



# The Parent Leadership Project's Parent Perspective

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**"Ways to get Involved—Ways to Share!"**

**Fall 2014/Winter 2015**

## Interagency Coordinating Council Retreat Update

On October 1, the Interagency Coordinating Council (ICC) hosted its annual retreat at the Wachusett Inn in Westminister, MA. The ICC is a federally mandated statewide interagency group made up of parents, professionals and providers that advise and assist, the Department of Public Health, on Early Intervention (EI). These "partners" are interested in the future of the Early Intervention system in Massachusetts.

Ron Benham, Director of the Bureau of Family Health and Nutrition, kicked off the day by providing a Department of Public Health update. Dr. Marilyn Augustyn, Division Director, Developmental & Behavioral Pediatrics at Boston Medical Center was the keynote at this year's retreat. Her presentation, "Trauma Informed Care with the Context of Young Children and their Families," was very informative, well received and provided attendees with much to think about. To view Dr. Au-



Dr. Marilyn Augustyn

gustyn's presentation, visit [www.eiplp.org/documents/icc2014trauma.pdf](http://www.eiplp.org/documents/icc2014trauma.pdf). The day rounded out with a panel presentation and discussion which included Enid Watson, MDiv., Director, Screening & Early Identification Projects at Institute for Health & Recovery; Amy Kershaw, Assistant Commissioner for Policy & Practice Innovation, Department of Children and Families; and Janet McDougall, Deputy Director of the Child Care Division, Catholic Charities Child Care. The day concluded with small group discussions and reporting out.



ICC Members Pictured: Melissa McCarthy, Central; Liz Cox, At-Large; Samuel Caraballo, Boston-Metro; Heidi Freidman, Metrowest; Paul Melville, ICC Co-Chair; Jennifer Chabott, West; Ron Benham, Director of the Bureau of Child and Maternal Health

To learn more about the ICC and its mission, please contact Darla Gundler at [darla.gundler@state.ma.us](mailto:darla.gundler@state.ma.us) or 413-586-7525 Ext. 3157.

**"Ways to get Involved—Ways to Share!"**

## Parent Involvement on the Interagency Coordinating Council (ICC)

By Samuel L. Caraballo, ICC Parent Representative Boston-Metro Region



As a parent of a child with developmental disabilities, I am often busy trying to catch up with my daughter's medical appointments, evaluations and therapy sessions. Meeting the needs of an exceptional child is a full-time commitment that leaves many parents like myself feeling apathetic toward the policy aspects of disability services. However, in my time in the ICC I have learned that getting involved in the policy-making process for Early Intervention services is as important as taking my daughter to her medical appointments. While doctors and health care providers deal with my daughter's developmental issues, the decisions taken by policy makers determines the extent to which those same impairments become actual disabilities. It is for this reason that I have embraced the challenge and the opportunity to participate in the ICC as a Parent Representative for my region.

In the ICC, I have had the chance to sit side-by-side with heads of state agencies responsible for orchestrating the complex network of early intervention services. Our discussions about budgets, training requirements for providers, and effective use of resources have helped me understand the myriad of issues that our agencies have to consider at the time of implementing their guidelines. Nevertheless, those same conversations at the ICC have made me realize that policies aimed at improving the lives of vulnerable kids are inherently incomplete without robust parental input.

As parents and caretakers of non-typical children, we are able to inform agencies about issues not accounted for in our current network of services. More importantly, as caretakers we are able to provide substantial evaluative input about programs and legislative initiatives. The agency leaders who attend the ICC know this, and that is why they encourage parents to voice our concerns during our meetings.

-Continued on page 3

## NCSEAM Family Survey Update

## Información sobre la encuesta familiar de NCSEAM

Dear Families,

Thank you for completing a Family Survey last year. In 2014, **3987** Surveys were received and analyzed which means that more families than ever completed and returned their Surveys. An exciting development in 2014 was that the Department of Public Health (DPH) made the Family Survey available in Portuguese, Vietnamese and Haitian Creole. The DPH will continue to expand access to the Family Survey in languages that families indicate, they are most comfortable.

