The Regional Consultation Programs (RCP) have had a very busy summer. We’ve offered a few fun events attended by families from all over the state! RCPs provide support to families of children with complex care needs. The RCPs are divided into 6 regions that cover the entire state. Each region has a coordinator who works with the local Early Intervention (EI) programs to provide a variety of services. Over the last couple of years, the RCPs have been working more collaboratively with each other. Combining efforts helps RCPs to offer some great family events—which have been very successful and well attended. The idea behind these family events is to get families together and out in the community, sometimes offering a space that would otherwise not feel so accessible, or may be a bit intimidating. Many children with complex care needs have extra equipment or specialized health care needs that makes getting out of the house more challenging. By providing these opportunities, families are in a group where they feel comfortable and are not just shuffling off to another doctor’s appointment (which is not fun for most!).

This summer the Central Region hosted three very exciting family events. The first took place in July at Southwick’s Zoo. Families took the zoo by storm sporting blue and purple RCP shirts! This helped them to be more identifiable to other families who attended the event, and gave everyone a chance to connect, talk and support one another. While this was an informal event, the RCPs did rent a pavilion space for family networking and providing respite from the sun and heat! The Early Intervention Parent Leadership Project (EIPLP) was at the pavilions to provide water and take photos of families—providing a captured memory of their time at the zoo. We were also joined by the staff at the Notre Dame Pedi Pals program, who offered snacks and a craft for children to do while they were sitting and taking a break from the zoo. At both pavilions, and during the time in the parking lot where we were passing out shirts, I saw a LOT of great connections being made. Some moms whose children had been in the NICU together were able to reconnect, and families who attend many events were able to find each other and catch up. It was such a wonderful event, so many parents were able to connect and meet new families!

Our “Everyone On Wheels” party at Roll On America was a smaller event, but also a lot of fun! Children of all ages and abilities (and their parents and caregivers) took to the roller-skating rink for a few hours of fun and music! It was so great to see how several of the children that attended were able to connect with one another, and have a wonderful and memorable time.

The third event this summer happened in August. Families from Boston and Central RCPs took a tour of Fenway Park! This was a wonderful way for many to have a “behind the scenes” look at the park, and to see the field up close and personal. We topped off the day with a family lunch at Pizzeria Uno that was generously hosted by the EIPLP. This gave parents a chance to sit back for a few minutes and enjoy each other and their children, while eating in a restaurant (again, this can be intimidating for many with a child with additional equipment or needs).
Dear Families,

The summer has flown by and it is again time to think about receiving and completing the NCSEAM Family Survey which is distributed in October and again in March. Families whose children have been enrolled in Early Intervention for at least six months and who did not fill out a Family Survey last March, will be getting an Information Flyer, a Survey and a stamped, self-addressed return envelope from their Service Coordinator in early October.

The Survey is an important tool to help the Department of Public Health and your Early Intervention (EI) program better understand how EI services are working for you and your family. When you receive your Survey, please complete and return it as soon as you can. We use the information you provide to measure the impact of EI services on families and to report these measures to the Office of Special Education Services, which funds EI.

The Early Intervention Parent Leadership Project (EIPLP) has several resources to help you understand the Family Survey and the importance of filling it out. One that might be particularly helpful to you, is a short YouTube video describing the process at http://youtu.be/Gd5nnKOrkI0

Thank You!

Family Survey Frequently Asked Questions

1. I answered a lot of questions on a survey from my program, why do I have to do it again?

   Many EI programs have their own satisfaction surveys. These surveys are not necessarily measuring all the information needed by DPH and by the Federal Department of Education, Office of Special Education Programs (OSEP). Please help us ensure that Early Intervention services in Massachusetts are the best they can be by filling out the NCSEAM Family Survey and sharing your thoughts.

2. Okay, I understand about reporting to people who give money for programs, but what does it really mean for my family and other families?

   Recently the DPH heard from an EI Program Director who told us that she uses the questions about family satisfaction to help train her staff and to identify specific areas where the program needs to improve. Your input about what works and what could be better about EI helps your program understand family needs and find ways to enhance services.

Estimadas familias:

El verano se ha pasado volando y ha llegado otra vez el momento de recibir y completar la Encuesta familiar de NCSEAM, que se distribuye en octubre y nuevamente en marzo.

Las familias con niños inscritos en Intervención Temprana durante al menos seis meses que no completaron una encuesta familiar en marzo, recibirán de su coordinador de servicios, a principios de octubre, un folleto informativo, una encuesta y un sobre con franqueo y dirección de destino.

