On September 22nd-23rd, the Interagency Coordinating Council (ICC) hosted its annual retreat at the Wachusett Inn in Westminster, MA. The ICC is a federally mandated statewide interagency group comprised 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, began the retreat by recognizing the major accomplishments of the ICC over the past year which included involvement with First Dollar Insurance Legislation, Federal Medical Assistance Percentages (FMAP) Funding, An Act Relative to Insurance Coverage for Autism (ARICA), cross-agency collaboration, development of digital stories and the commitment of legislative support, to name a few. Looking forward to the future he stated concerns for fiscal year 2012 and shortfalls that may impact EI services.

This year’s working retreat was facilitated by Sharon Walsh, National Early Childhood Governmental Policy Consultant. Sharon presented IDEA with a focus on Part C, the section that oversees Early Intervention nationwide. Part C has 14 indicators that determine Early Intervention compliance and provide data on how well state EI programs are adhering to the standards. These tools are vital as they determine Federal funding of the Early Intervention system.

In an effort to gather input from the many different stakeholders present, participants were asked to join Moving Forward work groups. These work groups included: Fiscal Stability; Self-Insured Plans; Intensive Specialty Services; Programs and Services; Education and Advocacy; and, Increased Collaboration. Each ICC representative present was given the opportunity to participate in up to two Moving Forward groups to brainstorm opportunities, challenges and issues. This resulted in an excellent opportunity to collaborate with a much broader group of constituents and assist in prioritizing ICC goals.

The retreat also included the opportunity for ICC Standing Committees to meet and take advantage of all members being present to discuss the outcomes of the Retreat and its impact on their missions and goals.

The ICC Retreat closed with a recap recognizing ICC’s accomplishments to date and the challenges that lay ahead. To learn more about the ICC and its mission, please contact Darla Gundler at darla.gundler@state.ma.us or 413-586-7525 Ext. 1157.

The Family Leadership Team (FLT), a new committee of the ICC, is comprised of parents, providers and community representatives. Each person on the FLT brings something different to the table; this gives us the ability to share diverse perspectives and knowledge with the entire team.

Our unique backgrounds and experiences have fostered openness to exploring new ideas. Many of us are able to work and attend conferences and meetings, where we gain valuable information. One of our goals is to create a structure for reporting information that we feel will impact the ICC back to the FLT.

A recent example of the opportunities that are available to FLT involved a Legislative Advocacy training and tour of the State House hosted by the Early Intervention Parent Leadership Project. This training and subsequent tour provided us with an insider look at how the legislative process works and when/how best to advocate at the different levels. It was a very exciting opportunity and one that I will take with me into my future advocacy efforts.

If you are interested in finding out more about the FLT or the ICC; please contact Darla Gundler at Darla.Gundler@state.ma.us or (877) 353-4757.
Dear Families:

Welcome to our first edition of the Parent Perspective newsletter for 2010-2011. As we do each year, we are pleased to provide information about the NCSEAM Family Survey (National Center for Special Education Accountability and Monitoring) and answer your questions about it. Please feel free to send any questions you might have to the Early Intervention Parent Leadership Project by phone at 1-877-353-4757 or by email to: eiplp@yahoo.com

First, you might want to know what the Family Survey is all about. It’s a way to determine if you are satisfied with your Early Intervention services and if they are helping you to:

- Know your rights
- Communicate your child’s needs
- Help your child learn and develop

The Federal government requires Part C Early Intervention programs to ask families these questions and report on their answers. The Department of Public Health which oversees Early Intervention in Massachusetts is responsible for providing this information. Families whose children have been enrolled in Early Intervention for at least six months will receive a Family Survey from their Service Coordinator in October and March.

Each family will only fill out one Survey a year. Your input is very important to us and will help to improve Early Intervention services for you and for other children and families. Please fill out the Survey using a pencil and return it in the self-addressed, stamped envelope provided.

If you have questions about completing the Survey ask your Service Coordinator or the Parent Leadership Project.

Family Survey Frequently Asked Questions
1. I like everything about my EI services. Do I still need to fill out the Family Survey or can I just tell my provider that everything is fine?

Please fill out and return the Family Survey. It’s the only way that the Department of Public Health can get your feedback directly.