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 report on Family Outcomes with the goal of continuously improving our Massachusetts Early Intervention system. Please keep it up!

In 2014 we learned that:

- 85.4%** feel that Early Intervention services helps your family know your rights
- 82.7%** say that Early Intervention services helps your family effectively communicate your children's needs
- 92.3%** feel that Early Intervention services helps your family help your children develop and learn



Out next NCSEAM Family Survey distribution will be in March 2015. Families whose children have been enrolled in Early Intervention for at least **six** months and who did not fill out a Survey in October 2014 will receive one from their Service Coordinators. Remember families complete only **one** Survey each calendar year. Look for yours and take a few minutes to complete your Survey 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 children and families.

### Family Survey Frequently Asked Questions

1. Are there a lot of families in EI who want to complete the Family Survey in other languages?

***The most common language families' use at home after English is Spanish. In 2014, 774 Spanish Surveys were returned.***

2. Is DPH really using the information that is collected on the Family Survey?

***DPH reports the percentages from returned Family Surveys – (listed above) to the Office of Special Education Programs in our Annual Performance Report. 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.***

Estimadas familias:

Gracias por completar la encuesta a familias el año pasado. En 2014, se recibieron y analizaron encuestas de **3987** familias, ¡el número más alto hasta la fecha! Una gran novedad es que en el 2014 el Departamento de Salud Pública pudo ofrecer la encuesta en portugués, vietnamita y haitiano criollo. El DPH seguirá ampliando el acceso a la Encuesta Familiar en los idiomas que las familias indiquen que prefieren.

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 utilizamos para preparar informes sobre los resultados para las familias, para mejorar continuamente el sistema de Intervención Temprana de Massachusetts. ¡Siga participando!

En 2014 aprendimos que:

- El **85,4%** de las familias opina que los servicios de Intervención Temprana las ayudan a conocer sus derechos.
- El **82,7%** dice que los servicios de Intervención Temprana las ayudan a comunicar eficazmente las necesidades de sus niños.

El **92,3%** opina que los servicios de Intervención Temprana promueven el desarrollo y el aprendizaje de sus niños.

La próxima encuesta a familias de NCSEAM se distribuirá en marzo de 2015. Las familias con niños inscritos al menos hace **seis** meses en un programa de Intervención Temprana que no completaron una encuesta en octubre de 2014, recibirán una de sus coordinadores de servicios. 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.

Los animamos a seguir compartiendo sus opiniones y pensamientos acerca de los servicios de Intervención Temprana para sus niños y familias.

### Preguntas comunes sobre la encuesta familiar

1. ¿Hay muchas familias en Intervención Temprana que quieren completar la Encuesta Familiar en otros idiomas?

***El idioma hablado en el hogar más común en el hogar después de inglés es español. En 2014, se contestaron 774 encuestas en español.***

2. ¿Está DPH realmente usando la información que se recoge en la Encuesta Familiar?

***El DPH informa los porcentajes de encuestas familiares contestadas (mencionadas anteriormente) a la Oficina de Programas de Educación Especial en el Informe Anual de Desempeño. El Departamento también busca tendencias y asuntos que las familias plantean en sus encuestas. Trabajamos con los programas de Intervención Temprana para mejorar las prácticas y hacer cambios según sea necesario.***

**"Ways to get Involved—Ways to Share!"**

## **Parent Involvement on the Interagency Coordinating Council (ICC)**

Continued

In all honesty, I think we still have a way to go to make sure all children with disabilities in the Commonwealth have access to appropriate early intervention services. Nevertheless, the inclusive and participatory nature of the ICC is a harbinger of things to come. We all play an important role in making sure we serve the most vulnerable children in our state. I am honored and grateful for the opportunity to voice the concerns and ideas of so many parents and caretakers that are committed to providing a better future for their children. Therefore, let us continue pressing toward that goal.