La encuesta es una herramienta importante para ayudar al Departamento de Salud Pública y a su programa de Intervención Temprana a comprender mejor la utilidad de los servicios de IT para usted y su familia. Cuando reciba su encuesta, le pedimos que la complete y envíe de vuelta lo más pronto posible. Usamos la información usted comparte para medir el impacto de los servicios de Intervención Temprana e informar los resultados a la Oficina de Servicios de Educación Especial, que provee los fondos para la Intervención Temprana.

El Proyecto Padres Líderes de IT tiene varios recursos para ayudarle a comprender la encuesta familiar y la importancia de completarla. Uno que podría ser especialmente útil es este video corto de YouTube que describe el proceso: http://youtu.be/Gd5nnKOrkI0

¡Gracias!

Preguntas comunes sobre la encuesta familiar

1. Ya he contestado muchas preguntas en una encuesta de mi programa, ¿por qué tengo que hacerlo otra vez?

   Muchos programas de Intervención Temprana tienen sus propias encuestas de satisfacción del cliente. Estas encuestas no miden necesariamente toda la información que necesitan el Departamento de Salud Pública y la Oficina de Programas de Educación Especial (OSEP, por sus siglas en inglés) del Departamento de Educación. Por favor, ayúdenos a asegurar que los servicios Intervención Temprana de Massachusetts sean los mejores posibles llenando la encuesta familiar de NCSEAM y compartiendo sus opiniones.

2. Muy bien, entiendo que haya que presentar informes a las personas que financian nuestros programas, ¿pero qué significa realmente esto para familias como la mía?

   Hace poco, la directora de un programa de Intervención Temprana le dijo al Departamento de Salud Pública que usa las preguntas sobre satisfacción familiar para capacitarse a su personal e identificar oportunidades para mejorar. Los comentarios de todos ustedes sobre lo que funciona bien de la Intervención Temprana y lo que podría mejorarse ayudan a que su programa entienda las necesidades de las familias y encuentre maneras de mejorar los servicios.
The Regional Consultation Programs (RCP) have been tremendous in offering numerous opportunities to attend activities through the year to families of kids with special needs. These activities have given me and my kids the opportunity to unplug from our day to day and enjoy some fun times with each other and other families. For starters, there were two activities I really enjoyed this summer; one was a night of yoga and another was a paint night event in town. These two are memorable events because they gave me the opportunity to have some much needed “me” time and pamper myself. Throughout this journey, as a parent of a child with special needs, I have found it necessary, if not essential, to take some time to recharge and reconnect with other adults as a therapeutic exercise for my body and soul. We as parents don’t always have the time to plan fun adult activities, but when a program like RCP does it for you and all you have to do is show up, well why not? I personally try to take advantage of these opportunities.

Other activities my family has enjoyed have included a mobile petting zoo called Barn Babies and roller skating at Roll on America. Barn Babies allowed my 2 year old with challenges, to be able to pet a bunny and a kitten in a controlled environment. I remember sitting on the floor with our furry friends in our laps, caressing them and enjoying every moment, this was golden! Meanwhile my 6 year old typically developing child, couldn’t get enough of the various animals she could hold, play with and pet for the afternoon. It was great! On another afternoon, we visited Roll on America. We had a blast and I was able to take both of my kids roller-skating for the first time. My two year old was in his stroller while my six year old daughter learned to skate and play at the arcade. This outing was a lot of fun, and I got my workout in the process – a few laps around the ring did help me burn some calories that day. Also, our RCP offered a CPR training for parents interested in getting certified. This provided an opportunity for us to be better equipped to care for our little ones in case of an emergency, which I thought was very valuable. Our RCP program has also offered other events I have not attended, like the Zoo, the Children’s Museum, the Aquarium, among others. They have made these events available and all we do is show up. As a parent, I have found these opportunities very enriching for me and for my family. We are very thankful for the opportunity to attend these events.

I believe that my family is fortunate to be part of an engaged RCP and for the various supports they offer their families. I am truly thankful for the effort that is put forward to make these activities possible for us to enjoy. I think that the quality of the activities they plan, are a reflection of the staff and their commitment to the program and the families they serve.
**"Ways to get Involved—Ways to Share!"**

This Mom’s Experience at the Western Regional Consultation Program In-door Picnic  
By Michelle Camerota