2. I got a Family Survey, but didn’t really understand what it was all about, so I didn’t mail it in.

Please share your questions and concerns with your Service Coordinator. Although he or she cannot help you actually fill out the Survey, they will be happy to explain the purpose and share ideas about where you can get help. AND…please mail it in as soon as you can.

We need to know if services are meeting your and your child’s needs and how we can do an even better job!

Estimadas familias:

Bienvenidos al boletín informativo de 2010-2011 de La perspectiva de los padres (Parent Perspective). Como lo hacemos cada año, nos complacemos presentar información sobre la Encuesta familiar de NCSEAM (Centro Nacional de Supervisión de la Educación Especial) y responder a sus preguntas sobre la misma. Por favor síntanse de libertad de hacer cualquier pregunta que tenga al Proyecto Padres Líderes de Intervención Temprana llamando por teléfono al 1-877-353-4757 o escribiendo por correo electrónico a: www.eiplp.org

En primer lugar, usted seguramente querrá saber de qué se trata la encuesta familiar. Es una manera de determinar si está satisfecho(a) con sus servicios de Intervención Temprana y si le están ayudando a:

...conocer sus derechos?
...comunicar las necesidades de su niño?
...apoyar su desarrollo y aprendizaje?

El gobierno federal exige que los programas de Intervención Temprana Parte C hagan estas preguntas a las familias y preparen informes con sus respuestas. El Departamento de Salud Pública, que supervisa la Intervención Temprana en Massachusetts, es responsable de dar a conocer esta información. Las familias de niños que han estado inscritos en Intervención Temprana durante al menos seis meses recibirán una Encuesta familiar de su Coordinador de Servicios en octubre y marzo. Cada familia llenará sólo una encuesta por año. Sus comentarios son muy importantes para nosotros. Nos ayudarán a mejorar los servicios de Intervención Temprana para usted y para otros niños y familias. Por favor, rellene la encuesta con un lápiz y envíela en el sobre provisto, con dirección de destino y franqueo prepago.

Si tiene preguntas sobre cómo completar la encuesta, consulte a su Coordinador de Servicios o a Proyecto Padres Líderes.

Preguntas comunes sobre la encuesta familiar
1. Estoy conforme con todos mis servicios de Intervención Temprana. ¿Aun así tengo que llenar la Encuesta familiar? ¿No puedo simplemente decirle a mi proveedor de servicios que todo está bien?

Por favor complete y envíe de vuelta la encuesta familiar. Es la única manera de enviar sus comentarios directamente al Departamento de Salud Pública.

2. Recibí una encuesta familiar, pero como no entendí de qué se trataba, no la envíé.

Por favor, dirija sus preguntas e inquietudes a su Coordinador de Servicios. Aunque no puede ayudarle a llenar la encuesta, con mucho gusto le explicará su propósito y le dará ideas de dónde puede conseguir ayuda. Y... por favor envíela por correo tan pronto como sea posible. ¡Necesitamos saber si nuestros servicios responden a las necesidades de usted y de su niño, y cómo podríamos mejorarlos aún más!

NCSEAM Family Survey Update
October 2010

Actualización sobre la encuesta familiar de NCSEAM
Octubre de 2010
I’ll never forget the day my children’s pediatrician suggested that my three month old daughter, Jordan, be “evaluated” by some organization she referred to as “Early Intervention” (EI). What's wrong with her? Who are these people? What are they going to do to my baby? Haven’t we already been through enough?

Jordan was born six years ago this Thanksgiving Day. Her twenty-month-old brother and a bevy of friends and family joined her mom and me as we welcomed this healthy baby girl into our family. We had some typical issues like infant jaundice and difficulty nursing, but all in all the first six weeks were as uneventful as bringing a new baby home can be.

That January, however; Jordan contracted RSV (Respiratory Syncytial Virus) and we started down a road that would have both father and infant daughter spending more nights in hospitals than at home over the next five weeks. RSV gave way to apnea-like episodes (imagine your baby’s skin turning an ashen-gray as she slept), severe reflux, and more tests than I could ever have imagined. That was a month that dragged on far too long.

Just as everything was finally returning to “normal”, our pediatrician noticed that Jordan’s gross motor development was behind schedule. Apparently being strapped into a hospital bed for half of your life can have that effect. That’s when she suggested an EI evaluation. I’m sure that many of you know the fear that sometimes accompanies the initial introduction of a government entity into your life as a law-abiding citizen/family. Thankfully, the doctor was able to explain that an Early Intervention evaluation is voluntary, free, and could take place in our home. She further explained that regardless of what the evaluation determined, we’d be under no obligation to receive services from EI unless we wanted them.

