (Early Intervention Family Alliance), para fomentar la participación de todas las familias con niños inscritos en programas de intervención temprana.

Durante las comidas y por las noches no había nada planificado y fue fantástico compartir el tiempo con tantas personas informadas de todo la nación. Pudimos aprovechar al máximo la increíble cultura de Washington D. C. al mismo tiempo que hicimos contactos y amistades con personas de todo el país.

Volví de la conferencia inspirada y fortalecida. Había una red fabulosa de padres y profesionales. Toda la gente que conoci preguntaba cómo nos iba con todo y si podían ayudar de alguna manera. Tuve la oportunidad de participar a nivel nacional en formas que jamás hubiera imaginado. Me hicieron sentir en todo momento respetada y valorada como madre. Y fue maravilloso sentir que pertenezco y contribuyo a una organización tan importante.

Lions (Paperwork), Tigers (Paperwork) and Bears (more Paperwork) – Oh My!

By Mary Dennehy-Colorusso, Director, Office of Family Rights & Due Process

If you have been in Early Intervention (EI) for a while, you may have noticed some changes to the Massachusetts Early Intervention and You family rights notice and some changes in the consent forms. But there is a new form: the Prior Written Notice Form which seems to have met with mixed reviews by both EI providers and families. So the Parent Leadership Project asked DPH to explain the new form to our readers:

DPH: The federal regulations for Early Intervention (Part C of the Individuals with Disabilities Education Act, aka IDEA) were released in September 2011. In order to receive federal funding for EI services, states must comply with the requirements of Part C of the IDEA. DPH needed to make changes to the policies and procedures in our Early Intervention Operational Standards in order to come into compliance with the new regulations. We also needed to make changes to the forms used with families.

ETPLP: What is Prior Written Notice?

DPH: Prior written notice (“PWN”) is a written explanation of what the EI program has offered/recommended or refused to do and the reasons related to their recommendation or refusal. For example, if the EI staff has recommended (“proposed”) a service, such as a home visit by an occupational therapist, 1x/week for an hour at home the program has to give you a verbal as well as a written explanation for this in writing and include the reason why they have proposed this particular service. On the other hand, if you, as an equal member of the IFSP team recommend home visit by a physical therapist, 1x/week for an hour at home but the other members of the team think the service could be provided by an occupational therapist, they need to explain their reasoning for this both verbally and in writing. They have “refused” an aspect of your recommendation (that the service be provided by an occupational vs. a physical therapist) and need to provide you with a basis for their recommendation.

ETPLP: What is the difference between “prior written notice” and “consent?”

DPH: “Prior written notice” is the written statement of the activity that is being proposed or refused and the reason for the proposal or refusal – often based on the results of an evaluation, assessment, or ongoing observations, and reminds parents to review their family rights notice for their options if they don’t agree with the EI team. The notice needs to be provided in your native language (unless clearly not feasible to do so) before the program moves forward to ask for your consent and implement the change or activity. You should always be fully informed and comfortable with your decision before you give your consent. Having the information in writing and giving parents a few days to consider what is being proposed is another way of ensuring you are a fully informed member of your child’s team.

(Cont’d page 7)
In December 2011, Massachusetts was one of nine states to be awarded a Race to the Top Early Learning Challenge (RTT) grant from the U.S. Department of Education. Under this four year, $50 million grant, the Department of Early Education and Care (EEC) initiated a set of projects to enhance the quality of early education and care in Massachusetts, with a particular focus on closing the achievement gap for young children with high needs and including new support for children with special health needs.

Building a high quality system of early education and care requires collaboration between the many state agencies who serve young children. Under RTT, EEC formed agreements with the Departments of Public Health (DPH), Mental Health, Children and Families, Housing and Community Development and the Office for Refugees and Immigrants to better coordinate services for children birth to five and their families. Through its agreement with EEC, DPH formed an early childhood health and mental health team within the Bureau of Family Health and Nutrition to embed health guidance and support across the early education and care system and maintain interagency partnerships around integrated services for young children.

