On April 13 and 14, families, Early Intervention providers and community members gathered together at the Best Western Royal Plaza Hotel in Marlboro for the 31st annual MEIC (Massachusetts Early Intervention Consortium) Conference. Through generous funding from the Massachusetts Department of Public Health, the Early Intervention Parent Leadership Project sponsored parents from Early Intervention programs across the state to attend the conference to learn more about Early Intervention, developing leadership skills, and opportunities for family involvement.

On the first evening of the conference, the Early Intervention Parent Leadership Project hosted its annual Parent Networking Dinner for all of the parents attending the conference. Suzanne Gottlieb, director of Family Initiatives at the Department of Public Health, spoke to the more than 100 parents who attended the dinner, saying, “Parents are our greatest resource. We hope this conference and this dinner inspire you to keep walking down the path of leadership.”

Guest Speaker Keith Jones, a disability rights advocate and consultant and one of the many people featured in Dan Habib’s award-winning documentary film, Including Samuel, shared his special brand of humor and insight with the families attending the dinner. “Your kids will only be as strong an advocate as you are. They will only believe they are great if you tell them they are,” Keith reminded the families. He shared his personal stories of growing up as a young man with a disability, many of which had parents laughing and nodding in agreement.

For the parents who attended the conference, Keith Jones’ theme of belonging, of the importance of being part of a larger community regardless of ability or disability, was an important one. Of families of children with disabilities and challenges, Keith said, “We need to remind the world that we are part of the human experience.”

As it does each year, the 2010 MEIC Conference brought together families and providers for two days of fun, learning and inspiration. Parents who attended this year’s conference took an important step on their leadership journey and will bring new skills back to their EI programs and communities to continue the important work of partnership.
Dear Families: Hopefully all of you whose children have been enrolled in Early Intervention for at least six months received a NCSEAM Family Survey in March and have filled it out and returned it in the stamped, self-addressed envelope provided!

EI programs have let us know that they distributed more than 6500 Surveys during the month of March. We should know in the next few weeks how many Surveys have been filled out and returned.

Those of you whose children had not been enrolled for six months during the March Survey distribution will get the Survey in October 2010. Thank you in advance for your support of this important initiative. The Department of Public Health appreciates your help in determining the effectiveness of EI services and will use the information you provide to improve services and supports.

If you have questions or thoughts about the NCSEAM Family Survey, please share them with your Service Coordinator or with the Early Intervention Parent Leadership Project.

Family Survey Frequently Asked Questions

1. I've heard that some families are only in Early Intervention for six months. What if my child and family are out before we get a Family Survey?

Families who did not receive a Survey in March and whose children are found not eligible for services before next October will not be asked to complete a Family Survey. However, families can always provide feedback, whether it is concerns or compliments. Each EI program has a number of ways for families to offer feedback. Ask your Service Coordinator how this happens at your program. In addition, you may share feedback directly with the Early Intervention Parent Leadership Project or DPH staff.

2. How can I find out what other families had to say about my EI program?

Each Early Intervention program receives a report annually that gives specific results based on information returned by families. Program results are given compared to state averages. You can ask your Program Director to show you this report. In addition, results of all federally mandated performance indicators are posted on the DPH website. You can find this information at www.mass.gov/dph/earlyintervention. Data for 2009 will be posted shortly.

Actualización sobre la encuesta familiar de NCSEAM

Estimadas familias: Esperamos que todas las familias con niños inscritos durante al menos 6 meses en Intervención Temprana hayan recibido una encuesta familiar de NCSEAM en marzo, ¡y que la hayan completado y enviado de vuelta en el sobre provisto con franqueo y dirección de destino!

Los programas de Intervención Temprana nos han informado que distribuyeron más de 6,500 encuestas durante el mes de marzo. En las próximas semanas deberíamos saber cuántas encuestas fueron completadas y enviadas de vuelta.

Las familias con niños inscritos durante menos de seis meses cuando se distribuyó la encuesta de marzo, recibirán la próxima encuesta en octubre de 2000 días. Les agradecemos de antemano por apoyar esta importante iniciativa. El Departamento de Salud Pública agradece su ayuda para determinar la eficacia del programa de Intervención Temprana, y usará la información que ustedes den para mejorar los servicios y apoyos que ofrece.

Si tienen preguntas o sugerencias con respecto a la encuesta familiar de NCSEAM, por favor compártanlas con su Coordinador de Servicios o con el Proyecto Padres Líderes del programa de Intervención Temprana.