I called the number the doctor had given me and proceeded to grill the local EI provider about our rights and responsibilities as the parents of a potential participant. We agreed to the evaluation.

A couple of weeks later, three very friendly professionals came to our house, asked us some questions, and played with Jordan for a little while. When they were through, they explained how delayed Jordan’s gross motor development was and how her developmental progress in six other key areas stacked up against “normal for her age”. It was neat to learn that she was way ahead in her social-emotional development. The team recommended a service plan (Individualized Family Service Plan [IFSP]) that included exercises for us to do with Jordan and a service coordinator visit in our home every week or so, at a time that was convenient for our family. We were under no obligation, could back out at anytime, and only had to pay a one-time fee, based on our income and family size. We signed up eagerly.

Life went on: the exercises became part of our routine, the whole family looked forward to each of Norma-Jean’s visits, and my baby got stronger.

Just when it seemed that we’d no longer need EI, Jordan broke her leg and wound up in a cast for several weeks. She was seven months old. With the help of Norma-Jean, we rewrote Jordan’s IFSP to support her (and us) while her leg healed and to minimize the negative impact this might have on her learning to walk. The cast came off ahead of schedule and she was taking her first steps before she was thirteen months old. With tears in our eyes, we said good-bye to Norma-Jean and the EI team about a year after they’d entered our lives.

Today, Jordan is a happy, healthy kindergartner who loves to run, jump, and climb with the best of them! My family still appreciates the help and support we received from EI when we needed it most!
Un par de semanas más tarde, tres profesionales muy amables vinieron a nuestra casa, nos hicieron algunas preguntas y jugaron con Jordan por un rato. Al terminar, nos explicaron el grado de retraso de Jordan en su desarrollo motor grueso, y también que su progreso en otras seis áreas clave el desarrollo no era “normal para su edad”. Fue consolador saber que en su desarrollo socio-emocional estaba muy avanzada. El equipo recomendó un Plan Individualizado de Servicios para la Familia (Individualized Family Service Plan, IFSP) que incluía ejercicios para que hiciéramos con Jordan, y una visita semanal del coordinador de servicios a nuestra casa, en un momento conveniente para nosotros. No teníamos ninguna obligación, podíamos retirarnos en cualquier momento, y sólo teníamos que pagar una cuota única, basada en nuestros ingresos y el tamaño de nuestra unidad familiar. Nos anotamos entusiasmados.

La vida continuó: los ejercicios se convirtieron en parte de nuestra rutina, toda la familia esperaba con interés las visitas de Norma-Jean, y mi beba se volvió más fuerte.

Justo cuando parecía que habíamos terminado con la IT, Jordan se fracturó una pierna y terminó con un yeso durante varias semanas. Tenía siete meses de edad. Con la ayuda de Norma-Jean, modificamos el IFSP de Jordan para apoyarla a ella —y a nosotros mismos— mientras su pierna sanaba, y para reducir al mínimo el impacto negativo que esto podría al aprender a caminar. El yeso se pudo quitar antes de lo previsto y antes de los trece meses de edad Jordan ya estaba dando sus primeros pasos. Con lágrimas en los ojos, un año después de que habían entrado en nuestras vidas, nos despedimos de Norma Jean y del equipo de IT.

Hoy en día, Jordan es una niña feliz y saludable de jardín de infantes. ¡Y le encanta correr, saltar y trepar como los niños más activos! Mi familia todavía agradece la ayuda y el apoyo que hemos recibido de IT cuando más lo necesitábamos.
Family TIES of Massachusetts is a parent-led network for families of children with special needs. We recognize that parents are an important source of knowledge and strength to other parents. Our staff provides information and referral services, facilitates emotional support through our Parent-to-Parent Program, and offers free trainings. To reach our staff for any reason, please call our toll-free line or visit our website for staff contacts: 800-905-TIES (8437) or www.massfamilyties.org.

Please join us in welcoming Cheri McLane, our new Metrowest Regional Coordinator. Cheri is familiar with the Early Intervention system and is happy to assist us as a newly trained Support Parent. Like all of the Regional Coordinators, Cheri is also happy to talk with parents who are looking for community-based programs for their children and families.