After attending our first Western Regional Consultation Program (WRCP) event, The Summer In-door Picnic, on August 13, I better understand how important Karen’s program is to the Early Intervention. My husband and I, along with our one and two year olds, had no idea what to expect when we arrived at The Log Cabin in Holyoke, MA. We could feel the positive energy from the children, staff and families as soon as we entered the room. After having a delicious meal and running around outside with the children, we decided to go inside and enjoy some dancing. The feeling of having a child with developmental delays along with complex medical issues is at most times overwhelming, especially when we are out in a large crowd, but at this event we felt as if we were all in our struggles together. We knew there were parents in the room who knew what it was like to live in a hospital for months or to spend your days nursing your child back to health – living just for the moment that they can hopefully get out on that dance floor to dance; as my son was able to do for the first time since being out of the hospital. There are many times you feel alone in your journey but at this event we felt right at home. No one looked twice at us or asked how my son was doing. For once, we were able to be a “typical family,” surrounded by people who "get it.” For our family the event was a complete success. We had fun, had a nice meal and we got to meet some great people in the process. Needless to say we had a wonderful time at this event and hope that there are more to come in the future!

Michelle Camerota, mom to a 2.5 year old with complex medical needs and developmental delays and a typically developing 1 year old

**Regional Consultation Programs (RCP)**

Thom Boston RCP  
RCP: Professional Center for Child Development  
RCP: Criterion Child Enrichment

Thom Western RCP  
RCP: South Shore Mental Health  
RCP: Schwartz Center for Children

Learn more...[www.eitrainingcenter.org/community/?p=consultation](http://www.eitrainingcenter.org/community/?p=consultation)

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

La experiencia de una madre en el picnic de verano del Programa de consultas de la región oeste  
Por Michelle Camerota

Después de asistir por primera vez al picnic de verano del Programa de consultas de la región oeste (Western Regional Consultation Program, WRCP) el 13 de agosto, comprendo mejor la importancia del WRCP para la Intervención Temprana. Mi esposo y yo y nuestros hijos de un año y dos años y medio no sabíamos que esperar cuando llegamos a The Log Cabin, en Holyoke, Massachusetts. Pero ni bien entramos a la sala, percibimos la energía positiva de los niños, el personal y las familias. Después de una comida deliciosa y de jugar y correr con los niños, decidimos entrar y disfrutar del baile. Tener un niño con retrasos del desarrollo y problemas médicos complejos a veces abruma, especialmente cuando estamos con un grupo grande de gente, pero en este evento sentimos que estábamos con personas que enfrentaban las mismas dificultades que nosotros. Éramos conscientes de que en la sala había padres que se sabían lo que era vivir en un hospital durante meses o pasar los días ayudando que un hijo recupere la salud. Y sin embargo, disfrutan de esta oportunidad de bailar con sus niños, como el mío, que pudo hacerlo por primera vez desde que le dieron el alta del hospital. En este recorrido hay muchas veces en que uno se siente solo, pero en este evento nos sentimos muy bien acompañados. Nadie nos miró más de una vez ni nos preguntó cómo estaba mi hijo. Por primera vez, pudimos ser una familia "típica", rodeada por personas que nos entendían. Para mi familia, el evento fue todo un éxito. Nos divertimos, disfrutamos de una comida deliciosa y tuvimos la oportunidad de conocer a gente magnífica. ¡Huelga decir que la pasamos de maravilla y que esperamos que este evento se repita muchas veces!

Michelle Camerota, madre de un niño de dos años y medio con necesidades médicas complejas y retrasos del desarrollo, y de otro niño de un año de desarrollo normal.

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Check out more pictures on our EIPLP FaceBook page!
On July 28th the Criterion Early Intervention Program held their annual family picnic. The picnic was at Ipswich River Park in North Reading, MA.

Families were asked to bring their own dinner and a dessert to share. The park has a great playground for kids of all ages. There was also a children’s musician who performed a variety of songs. Children sang, danced and played musical instruments. The picnic was a great way for early intervention families to meet and share information. Everyone had a great time!

The top picture is my son, Sean, & husband Mike Plumer. Sean is 19 months old. He has Down syndrome and is doing really well learning to walk. The bottom picture is of all the kids having fun!

El 28 de junio, el programa de Intervención Temprana de Criterion celebró su picnic familiar anual. El evento tuvo lugar en Ipswich River Park, en North Reading, Massachusetts.

Se pidió que las familias llevaran su propia cena y un postre para compartir. El parque fue un espacio de juego espléndido para niños de todas las edades. Además, había un músico para niños que interpretó una gran variedad de canciones. Los niños cantaron, bailaron y tocaron instrumentos musicales. El picnic fue una gran oportunidad para que las familias de Intervención Temprana se pudieran conocer y compartir información. ¡Todo el mundo la pasó maravillosamente bien!