Preguntas comunes sobre la encuesta familiar

1. He oído que algunas familias están en Intervención Temprana sólo por seis meses. ¿Qué pasa si mi niño y mi familia terminan el programa antes de recibir una encuesta familiar? A las familias que no recibieron una encuesta en marzo y cuyos niños no son elegibles para recibir servicios antes de octubre próximo, no se les pedirá que completen una encuesta familiar. No obstante, las familias siempre pueden ofrecer comentarios, ya sea si se trata de preocupaciones o de elogios. Cada programa de Intervención Temprana ofrece a las familias varias maneras para compartir sus opiniones. Pregunte a su Coordinador de servicios cómo se hace esto en su programa. Usted también puede compartir sus comentarios directamente con el Proyecto Padres Líderes del programa de Intervención Temprana o con el personal del Departamento de Salud Pública.

2. ¿Cómo puedo averiguar lo que otras familias han dicho sobre mi programa de Intervención Temprana? Cada programa de Intervención Temprana recibe un informe anual que da resultados específicos en base a la información ofrecida por las familias. Los resultados del programa se muestran comparados con los promedios estatales. Usted puede pedirle al director de su programa que le muestre estos resultados. Además, los resultados de todos los indicadores de rendimiento requeridos a nivel federal se anuncian en el sitio web del DPH. Esta información puede encontrarse en www.mass.gov/dph/earlyintervention. Los datos para 2009 se anunciarán próximamente.
The Early Intervention Parent Leadership Project was created to support families of children in Early Intervention. Over the last 19 years the project has partnered with parents from across Massachusetts to help them develop leadership skills. Parents and family members have used those skills to take on a variety of leadership roles, from local involvement in their Early Intervention program and their communities, to national-level advocacy for Early Intervention and funding and support for health care for all children. Parent leaders can make a difference—and we want to show you how!

When my Early Intervention therapists first mentioned my son had red flags for autism 2 ½ years ago, little did I know where this new path of my life would take me. As I learned more and more about autism, Early Intervention, Special Education, public benefits, and other resources, I slowly learned that the power of a parent’s voice can make a difference. So I continued talking!

In the past year, I have served as the Metrowest Parent Representative on the Massachusetts Interagency Coordinating Council (ICC) and participated in skill building and networking activities through the Parent Leadership Project, as well as other advocacy activities. Now, I have been asked to participate in other projects relating to Early Intervention in our state.

Most recently in April 2010, I was asked to attend the Act Early on Autism Regional Summit in Providence, RI. This summit was one of ten regional summits held around the country and consisted of teams from each of the five New England states. I was invited to provide the family perspective for the Massachusetts team. The Act Early Summit was created by a partnership of the Association of University Centers on Disabilities (AUCD), National Center on Birth Defects and Developmental Disabilities (NCBDDD), and the Centers for Disease Control (CDC) and was based on their “Learn the Signs. Act Early.” campaign that began in 2004.

The purpose of this regional summit was to “bring together key state leaders from the early intervention and early childhood community for the purpose of enhancing relationships and collaborations and providing a forum to share information and insights on the opportunities, challenges and barriers for families and children with Autism Spectrum Disorders and related disabilities in the areas of identification, assessment, diagnosis, and intervention. Our 24 member state team has leading clinical doctors in autism and autism research,

At the end of the two day conference, we left with the beginning of an Action Plan of the specific things our team wants to focus on to make identification, assessment, and diagnosis easier for families to access. Our Action Plan is still being formulated and will need further changes, but we have a place to start to move Massachusetts forward in acting early in autism.

Never in my wildest dreams did I think I would be sitting at the same table as an equal partner with some of the individuals who attended the Summit and have my feedback so valued and necessary. My participation in the Summit and on the MA team is only one example of where Parent Leadership can take you… “you’re off to Great Places! Today is your day! Your mountain is waiting. So...get on your way!”
El Proyecto Padres Líderes fue creado para apoyar a las familias de niños que reciben servicios de Intervención Temprana. Durante los últimos 19 años, ha colaborado con padres de todo Massachusetts para ayudarles a desarrollar habilidades de liderazgo. Los padres y familiares han usado estas habilidades para asumir una variedad de roles de liderazgo, desde trabajar localmente en sus comunidades y programas de Intervención Temprana, hasta participar en campañas nacionales a favor de la IT y de la subvención y el apoyo a la atención médica para todos los niños. Los padres líderes pueden marcar una diferencia importante, ¡y queremos mostrarles cómo!

