



The Parent Leadership Project's *Parent Perspective*

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Early Intervention Information and Resources

September/October 2007

Paths to Leadership: Becoming a Parent Leader

Grant-Writing Workshop Inspires Parents

The Parent Leadership Project hosted a “Kitchen-Table Grant Writing Workshop” for families interested in learning more about how to write a grant to support their projects or ideas. The workshop, presented by Evelyn Haussein, was held on September 20 at Criterion Valley Early Intervention Center in Milford. Discussion included the basic elements of writing a grant, including the requirements for the Haussein Parent Leadership Awards. Named in honor of Evelyn Haussein, one of the most influential parent leaders in Early Intervention, the Haussein Awards were created to support families in taking leadership roles at their Early Intervention programs and within their communities.

Evelyn has worked as a grant reviewer for the Federation for Children with Special Needs, the Massachusetts Department of Education, and several other organizations. She told the group that “it’s important to never write a grant by yourself. Talk your ideas over with someone else.” Evelyn encouraged parents to collaborate with others in their Early Intervention program and community to spark ideas and interest for their projects. Several of the parents who attended the workshop have written grants for community projects and were able to have them funded.

The Haussein Parent Leadership Awards are funded through the support of the Department of Public Health, and the project ideas submitted by parents must meet certain criteria. The awards are



Evelyn Haussein shares information with a parent.

given to projects that are parent-driven and demonstrate collaborations between families and community organizations. This year, families whose children have graduated from EI within the last three years are also encouraged to apply.

Deadline for this year’s Haussein Parent Leadership Awards application is **October 26**. For more information, contact the Early Intervention Parent Leadership Project at 1-877-353-4757 or visit www.eiplp.org.

Save the Date!

Joining Voices Conference — Nov. 29th

The Massachusetts chapter of Family Voices, a grassroots organization of families and friends speaking on behalf of children and youth with special health care needs, announces its seventh-annual *Joining Voices* Conference. The conference will be held on November 29 at the UCC Conference Center in Framingham. Massachusetts Family-to-Family Health Care Information & Education Center, a project of Massachusetts Family Voices at the Federation of Children with Special Needs, will be hosting the conference.

Joining Voices is a *free* day-long conference that offers support to families of children and youth with special health care needs. Parents will have the opportunity to network with other families and learn specific skills to help them be effective partners in decision-making with providers, sys-

tems of care and policymakers. Workshop topics for this year’s conference include: Parent Advisory Groups at Pediatric Practice, Legislative Advocacy, “Title V & You” and other topics of interest.

The full conference agenda along with directions to the UCC Conference Center is available online at the Massachusetts Family Voices website, www.massfamilyvoices.org. For more information about the conference or to register, please contact Beth Dworetzky at 1-800-331-0688 ext. 210, or register online or by email at massfv@fcsn.org.

**MASSACHUSETTS
FAMILY VOICES**

Families! The NCSEAM Family Survey has arrived

Each Early Intervention program received a packet of materials in the last few weeks. By now some of you may have been given your Survey to fill out. We hope that the questions make sense and are a useful way to describe your Early Intervention experience. The exciting news is that some have already been returned. Surveys that are received and analyzed between September and December will be used in the next Part C Federal report. Information gathered from all surveys from September to June will be analyzed and reported out to every EI program. DPH will use the information to improve the statewide EI system; your program will know a lot more about what you need and whether the services they provide meet these needs. **You can see that your voice and your thoughts really count!**

Last year, which was the first year of a statewide Family Survey, DPH distributed 1200 surveys. We had a remarkable return rate of 40%, more than triple what is usually expected. With your help, we hope to do at least as well this year. So please, look for the Family Survey at the time of your six month IFSP review, fill it out in **pencil** and return it in the self-addressed, stamped envelope provided.

Family Survey Frequently Asked Questions

1. What if I need some help in understanding or filling out the Survey?

One resource is Parent Liaisons. DPH and the EI Parent Leadership Project (EIPLP) provided training to Parent Liaisons to answer questions from families about completing the survey.

2. What's a Parent Liaison and how would I know if my program has one?

Parent Liaisons are family members whose children went through EI who are hired by their EI program to help families get the information they need and get involved in program activities. Right now, 15 programs have Parent Liaisons. You can ask your Service Coordinator or Program Director if your program has a Parent Liaison.

3. Who can help if my program does not have a Parent Liaison?

Your Service Coordinator, other staff within the EI program or agency, family members, other community agencies where you receive services or the Parent Leadership Project.

¡Atención familias! Ha llegado la encuesta familiar de NCSEAM

Durante las últimas semanas, todos los programas de Intervención Temprana (*Early Intervention*) han recibido un paquete con materiales. Algunos de ustedes tal vez ya hayan recibido una encuesta para rellenar. Esperamos que las preguntas tengan sentido y le resulten útiles para describir su experiencia con el programa de Intervención Temprana. Lo interesante es que algunas encuestas ya fueron completadas y enviadas de vuelta. Aquéllas que se reciban y analicen entre septiembre y diciembre se usarán en la Parte C del próximo informe Federal. Y la información que se recopile de todas las encuestas entre septiembre y junio se analizará e informará a todos los programas de Intervención Temprana. El Departamento de Salud Pública usará esta información para mejorar el sistema de Intervención Temprana a nivel estatal. De esta forma, el programa que le brinda servicios a usted entenderá mucho mejor sus necesidades y en qué medida sus servicios las satisfacen. **Como puede ver, ¡su voz y sus opiniones realmente cuentan!**