We are pleased to announce that Family TIES is an Alliance Member of Parent to Parent USA, a national organization that provides technical assistance and support to networks that offer emotional support through the Match process. P2PUSA participated in scientific research which concluded that parent to parent support increases parents’ acceptance of their life circumstances and their sense of being able to cope. This demonstrates the importance of facilitating connections between parents who share similar experiences in raising their children with special needs. Learn more about P2PUSA at their website, www.p2pusa.org. To arrange for a Match with another family here in Massachusetts, contact our program staff: 800-905-TIES (8437) or www.massfamilyties.org.

Our Parent-to-Parent Program relies on our volunteer Support Parents, to offer emotional support. To join the corps, parents must participate in our “Listening & Learning” training. Trainings are scheduled in Acton (November 10), Waltham (November 17), Worcester (December 7), and Andover (December 9). Again, please contact our staff to learn more or to RSVP for one of the trainings.

**Save the Date!!!**

**Visions of Community Conference 2011—**Saturday, March 12th, 2011 at the Seaport/World Trade Center in Boston. This conference features dozens of break-out sessions (many presented in or translated into Spanish, Portuguese and Cantonese) with topical strands and information covering Early Childhood, Special Education, Health Care for Children with Special Needs, Social/Recreational Opportunities and more. For more information, visit the Federation for Children with Special Needs website at www.fcsn.org.

**Save the Date!!!**

**Massachusetts Early Intervention Consortium (MEIC) Conference—**May 4th and 5th, 2011 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 877-353-4757 or visit www.eiplp.org.

**Federation for Children with Special Needs Trainings**

www.fcsn.org
800-331-0688

**Turning Three**—This workshop, presented by the Federation for Children with Special Needs, highlights the difference between Early Intervention and publicly funded pre-school for children with disabilities. Discussion includes eligibility, the Team process for decision making and parents’ role in the transition process. This workshop is held at various locations throughout the State. Contact the Federation for Children with Special Needs for more information.

**Basic Rights**—This workshop provides families with an introduction to their rights and responsibilities under state and federal special education laws. For more information about dates and locations, contact the Federation for Children with Special Needs.

**Early Intervention Training Center**

**Building a Community**—This workshop, offered by the Early Intervention Training Center, provides an overview of the Massachusetts Early Intervention system. The orientation series is presented by a team of three facilitators, including EITC staff or consultant, a parent, and DPH staff. Parents are welcome to attend. For more information, visit www.eitrainingcenter.org

**HOLIDAY RESOURCE INFO**

Gift buying season is almost upon us… Check out these great tools for advice and ideas on purchasing children’s gifts...

**Toy Queen**

www.toyqueen.com

**Toys ‘R’ Us Toy Guide for Differently-Ability Kids**

www.toysrus.com/shop/index.jsp?categoryld=3261681
Ever heard your Pediatrician use the phrase “low muscle tone” and wonder what does that mean and how will it affect my child's development? The technical term is Hypotonia and there could be any number of causes. It can be difficult to point exactly why a child may have developed low muscle tone unless there is a specific neurological or genetic syndrome. Otherwise, there are still many questions around the source of muscle tone problems.

So what is low muscle tone? Let's start with first understanding normal muscle tone. Muscle tone basically refers to the resting position of each muscle in your body. Typically even with our muscles at "rest" there is a certain degree of tension on each muscle that allows us to maintain a variety positions with minimal effort. For example, while sitting at your desk you are able to maintain an upright seated position and control your head movements without tiring quickly or without having to exert much effort to get into that position. For a child with low muscle tone to achieve a seated position and control his/her head can be much more work. While his/her muscles are at rest they are in a much more relaxed or “loose” state. You may notice that it seems extremely easy to move a child's arms and/or legs while they are relaxed or that they feel as though they might slip through your hands when you try to pick them up.

In order for a child to activate his/her muscles to perform any variety of activities their muscle fibers have to work extra hard to tighten up from their “loose” state. This is why children with low muscle tone also tire more easily than other children. Their muscles essentially have to do twice the work to activate and maintain their position. This may be why a child has delays in motor skills, coordination problems, and overall muscle weakness. It is hard work for them perform skills that others might take for granted such as belly play or sitting up.