Cuando los terapeutas de Intervención Temprana mencionaron por primera vez, hace dos años y medio, que mi hijo mostraba signos de autismo, poco me imaginaba por qué caminos de la vida me llevaría esta nueva situación. A medida que me fui informando más y más sobre el autismo, la Intervención Temprana, la educación especial, los beneficios públicos y otros recursos, aprendí gradualmente que la voz de los padres tiene mucho poder y puede hacer una gran diferencia. ¡Y por eso he seguido hablando!

Durante el último año, he servido como representante de padres de la región MetroWest en el Consejo Coordinador entre Agen- cias (ICC por sus siglas en inglés) de Massachusetts, y he participado en actividades de desarrollo de habilidades y de redes de contactos a través del Proyecto Padres Líderes, así como en otras tareas de intercesión. Ahora me han pedido que participe en otros proyectos relacionados con la Intervención Temprana en nuestro estado.

Recientemente, en abril de 2010, me invitaron a concurrir a una reunión regional de Act Early on Autism (Actuar temprano con el autismo), en Providence, Rhode Island. Fue una de diez reuniones cumbre llevadas a cabo en diferentes puntos del país y en la misma participaron equipos de cada uno de los cinco estados de Nueva Inglaterra. Yo fui invitada para representar la perspectiva de las familias en el equipo de Massachusetts, así como en el equipo de Intervención Temprana. La reunión Act Early Summit fue creada por una colaboración entre la Asociación de Centros Universitarios para Discapacidades (Association of University Centers on Disabilities, AUCD), el Centro Nacional para Defectos de Nacimiento y Discapacidades del Desarrollo (National Center on Birth Defects and Developmental Disabilities, NCBDDD), y los Centros para el Control y la Prevención de Enfermedades (Centers for Disease Control and Prevention, CDC), y se basó en su campaña “Aprenda los signos. Actúe Temprano” lanzada en 2004.

El propósito de esta cumbre regional fue “reunir a los líderes clave de cada estado en materia de intervención temprana y primera infancia, con el fin de fortalecer los vínculos y la colaboración y ofrecer un foro para compartir información e ideas sobre oportunidades, retos y barreras para las familias de niños con trastornos del espectro autista y discapacidades relacionadas, en lo referente a identificación, evaluación, diagnóstico e inter- vención. Nuestro equipo estatal de 24 miembros cuenta con médicos e investigadores líderes en el campo del autismo, médico que son profesores universitarios, representantes de agencias estatales (como Intervención Temprana, Educación y Cuidados Tempranos, y Salud Infantil, Adolescente y Familiar), directores de programas de la organización Leadership Education in Neurodevelopmental and Related Disabilities (LEND), trabajadores sociales y psiquiatras muy conocidos, representantes de centros de recursos para el autismo de Massachusetts, y organizaciones como Autism Speaks, Advocates For Autism of Massachusetts (AFAM), Family Voices, así como la Federación para Niños con Necesidades Especiales (Federation for Children with Special Needs, FCSN) y miembros de agencias privadas.

Terminamos la conferencia de dos días con el principio de un plan de acción, con objetivos específicos que nuestro equipo desea abordar para facilitar a las familias el acceso a los servicios de identificación, evaluación y diagnóstico. Aunque nuestro plan de acción todavía está siendo formulado y requerirá cambios, ahora contamos con un punto de partida firme para hacer avanzar a Massachusetts en el reconocimiento temprano del autismo.

Jamás me hubiera imaginado que estaría sentada en la misma mesa como socia igualitaria con algunas de las personas que asistieron a esta reunión cumbre, y que mis comentarios serían valorados y considerados tan necesarios. Mi participación en este encuentro y en el equipo de Massachusetts es sólo un ejemplo de a dónde podemos llegar con el liderazgo de los padres… Como dice el Dr. Seuss “¡Hoy es tu día! ¡Emprende el camino hacia tu destino! Tu montaña te espera. Así que... ¡ponte en marcha!”
Family TIES of Massachusetts: Together In Enhancing Support
By Mary Castro Summers

Family TIES of Massachusetts is a network for parents of children with special needs. Just like you, we are parents of children with special needs and know that parents are an important source of knowledge and strength to other parents.

Family TIES staff provides information and referral services, facilitates parent-to-parent support, and offers trainings to build important skills for families of children with special needs.

Family TIES Regional Coordinators are located in Department of Public Health offices across the state, responding to telephone and email contacts from parents and providers looking for community-based resources. Our annually updated Directory of Resources for Families of Children and Youth with Special Needs is available in print and electronic format, on our website. In addition, staff compile information about local support groups, community organizations and activities, and ways to support you through the process of raising a family.