**"¡Maneras de participar-Maneras de compartir!"**

## **La participación de los padres en el Consejo Coordinador entre Agencias (Interagency Coordinating Council, ICC)**

Por Samuel L. Caraballo, Representante de padres en el ICC por la Región Metropolitana de Boston

Como padre de un niño con discapacidades del desarrollo, suelo estar ocupado con las citas médicas, evaluaciones y sesiones de terapia de mi hija. Responder a las necesidades de un niño excepcional requiere un compromiso de tiempo completo que deja a muchos padres sintiéndonos indiferentes hacia las políticas relacionadas con los servicios para la discapacidad. Sin embargo, en el tiempo que llevo en el ICC, he aprendido que participar en el proceso de formulación de políticas de servicios de Intervención Temprana es tan importante como llevar a mi hija a sus citas médicas. Los médicos y demás profesionales de la salud se ocupan de los problemas de desarrollo de mi hija, pero las decisiones de los que formulan las políticas determinan el grado en que esos problemas se convierten en discapacidades reales. Es por eso que acepté el reto y la oportunidad de participar en el ICC como representante de padres de mi región.

En el ICC he tenido la oportunidad de sentarme lado a lado con jefes de organismos estatales responsables de orquestar la compleja red de servicios de Intervención Temprana. Nuestros debates sobre presupuestos, requisitos de formación para proveedores y uso eficaz de los recursos me ayudaron a entender la gran variedad de asuntos que nuestras agencias tienen que considerar al aplicar sus di-

rectrices. Sin embargo, esas mismas conversaciones en el ICC me hicieron dar cuenta de que las políticas para mejorar la vida de los niños vulnerables son intrínsecamente incompletas sin el robusto aporte de los padres.

Como padres y cuidadores de niños no típicos podemos informar a las agencias sobre temas no considerados actualmente en nuestra red de servicios. Más importante aún, como personas que brindan cuidados podemos aportar información evaluativa sustancial a programas e iniciativas legislativas. Los líderes de la agencia que asisten al ICC lo saben y por eso animan a los padres a expresar sus preocupaciones en las reuniones.

Para ser franco, creo que todavía tenemos mucho camino por recorrer para asegurar que todos los niños con discapacidades de nuestro estado tengan acceso a servicios de Intervención Temprana apropiados. Pero el carácter inclusivo y participativo del ICC es un presagio de lo que vendrá. Todos jugamos un papel importante en asegurar que sirvamos a los niños más vulnerables de nuestro estado. Me honra y agradezco la oportunidad de expresar las preocupaciones e ideas de tantos padres y proveedores de cuidados comprometidos a brindarles un mejor futuro para sus hijos. Sigamos esforzándonos entonces por cumplir esa meta.

**"Ways to get Involved—Ways to Share!"**

## **Trauma Through the Eyes of a Child**

By Melissa McCarthy, ICC Parent Representative Central Region

This year's ICC retreat brought me insight into the world of trauma...trauma, from a child's view, and how it impacts his/her behavior and perception of the world. Trauma can come from many different experiences. In this article I will speak about the medical piece of trauma.

My son like many children with chronic medical conditions has tests, procedures, and medical upsets that can be extremely intimidating and scary for both parent and child. As a child, he does not have the words to string together to express his fears or explain his behaviors. As parents we do the best we can to soothe our babies and let them know we are there and understand what they are going through, but honestly, we don't. Testing, blood work, and procedures are things that have to be done. We know as parents it is necessary, but as children they fear the person who is making these demands of them, and worry about what is going to happen next, and why it hurts.



-Continued on page 4

*"Ways to get Involved—Ways to Share!"***Trauma Through the Eyes of a Child**

continued

I speak only as a parent in this matter and not a medical professional, but as the person who holds her child and sees his strengths and struggles. I also would like to speak of the reflective piece of trauma. As my youngest son goes through these many medical events, his older brother watches with concern and uncertainty of what exactly is going on. My oldest tries to take in what he can understand, but he worries and wonders at times, scared as to what is happening to his brother and when his parents will return from the hospital.