The DPH Early Childhood Health and Mental Health Team includes:

**An Early Childhood Mental Health Specialist (LICSW) who** works within DPH to support state-funded programs serving young children and their families. She serves as a resource for EEC staff, child care programs and consumers on promotion of young children’s social-emotional development and prevention and intervention strategies for children with mental health needs. She provides training on the CSEFEL Pyramid Model approach and other ECMH-related topics and as well as technical assistance around ECMH-specific child care licensing and policy questions.

**An Early Childhood Health Specialist (RN) who** serves as the state’s lead health consultant for early education and care. She advises state agencies on important health policy issues affecting young children in child care including nutrition standards, safe sleep practices, cleaning and sanitation, and caring for children with chronic health conditions. She also supervises the four new QRIS Health Advisors, regionally-based nurses who are part of the RTT Early Childhood team.

**4 QRIS Health Advisors (RNs):** As of June 2013, the team of QRIS Health Advisors is fully staffed. These nurses sit at EEC Regional Offices in Lawrence, Taunton, Worcester and Springfield. Their role is to support child care programs in: 1) accessing health related standards in QRIS (EEC’s quality rating system); 2) identifying areas for quality improvement related to health and safety and; 3) providing appropriate referrals and resources. The QRIS nurses also provide technical assistance to EEC licensing staff on key health and safety issues and guidance to child care health consultants in their regions. To reach the QRIS Health Advisor in your area, contact Eve Wilder or your regional EEC Licensing Office.

**Regional Part-Time Nurses (Medication Administration):** A part-time nurse is located at each of the 6 DPH funded Regional Consultation Programs (RCPs) across the state. The nurses work 8-10hrs per week and provide free training to child care programs on complex medication administration for commonly occurring chronic conditions in early childhood including asthma, anaphylaxis, diabetes and seizure disorders. Training provided by the RCP nurses can be used by child care programs to meet certain EEC medication administration regulations. Contact the RCP in your region to learn more about the medication administration trainings.

The Early Childhood Health & Mental Health Team is also working with other DPH staff and agency partners on developing a unified approach to early childhood professional development, with a focus on training across disciplines and on topics related to mental health and supporting families facing difficult challenges. Recent trainings for educators, family support providers and EI practitioners have included supporting young children impacted by trauma, developmental screening using the Ages and Stages Questionnaire, and supporting young children with emotional and behavioral needs through the CSEFEL Pyramid model approach.

For more information about DPH Race to the Top programs or activities, please contact Eve Wilder at eve.wilder2@state.ma.us or by phone at 617-624-5442.
The Massachusetts Early Intervention Training Center (EITC) is pleased to welcome two new parent facilitators this fall...Alanna MacDonald, an ICC Parent Representative, and Liz Cox, an experienced facilitator with the Western Regional Consultation Program. Alanna will be facilitating workshops in the Southeastern part of the state while Liz will be working primarily in the West.

Every EITC offering is presented by a panel of facilitators. At least one parent of a child who is or has been enrolled in EI, is included on the training team for each workshop. Workshop facilitators are contracted with the EITC and receive a stipend for facilitating.

The EITC hosted a Facilitator Training earlier this fall in order to provide a refresher for existing facilitators, and to orient new facilitators to the process of leading a workshop, as well as to introduce new Training Center content.

We are always seeking parents and other family members who have an interest and skill in professional development to join our training team. If you would like additional information about becoming a workshop facilitator, please contact Jean Nigro at jean.nigro@state.ma.us.

**DID YOU KNOW?** EITC online trainings are available to parents? Interested in one of our topics? Take the class! Visit the EITC website — [www.eitrainingcenter.org](http://www.eitrainingcenter.org)

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**FAMILY TIES**

*Massachusetts — A Life of Eternal Transitions*

By Mary Castro Summers

For families of children with special needs, it is crucial to enjoy a series of successful transitions during their children’s earliest years. Those experiences will establish the expectations for what may be a lifetime filled with transitions for their child with special needs.