Regional Coordinators also provide workshops to parent groups. Our LET’S GET ORGANIZED training helps reinforce parents’ important role as the central source of information and support for their child with special needs. We focus on taking charge of the massive amounts of paperwork that often overwhelm families. By the end of the training, you will have many new ideas on managing your life and a useful notebook in which you can keep the most current, important reports and documents related to your child’s medical, educational, and community life.

Our Parent-to-Parent Program offers parents an opportunity to find another parent who is facing similar circumstances in raising a child with special needs. Matches are often made by a child’s diagnosis, prescribed treatments or therapies, or a current concern for the family. Some examples include: the emotions of a new diagnosis, understanding certain aspects of a diagnosis, transition from Early Intervention or other stages in the educational process, sibling or family concerns, or finding opportunities for a child within the community. A parent who requests a match will complete a Match Request form to give our staff information that is key to finding the right person for the connection. The Match process involves contact with our staff before and after the process, with a minimum of two phone calls with a trained Support Parent. We have learned through years in this process that many times, parents will find just the right match – and continue contact into the future, on their own terms. Truly, it is a success when you are able to affirm YOU ARE NOT ALONE in raising a child with special needs.

For more information about our program, visit our website: www.massfamilyties.org or call our toll-free line, 800-905-TIES (8437).

Family TIES of Massachusetts is a project of the Federation for Children with Special Needs, with funding from and in collaboration with the Mass. Department of Public Health, Bureau of Family Health and Nutrition, Division for Perinatal, Early Childhood, and Special Health Needs.

Opportunity Knocks

The Early Intervention Parent Leadership Project is currently recruiting family members of children who will be graduating from Early Intervention before July 1, 2010 to participate in the EI Focused Monitoring process.

Family members will need to commit to an orientation training which will be held in May or June of 2010. Following the training, families who are interested in becoming involved in the focused monitoring process will then be asked to make a commitment of participating in up to two onsite visits during the upcoming fiscal year (July 2010- June 2011). An onsite visit consists of a pre-onsite interview, desk audit meeting, which is a discussion of the data from the EI program chosen, and two full days onsite at an Early Intervention program to gather information. Most program assignments are located within the region in which you live. Families will not be assigned onsite visits to the program from which their child graduated or any program with which they were previously involved.

For more information on the focused monitoring process or how you can be involved please contact Faith Piaggi at the Early Intervention Parent Leadership Project toll free line 1-877-353-4757.
“Can We Talk?” by Ellen McGrail Waddill

On March 1, members of the Early Intervention Community, more than 200 parents, young children and Early Intervention professionals held a “Stroller-In” at the Massachusetts State House to bring attention to the proposed changes to EI services. Many families of children who received Early Intervention services also wrote letters to their State Legislators. In April, the Professional Center for Child Development, one of the 58 Early Intervention Programs in Massachusetts, held a “Legislative Coffee Hour”, inviting local legislators to meet with parents and staff members.

“You got our letters… Now, let’s talk” was the theme of The Professional Center for Child Development’s Legislative Coffee Hour. Over 55 children, parents, Massachusetts law makers, Staff, and friends of the Center were on hand to join in conversation about the importance of Early Intervention. Senators Baddour, Tarr, and Tucker along with Representatives Finegold, L’Italien, and Torrisi spoke of how Early Intervention has touched their lives in personal ways. Some shared experiences with friends or relatives and some as the parent of a child who received EI services. The legislative delegation in the Merrimack Valley has been receptive and understanding throughout the years in regard to children and families – and we thank them for that.

Adrienne Ward, a former EI parent talked to the group about her experience: “Five years ago at the tender age of 2, my son Gavin, who was born premature, spoke only 3 words”. She went on to share her fears for the future and how the PCCD EI Program helped Gavin become the confident first grader he is now. Erin Knyff also spoke about the challenges and joys of parenting a child who is not typically developing.

The families at the PCCD sent letters, emails and made phone calls to Beacon Hill. Many of the letters and photos of the children were suspended from the ceiling of the Andover Center so the legislators could once again read the words of a worried Methuen grandparent “what happens if these children don’t receive help? How will they be able to perform when it’s time to attend preschool?” and concern from a North Andover couple… “Under the proposed cutbacks, our twins would not have been eligible for services. I cannot imagine our family’s life without Early Intervention”.

The PCCD’s Parent & Community Liaison hosts this coffee hour each year bringing together the legislators, their youngest constituents and the adults who are concerned for them. We were pleased to have a lively discussion and an opportunity for our elected officials to hear of the amazing work done at The Professional Center for Child Development.