My youngest son is 4 years old and unlike "typical" 4 year old boys he has had many challenges that he has had to face. His strength and courage inspires me. Well visits and check-ups are routine events that each child will typically experience. In the case of my son, it has become more frequent appointments, tests, and blood work. Doctors are human and approach children in varying ways. As parents, we know how important the doctor's approach is and how challenging their requests can be. We have been asked to "hold him down," "quiet him down," "stop him from kicking." How can you stop a child from expressing his fears in whatever way he can? Along this journey, our son has also received a diagnosis of Autism Spectrum Disorder. We explain that he is our 0-60 kiddo. I am not saying that his diagnosis is not legitimate; however, after hearing Dr. Marilyn Augustyn speak on how trauma symptoms can sometimes mimic autism, I am starting to wonder. Dr. Augustyn stated, "5 out of 100 children are hospitalized for major, acute, or chronic illness." Seeing these numbers and reading medical journals that state that the numbers for Autism continue to grow sends a red flag to the autism community. More attention and exploration in this area needs to be done as we sort out exactly what is going on with our son.

*"¡Maneras de participar-Maneras de compartir!"***El trauma a través de los ojos de un niño**

Por Melissa McCarthy, Representante de padres en el ICC por la Región Metropolitana de Central

**E**ste año, el retiro del Consejo Coordinador entre Agencias (Interagency Coordinating Council, me ayudó a entender el trauma desde la perspectiva de un niño, y cómo influye en su conducta y percepción del mundo. El trauma puede provenir de muchas experiencias diferentes. En este artículo hablaré de su componente médico.

Mi hijo, como muchos niños con enfermedades crónicas, tiene pruebas, procedimientos y problemas médicos que pueden ser intimidantes y aterradores tanto para los padres como para el niño. A su edad le faltan palabras para expresar sus temores o explicar sus comportamientos. Como padres hacemos lo que podemos para calmar a nuestros bebés y hacerles saber que estamos ahí y entendemos lo que les pasa, pero para ser francos, no es cierto. Las pruebas, los análisis de sangre y los procedimientos son necesarios. Como padres, lo sabemos. Pero ellos, como niños, le temen a la persona que los hace y les preocupa qué va a pasar a continuación y el dolor. No hablo como profesional médico, sólo como padre, como persona que sostiene a un hijo y ve sus fortalezas y dificultades. También me gustaría hablar del componente reflector del trauma. Mientras mi hijo menor pasa por estos eventos médicos, su hermano mayor mira con preocupación e incertidumbre. Trata de tomar lo que puede para comprender, pero se preocupa y se pregunta a veces con temor qué le pasará a su hermano y cuándo regresarán del hospital sus padres.

Mi hijo menor tiene cuatro años, pero a diferencia de un niño típico de su edad ha tenido que enfrentar muchos desafíos. Su fuerza y coraje me inspira. Las visitas y controles médicos son algo de rutina para la mayoría de los niños. Para mi hijo se ha convertido en una mayor frecuencia de citas, pruebas y análisis de sangre. Los médicos son seres humanos y se acercan a los niños de diferentes maneras. Como padres, sabemos lo importante que es el enfoque del médico y lo difíciles que pueden ser sus pedidos. Se nos ha pedido los "sujetemos", "calmemos" o que hagamos que nuestros niños "dejen de dar patadas". ¿Cómo se puede lograr que un niño deje de expresar sus temores de la manera que pueda? En este recorrido a nuestro hijo también le han diagnosticado un trastorno del espectro autista. Nosotros explicamos que es nuestro niño rápido. No digo que su diagnóstico no sea legítimo. Pero después de escuchar a la Dra. Marilyn Augustyn hablar de los síntomas del trauma y cómo a veces pueden parecerse a los del autismo, me lo estoy empezando a cuestionar. La Dr. Augustyn dijo que, "5 de cada 100 niños son hospitalizados por una enfermedad grave, aguda o crónica". Estas cifras y las revistas médicas que afirman que el autismo sigue en aumento le envían una señal de alerta a la comunidad del autismo. Hace falta más atención y exploración de este tema mientras seguimos averiguando qué le pasa a nuestro hijo.