There are ways to help a child manage his/her low muscle tone and develop more strength and endurance for play with family and friends. With infants you can help stimulate their little muscles before attempting sitting, for example. Bouncing up and down on your legs is a great way to start. GENTLE tickling or stroking will help to wake up each muscle. I emphasize gentle because it is this light touch that actually sparks the muscles versus a firm massage that can relax them. Follow these activities with the positions that are tough for your little one like belly play or sitting.

For older children with low muscle tone you want to encourage as much activity as possible throughout the day to help build his/her strength and coordination. In the warmer weather try visiting the park, encouraging climbing, sliding and running on different surfaces. If he/she is hesitant to do certain things, which is not uncommon as children can be very aware of what is difficult for them and avoid that activity. Encourage children to try and offer lots of support to start. Also try focusing on the activities that they seem to really enjoy whether it's a parent-child gym class, swimming, or playing ball with older siblings. Any physical activity is going to be beneficial for these children. They may not be athletic superstars, but they should be able to keep up with and enjoy playing their peers.

In some cases low muscle tone is not a life long issue, with the exception of specific genetic and neurological conditions. The low muscle tone may either decrease in severity or resolve completely. It is different for every child. Work with your child and always keep in mind that his/her body is working hard to perform basic tasks, so be patient and persistent.
**EARLY INTERVENTION ANNUAL FEE**

The DPH recently implemented changes to the Early Intervention Annual Fee. Effective September 15th, an increase in fee amounts at all levels was instituted. Families are now required to provide proof of income and complete an Income Attestation Form.

In early September, the Parent Leadership Project hosted an information call for parent contacts and parent liaisons on the changes to the Annual Fee. The conference call and PowerPoint presentation are available to families at [www.eiplp.org/documents/feeconferencecall.wmv](http://www.eiplp.org/documents/feeconferencecall.wmv). Additional information regarding the Annual Fee may be found on the Massachusetts DPH website at [www.mass.gov/dph/earlyintervention](http://www.mass.gov/dph/earlyintervention). Questions regarding the Early Intervention Annual Fee may be directed to Mary Dennehy-Colorusso at 978-851-7261 x4016 (TTY 978-851-0829).

**STATEWIDE FAMILY SIGN LANGUAGE PROGRAM (FSLP)**

The DPH recently awarded a three-year contract to the Gallaudet University Regional Center (GURC) at Northern Essex Community College to operate a state-wide Family Sign Language Program (FSLP). The goal of the FSLP is to introduce family members to Sign Language, enabling them to communicate with their child who is deaf or hard of hearing at the earliest age possible.

To participate, families must have a child who is deaf or hard of hearing and be currently enrolled in an Early Intervention Program. Eligible families receive 20 weeks of child-centered instruction from qualified sign language instructors; 10 weeks in home with the remaining 10 weeks at home, online or in a group setting with other families.

This program is committed to meeting the needs of families throughout Massachusetts, so programs are encouraged to refer families who live in all parts of the state. GURC has strong connections with members of the Deaf community throughout the state and has been quite successful in attracting instructors to the program. If you would like additional information about the Family Sign Language Program please contact the Gallaudet University Regional Center at 978-556-3701 v/tty, or email at [fslp@necc.mass.edu](mailto:fslp@necc.mass.edu).

**ACROYNMS DEMYSTIFIED...**

Try to find these commonly used acronyms.

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<thead>
<tr>
<th>PT</th>
<th>Physical Therapy</th>
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<td>OT</td>
<td>Occupational Therapy</td>
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<td>Parent Advisory Council</td>
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<td>SAFE</td>
<td>Schools Are For Everyone</td>
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<td>LD</td>
<td>Learning Disability</td>
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<td>No Child Left Behind</td>
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<td>IEP</td>
<td>Individualized Education Program/Plan</td>
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<td>Centers for Disease Control and Prevention</td>
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<td>MASSPAC</td>
<td>MA Special Education Parent Advisory Council</td>
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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, Education Coordinator and Collaboration & Outreach Coordinator. Please feel free to contact any of them with your thoughts, suggestions, and concerns.

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Early Intervention Parent Leadership Project

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

NEXT DEADLINE: We welcome your input and suggestions for resources and articles. The next deadline is January 5, 2011. 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 five times a year by the Early Intervention Parent Leadership Project, through funding from the Massachusetts Department of Public Health.