En la foto de arriba está mi hijo, Sean, y mi marido, Mike Plumer. Sean tiene 19 meses. Tiene síndrome de Down y está aprendiendo a hablar muy bien. ¡En la foto de abajo aparecen todos los niños divirtiéndose a lo grande!
The Parent Leadership Project's Parents learn so much along the way in caring for their children’s health, academic, social, and emotional needs. In caring for a child with special needs, we learn so many golden nuggets every day. What can you do with that knowledge?

The DPH/Family TIES Parent Advisor Program offers parents an opportunity to share their experiences. Topics and opportunities vary greatly. Participants may be invited to share their expertise with the Massachusetts Department of Public Health on many topics, such as access to medical care, program and policy development, family support programs, or transition issues. Parents may be offered the opportunity to participate in focus groups, serve on an advisory board or committee, review educational materials or grant proposals, or even share their experiences among a group of interested professionals. Time commitments vary, and availability is always based on family circumstances. Our Parent Advisors also receive periodic listings of upcoming leadership opportunities, including workshops and conferences.

Please take this first step to parent leadership; bring the Parent Perspective to forums where you can make a difference. The SHARE YOUR VOICE! Form is available (in English, Spanish, and Portuguese) on the Family TIES website: www.massfamilyties.org, or call our Regional Coordinators for more information: 800-905-TIES (8437).

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 a proud 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 1-800-905-TIES (8437) or visit www.massfamilyties.org.

SAVE the DATES—SAVE the DATES—SAVE the DATES
Saturday, March 5, 2016

Federation for Children with Special Needs
Visions of Community 2016 Conference

Seaport World Trade Center, Boston

Workshops, Networking, Resources & Exhibit Hall

SAVE the DATES—SAVE the DATES
Monday, May 9 & Tuesday, May 10, 2016

Massachusetts Early Intervention Consortium
MEIC Conference 2016

Sheraton Framingham Hotel & Conference Center
Framingham, MA

Workshops, Networking, Resources & Exhibit Hall
What Does an Early Intervention Physical Therapist Do?
By Katie Wozniak, DPT, CEIS

The definition of a Physical Therapist will often be describe as a medical professional whose focus is improving strength, function, and mobility. A Physical Therapist (PT) in Early Intervention works on much more! The most important piece of being a PT in Early Intervention is remembering that everything you do during your sessions needs to have a focus on the family, their daily lives, and how they can incorporate the exercises/strategies into their day. To achieve success the PT and family must work together as a team!

Working as a Team we hope to improve the child’s ability to participate in age appropriate activities in their home and community with their peers. There are a variety of ways a PT and the family can help children thrive in their daily lives and it all starts with understanding what a PT will focus on, based on family identified outcomes. They will work during sessions to achieve these outcomes and help the family identify opportunities to carryover strategies in daily routines.

A Physical Therapist in Early Intervention will...
◊ Work on meeting developmental milestones such as; rolling, sitting, crawling, standing, and walking.
◊ Improve age appropriate strength, balance, and coordination.
◊ Manage tight muscles/improve joint range of motion due to muscle restrictions (i.e. Torticollis)
◊ Evaluate the need for orthotics (braces) or other supportive equipment.
◊ Evaluate for appropriate seating and mobility options.
◊ Assist families with ordering any necessary adaptive equipment (braces or wheelchairs)
◊ Ensure that the focus is on helping the child be an active part of the family and finding opportunities to interact with peers despite developmental delays.

During a home visit a Physical Therapist may...
◊ Teach how to stretch specific muscles to improve mobility.
◊ Focus on belly play with both infants and toddlers.
◊ Get creative with crawling and climbing activities by using couch cushions, pillows, blankets and even laundry baskets!
◊ Discuss strategies that allow families to easily incorporate stretching and strengthening activities into the child’s play or other activities of daily living (ex: stretching neck or ankles at each diaper change).
◊ Trial adaptive seating and mobility equipment.
◊ Identify the need for further testing or consults with other medical professionals (Neurologist or Orthopedist)
◊ Consulting with other professionals within Early Intervention if other developmental concerns arise.

Carry over is key in Early Intervention! Our goal is to support each family in helping their child to meet their goals and enhance their overall motor development. Following a home visit a family should...
1. Pick 2-3 activities that the PT suggested and try to incorporate them into the child’s day over the week before the next scheduled visit.
2. Think about what seemed to work well and what didn’t.
3. If something feels like you’re doing it wrong, stretches for example, hold off and ask the PT to review the technique. Try to always keep it playful! You will have much more success with the little ones!

Ms. Wozniak has been a licensed Physical therapist at the Professional Center for child Development, in Lawrence and Andover for 10 years.
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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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 December 31, 2015. 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@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.

Like the EIPLP page on FaceBook or follow EIPLP on Twitter!