## Trauma: The Importance of Identifying It Early

By Karen Welling, Early Childhood Trauma Specialist

**W**hy is it important for the EI field to focus on trauma? For one thing, it is more widespread than we may think. A groundbreaking study of more than 17,000 middle class adults revealed that as children 11% had experienced emotional and physical abuse; 22% had experienced sexual abuse; 25% had lived with a household member who abused drugs or alcohol. That means that anywhere between 1 in 10 and almost 1 in 4 people reading this newsletter may have experienced difficult, perhaps traumatic things, in their lives.

We have learned from research and experience that it's important to be sensitive to the possibility that anyone—a caregiver, co-worker, or child—may have experienced, or currently be experiencing trauma. It is important to learn ways to make everyone—especially people who have experienced trauma—feel safe. It is also important to avoid inadvertently doing things that will make the person have the feeling of being traumatized all over again. Finally, we want to make sure that needed services that build resilience and recovery are in place.

Awareness of trauma and its effects on young children is important within the EI community for many reasons. Obviously, if a child is unsafe in any way we will want to offer assistance. Also, trauma can effect development. If a child is experiencing trauma, the parts of the brain that help the child cope with the trauma develop more rapidly than others, as they may be critical to the child's ability to cope. Other parts of the brain—for example, the parts that help with speech, movement, or social skills develop—are less built up. It's important to have trauma considerations in the mix as EI assesses and works with the child and family, from assessment to IFSP development to service planning, so we can identify what's most likely to help. And again, so we don't accidentally do something that will make the child or caregiver feel like trauma is happening again.

There is good news about trauma. People can and do heal. Studies show that the key factor in children's recovery from trauma is the presence of a safe, involved, nurturing caregiver. In addition, because children's brains grow so much in the first 3–4 years, there is opportunity for parts of the brain that might be lagging behind because of trauma to catch up. EI can assist with this for eligible children, and can make referrals to other resources if needed.

## El trauma y la importancia de la identificación temprana

Por Karen Welling, Early Childhood Trauma Specialist

¿Por qué es importante que el campo de la Intervención Temprana (IT) se enfoque en el trauma? En primer lugar, porque es un fenómeno más extendido de lo que se piensa. Un innovador estudio de más de 17.000 adultos de clase media reveló que en la infancia, el 11% había sufrido abuso emocional y físico, el 22% había sufrido abusos sexuales, y el 25% había vivido con un familiar que abusaba de drogas o alcohol. Eso significa que entre las edades de 1 a 10, casi 1 de 4 de las personas que leen este boletín pueden haber experimentado sucesos difíciles y tal vez traumáticos en la vida.

La investigación y la experiencia nos enseñan que hay que prestar atención a la posibilidad de que cualquier persona —cuidador, compañero de trabajo o niño— pueda haber experimentado o experimente actualmente una situación de trauma. Es importante aprender maneras de hacer que todos, especialmente quienes han experimentado un trauma, se sientan seguros. También hay que evitar hacer inadvertidamente cosas que hagan que la persona tenga la sensación de estar siendo traumatizada otra vez. Por último, hay que asegurar que existan los servicios necesarios para fomentar la capacidad de adaptación y recuperación.

La conciencia del trauma y de sus efectos en los niños pequeños es importante dentro de la comunidad de IT por muchas razones. Obviamente, si un niño no está en una situación segura por cualquier motivo, hay que ofrecer ayuda. Además, el trauma puede afectar el desarrollo. Si un niño está experimentando trauma, las partes del cerebro que lo ayudan a lidiar con el trauma se desarrollan más rápidamente que las demás porque pueden ser críticas para su capacidad de hacerles frente. Otras partes del cerebro, por ejemplo, las que ayudan con el habla, el movimiento o el desarrollo de las habilidades sociales, están menos desarrolladas. Es importante incluir las consideraciones sobre el trauma para identificar qué es lo más probable que ayude, ya que la Intervención Temprana trabaja con el niño y la familia en la evaluación y el desarrollo de un plan individualizado y la planificación de los servicios. Y, reiteramos, para no hacer accidentalmente algo que haga que el niño o cuidador sienta que el trauma está volviendo a suceder.