Sounds good, but what is *transition*? This term may be new to you, especially when thinking about the stages in our children’s lives. I don’t remember ever seeing it in baby books, do you? Some natural transitions include where baby sleeps (cradle to crib to bed) or nourishment (breast/bottle to cup, and liquid-only to solid foods) or movement (lying to rolling to crawling to walking). These are considered natural passages in the stages of our children’s lives. For most children, their families will move from stage to stage without too much thought. Not this audience; we celebrate each and every transition, right?

Not all transitions are easy to coordinate, which can make parents want to just stay where they are. When you are feeling frustrated, take that time to reflect on where you’ve been, where you are next going, and the growth and changes in your child. Take stock of the hard work and considerable efforts that have brought changes and success to your child and you, as a parent. Remember, we grow with our children, too. Yes, it’s hard to say good-bye to professionals who have been instrumental in getting through certain periods in your child’s life. Be assured, there are many more dedicated and talented medical, educational, and community contacts that will support your child through the blossoming that is yet to come.

If you have questions about transitions and directions for your child and family, call Family TIES of Massachusetts. As parents who have been through many ages and stages in parenting our children with special needs, we can offer emotional support, practical advice, and referrals to community programs that can help you along the way. Our Parent-to-Parent Program is available to connect parents who just need to talk, and in the process realize you are not alone.

Contact us through our toll-free line, or visit our website to learn more about the kinds of supports and resources we can offer.

**Family TIES of Massachusetts** 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 an Alliance Member of Parent to Parent USA, a national organization that provides technical assistance to parent-to-parent programs across the country. For more information, call 800-905-TIES (8437) or visit [www.massfamilyties.org](http://www.massfamilyties.org).
EIPLP: But do they have to give the form every time there is a change?

DPH: Yes, if the proposed or refused change or EI activity (services) has to do with the program determining eligibility (sometimes known as “identification” and “evaluation”), when the program proposes any change in the type of service, frequency, duration, location, or discipline of the EI provider, or when a parent makes a recommendation about a service that the program decides not to implement.

EIPLP: What if everyone on the IFSP team agrees about a change the program has proposed? Do they still have to give the form? Must a parent wait three (3) days before giving consent?

DPH: A parent always has the option to move forward and provide consent. Parents should just be aware that they have the option to delay making an immediate decision if it’s something they’d like to give some additional thought or talk about with other important people in the child’s life.

EIPLP: So many forms! So little time! The Prior Written Notice form was developed so it could be completed in just a few minutes.

EIPLP: It just feels unnecessary sometimes! I have a good relationship with my EI team and for the most part, we are on the same page.

DPH: Excellent! Based on the low numbers of calls DPH receives with concerns or complaints from parents, we generally believe that most parents are pleased with the services and EI staff are following all the steps they should be to ensure a family’s rights. That’s not to say that parents and EI are always in agreement 100% of the time, but usually the differences of opinion are worked out.

Prior written notice is an important procedural safeguard required by the IDEA. Aside from being required, we believe it is another way for our system to respect every parent’s ability to make informed decisions about his/her child’s IFSP services.

ACROYNMS DEMYSTIFIED...
Try to find these commonly used acronyms.

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<thead>
<tr>
<th>ECC</th>
<th>Department of Early Education &amp; Care</th>
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<tbody>
<tr>
<td>PE</td>
<td>Physical Education</td>
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<td>NCLB</td>
<td>No Child Left Behind</td>
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<td>CTF</td>
<td>Children’s Trust Fund</td>
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<td>Health Maintenance Organization</td>
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<td>Learning Disability</td>
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<td>Neonatal Intensive Care Unit</td>
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<td>Special Needs Advocacy Network</td>
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EIPLP  “Like” us on
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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 Statewide Director, a Media Coordinator, a Communications Coordinator, an EI Program Focused Monitoring Parent Coordinator and an Education 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 four 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, suggestions for resources and articles. The next deadline is December 30, 2013. 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 four 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@yahoo.com.

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