Youth Leadership

“Everyone is Different...Everyone Belongs”

Sixteen years ago, Carrie Piaggi and Tiffany Gundler were infants enrolled in the Massachusetts Early Intervention System. They both received services from a variety of providers, and at three years old, they transitioned to preschool programs. Through their challenges and triumphs, they have developed leadership skills and become self-advocates. Today, Carrie and Tiffany are busy, active teenagers involved in their schools and communities.

This March, Carrie and Tiffany stood before a group of parents and professionals at the Federation for Children with Special Needs’ annual conference, Visions of Community, to share their experiences with inclusion. Together with Dr. Joseph Petner, former principal of the Haggerty Elementary School in Cambridge, Carrie and Tiffany discussed what inclusion means and highlighted the many ways in which inclusion benefits both children with disabilities and their typically-developing peers. Dan Habib’s award-winning documentary, Including Samuel, in which Dr. Petner is featured, was used to provide examples of the ways in which families, students, schools and other community members can come together to create opportunities for all children to belong.

For Tiffany and Carrie, inclusion has meant more than just being in classes with their peers. “Inclusion means offering the same opportunities to everyone, and fostering a sense of belonging.” Tiffany explained. She feels strongly that all children learn social skills and acceptance when they are encouraged to work and play together in school, sports, and community activities. Both Carrie and Tiffany encouraged the parents and professionals in the audience to think about the ways in which inclusion is working and what kinds of things could provide more opportunities for successful inclusion.

Carrie Piaggi, Joe Petner and Tiffany Gundler share their experiences with inclusion in education and the community.

Carrie Piaggi, Joe Petner and Tiffany Gundler share their experiences with inclusion in education and the community.
As Parent Representatives on the Massachusetts ICC (Interagency Coordinating Council), we wanted to know how our work and efforts could benefit all families of children enrolled in Early Intervention. We thought about the things that we would want to know and how we could best encourage other families whose children receive EI services to get involved in the system. As parents, we have gained a lot of knowledge and experience living our own lives with our children. We wanted to be able to take what we had learned and share it with other parents.

We decided to propose a new committee to the ICC. This new committee is called the Family Leadership Team. Our purpose is simple: to work collaboratively with the Parent Leadership Project and other organizations to help parents and to ensure that the information we receive, as ICC parents, is disseminated appropriately in a streamlined process. As members of the ICC, we want to make sure that our time serving as ICC Parent Representatives is meaningful for all families. Creating this new Committee will allow us all to find our voice and help other parents find their voices as well.

Our first meeting was held on April 28, 2010. We are in the very beginning stages of getting the Committee up and running. We re-wrote our Charge, are trying to find the best methods of communication for the committee and are in the process of putting together a schedule for the members to write articles for the Parent Perspective Newsletter.

At the ICC Meetings, we wanted to find a way to let the members of the Committee know something about us. We are going to take turns sharing a “Parents Piece”. This will be a short piece that will allow us to share one of the following:

- How we became Parent Leaders
- How we built strong Parent-Provider relationships
- How Early Intervention helped our children

We wanted to be able to share something meaningful with the whole ICC to let them know why we do what we do or who in Early Intervention helped us get where we are. We think this will be a great opportunity for the Committee members to really get to know us.

Although we have a long road ahead of us, we are very excited about what the future holds for the Family Leadership Team. We hope to grow as individuals, grow as a team and enable parents to start on the same paths that we did in order to help make a difference for all children in Early Intervention.

Look for the “FLT Corner” in future issues of the Parent Perspective Newsletter for the latest news about the Family Leadership Team.

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**Family Leadership Corner:**

**Introduction to the Family Leadership Team**

*By Crystal Hebert, Chair of the Family Leadership Team*

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**Parent Participation Opportunity**

**Join the Parent Leadership Project**

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**The Early Intervention Parent Leadership Project is Hiring!**

**Communications Coordinator**

- Develop and edit the Parent Perspective newsletter
- Collaborate with other family organizations and Early Intervention programs
- Assist in development of the EIPLP website
- Increase awareness of the Parent Leadership Project and opportunities for family involvement
- 22 hours per week, office space in a regional health office

If you are the parent of a child who has been enrolled in the Massachusetts Early Intervention System within the last five years and are interested in learning more about this opportunity, we would love to hear from you! Please contact the Parent Leadership Project toll-free at 1-877-353-4757, by e-mail at eiplp@yahoo.com or watch for the posting on the www.eiplp.org website!
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, an EI Program Focused Monitoring Parent 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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English and Español

To receive the Parent Perspective Newsletter, a free publication published 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 August 2010. Please call our toll-free number (877) 353-4757 or the email the newsletter editor at Brenda.allair@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.