Hay buenas noticias con respecto al trauma. La sanación es posible. Los estudios demuestran que el factor clave en la recuperación de los niños de un trauma es la presencia de un cuidador seguro, dedicado y protector. Además, como los cerebros de los niños crecen tanto en los primeros 3 a 4 años, las partes del cerebro que podrían estar rezagándose por un trauma tienen la oportunidad de ponerse al día. La IT puede ayudar con esto a los niños que reúnen los requisitos y puede derivarlos a otros recursos necesarios.



## Welcome, Liz!

Liz Cox was introduced to Early Intervention almost six years ago when her daughter started receiving services, and first joined forces with the Early Intervention Parent Leadership Project while presenting workshops in conjunction with the Regional Consultation Programs at MEIC in 2012. While she continued to work with both the RCP and the EIPLP to provide hands on workshops to parents and providers alike, she took on the role of the at-large parent representative on the ICC, and became active on the specialty services ICC subcommittee. In 2013 she attended the IDEA Leadership Conference in Washington, DC as a MA parent representative and became a parent presenter with the Early Intervention Training Center. The following year she spent six months as office staff at the Western Regional Consultation Program. Liz has recently joined the EIPLP as the Statewide Family Training and Technical Assistance Coordinator, dedicated to helping parents make the most of their time as an EI Parent Contact. In her new role, working closely with Parent Contacts and their EI programs, Liz is hoping to help strengthen and grow the parent leader network, and its involvement within the Early Intervention system.



Massachusetts Early Intervention  
Training Center

## Newborn Behavioral Observation

The Brazelton Institute at Boston Children's Hospital is in the process of applying for grant funding to support a research and intervention project in Massachusetts Early Intervention programs utilizing the Newborn Behavioral Observation system (NBO). The NBO is a tool that home visitors can use with infants and their families that supports parents' ability to read and respond to their baby's cues, parent-infant interaction, infants' early self-regulatory skills and infants' later social-emotional development.

The proposed grant would include provisions for infants referred to Massachusetts Early Intervention to receive an NBO intervention at the initial eligibility evaluation and during each home visit up to the infant's corrected gestational age of 12 weeks. Infants will be followed for up to 12 months corrected age. Several measures of parent-infant interaction and infant development will be collected over time as part of the project.

Local early intervention providers participating in the project may be approaching newly referred families to inquire as to their interest in participating. This is an opportunity for new parents to discover a new way of observing and learning about their babies. Additional information about the NBO can be found on the Brazelton Institute's web site at <http://www.brazelton-institute.com/clnbas.html>.



Parenting takes a great deal of time, energy, and commitment. For parents of children with special health needs, there are added layers to this statement. We must become familiar with our child's health and developmental challenges, and also learn where to find help and support to address those challenges and their impact on our families. At times, it is hard to be a Superhero.

Truth be told, there are important ways for parents to maintain a healthy inner balance, in order to keep up with this fast-paced life circumstance. It is essential for all parents to take care of their own needs in order to have the energy and optimism to manage the everyday ups and downs they face.

- Address your own physical needs. Eat a balanced diet to ensure you have a nutritional balance to maximize your energy. Be a good role model; try to eat just one sweet treat a day. Forgive yourself for occasional days when anything chocolate goes! If they become a habit, take time to reflect on what is interrupting your ability to focus and eat well, so you can nourish your body and soul.
- Adequate sleep and rest go a long way toward making sound judgments. Talk with your physician to find out if there are physical reasons why sleep and nutrition may be challenges for you.
- Think of exercise in a whole new way. It's fun to move your body and reap the benefits when endorphins are released and replenish your spirit. There are lots of options, both indoors and out; Head to the pool at the local YMCA, walk a trail in a nearby state park, or a bicycle ride by the sea will boost your spirits in so many ways. Don't just do it alone; take along members of your family and friends when you can.
- Understand that life, in general, is unpredictable for everyone. Find emotional support to address the challenges that interrupt smooth sailing for you and your family. Talk with family and friends, your doctor, members of a support group, members of the professional community that supports you around your child's special needs: your medical team, EI staff and or school personnel, other parents you meet like EIPLP and Family TIES staff. What's most important is that you open up and share your joys and concerns, both to celebrate the good times and expand your circle of support and helpful suggestions for challenging times.
- Show gratitude. Thank your Circle of Friends for their presence in your life – and realize that YOU are important to them, too.

To learn more about Family TIES of MA and the resources they have available, call 1-800-905-TIES (8437) or visit [www.massfamilyties.org](http://www.massfamilyties.org).

**DPH Spotlight**

**Creating a Safe Sleep Environment for Your Baby**

By Lisa McCarthy-Licorish, MPH, State Child Fatality Review Coordinator



**O**ne of the most precious feelings in the world is to hold an infant safely in your arms. Babies are welcomed into a world that is not familiar to them. They rely on parents and caregivers to protect them from harm. It is a wonderful time for family and friends to not only gush over

the new infant, but also to share advice on up-to-date infant safe sleep practices. Creating a safe environment for a newborn is a priority for parents.

Here are some of the current infant safe sleep tips from the American Academy of Pediatrics (AAP):

- Put your baby on his or her back to sleep for naps and at bedtime.
- Keep the baby near, but in his or her own bed (crib, bassinet, or pack n play) with a firm mattress and tight-fitting sheet.
- Do not put toys, pillows, blankets or bumper pads in the crib.
- Avoid smoking near the baby.
- Breastfeed your baby if you are able. Experts recommend that mothers feed their children human milk for as long and as much as possible, and for at least the first 6 months of life, if possible.
- Provide supervised tummy time while baby is awake to help bond with your infant and also to develop upper body and neck muscles.
- Educate parents, grandparents and other caregivers


about the most current safe sleep practices.

Some of this information may conflict with what you already know or learned from *your* parents. Bear in mind, information on safe sleep has changed over time. You want the most current information to help protect your baby. Here in Massachusetts 30-50 infants die every year as a result of unsafe sleep practices.

If you follow these steps, you will give your infant the gift of safe sleep.

Infant Sleep-related Deaths are Preventable!

For more information on infant safe sleep, please visit [www.mass.gov/safesleep](http://www.mass.gov/safesleep).



**Federation for Children with Special Needs**  
[www.fcsn.org](http://www.fcsn.org)  
**800-331-0688**

**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 a 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.

A R C C Z U E I L P L S Q  
 F S S P S R C E T Q L D A  
 E A D N I Q O P E P B Z X  
 R Y G M N M Z A O L D S I  
 P Q A E I A V F M P C P S  
 A P W I C E E W H P L A S  
 S O D C U R O Y R T E D P  
 D I C C W F P N C L B R I  
 G L D A H I T I F S P F C  
 M E I R K M A O Y K C P U

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

**IFSP** - Individualized Family Service Plan  
**IEP** - Individualized Education Plan  
**MEIC** - MA Early Intervention Consortium  
**TA** - Technical Assistance  
**ICC** - Interagency Coordinating Council  
**PT** - Physical Therapy  
**NICU** - Neonatal Intensive Care Unit  
**PICU** - Pediatric Intensive Care Unit  
**RFI** - Request for Information  
**SSP** - Speciality Service Provider

**EIPLP**

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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 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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## ***IN THIS ISSUE***

***ICC Retreat Update . . . . . 1***

***Parent Involvement on the ICC . . . . 1, 3  
English and Español***

***NCSEAM Survey Update . . . . . 2  
English and Español***

***Trauma Through the Eyes of a Child 3, 4  
English and Español***

***Trauma: The Importance of Identifying  
It Early—English and Español . . . . . 5***

***Welcome Liz, Newborn Behavioral Ob-  
servation & Family TIES. . . . . 6***

***Creating a Safe Sleep Environment. . . . 7***

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