El año pasado —el primero en que se llevó a cabo una encuesta a familias de todo el estado— se distribuyeron 1200 encuestas. La tasa de respuesta fue notable, 40%, más del triple de lo que comúnmente se espera. Con la ayuda de todos ustedes, este año esperamos tener como mínimo el mismo nivel de participación. Así que, por favor, estén atentos a la Encuesta Familiar cuando llegue el momento del repaso de su Plan individualizado de servicios familiares (*Individualized Family Service Plan* o IFSP, en inglés) a los seis meses. Rellenen la encuesta con **lápiz** y envíenla en el sobre provisto, ya franqueado y con dirección de destino.

Preguntas comunes acerca de la Encuesta Familiar

1. ¿Qué hago si necesito ayuda para entender o completar la encuesta?

*Un recurso posible es el servicio de enlace con otros padres llamado Parent Liaisons. El Departamento de Salud Pública y el Proyecto Padres Líderes del programa de Intervención Temprana (*Early Intervention Parent Leadership Project* o EIPLP, en inglés) capacitaron al personal de *Parent Liaisons* para contestar las preguntas de las familias sobre cómo completar la encuesta.*

2. ¿Que es un *Parent Liaison* y cómo puedo saber si mi programa tiene uno?

Los Parent Liaisons son familiares de niños que han recibido servicios de Intervención Temprana y a quienes su programa de IT contrata para que ayuden a otras familias a obtener la información que necesitan y a participar en las actividades del IT. Actualmente hay 15 programas que tienen Parent Liaisons. Pregunte a su coordinador de servicios o director local si su programa tiene un Parent Liaison.

3. Si mi programa no tiene un *Parent Liaison*, ¿quién puede ayudarme?

Usted también puede recibir ayuda de su Coordinador de servicios, otro personal de su programa o agencia de Intervención Temprana, familiares, otras agencias comunitarias donde usted recibe servicios, o del Proyecto Padres Líderes (Parent Leadership Project).

One Path to Leadership . . .**Finding Your Way:
One Parent's Journey to Leadership***By Lynn Bopp*

Parent Leadership means different things for different families. It can be chairing a large meeting, giving your opinion about a policy or program or deciding to learn everything you can about your child's particular diagnosis. What's the same for every family is that becoming a parent leader is a journey. Here's how one family took a step on the path.

Many times we were told "Your son has the cutest button nose!" Those words rang clear in our minds after our son Tyler was diagnosed at 10 months with Isodicentric 15 (IDIC15), a specific type of chromosomal abnormality. There are not many physical characteristics with this syndrome, but one of the few happens to be a button nose. To say the least, we were devastated by the diagnosis.

It can be somewhat confusing explaining this syndrome because it involves detailed information on chromosomes and genes. Isodicentric 15 occurs when a child is born with extra genetic material from Chromosome 15. Typically, people have 46 chromosomes. Children born with this syndrome have 47. The 47th chromosome is made up of a piece of chromosome 15. This extra piece is a mirror image of a specific area on chromosome 15. To fully understand this syndrome, I encourage everyone to visit <http://www.idic15.org/index.php>.

Shortly after the diagnosis, we joined an online support group called IDEAS. IDEAS provides family support and promotes awareness, research and targeted treatments for chromosome 15q duplication syndrome. We were warmly welcomed into the group and immediately informed of a conference, *Sharing the Journey*, that was to be held in Boston. This was a three day conference covering all aspects of IDIC15. We were hesitant to go, but were strongly encouraged by so many members of the IDEAS group.

To be expected, the conference would come with a financial expense that would hit us hard because of many out-of-pocket expenses we had already faced. We mentioned the conference to our Early Intervention provider and were given some contacts that can help provide financial support to attend conferences. After many calls, we were unsuccessful due to the short notice of two weeks. Our EI program contacted the Parent Leadership Project for more ideas. We were so blessed when the PLP worked with us to locate funds that paid for the entire cost of the conference. We were thrilled beyond words because it was something positive in our lives when we felt so hopeless and alone. To know there are people out there that care and want to help means so much to us.

As we entered into the conference we thought to ourselves, "RUN!". It was very overwhelming at first to see all the children with this syndrome. Some of the children were mildly affected and others were more severely affected. But within minutes our thoughts changed to we *never* want to leave! What an extraordinary experience we had at this conference. The IDIC15 conference is held every two years around the States. We plan to attend all future conferences.

The conference committee did such an amazing job. The conference sessions offered us a detailed explanation of the syndrome. There were so many seminars to choose from that addressed specific needs of children with this syndrome. The panel of doctors, the speakers, the slideshows, the handouts, the conversations could never have been accessible anywhere else. We could never find this level of information in a book, on the internet, or from a pediatrician. After each seminar the doctors met with families to answer their questions. There was such a large panel of professionals put together that covered each symptom of this syndrome. The most amazing experience was meeting so many families. Just knowing we were not alone felt incredible. The experiences, the tears, and the triumphs these families brought to the conference were priceless. We learned so much about this syndrome from attending this conference and at the same time we made life long friends. We are part of an amazing IDIC15 family!

Our experience at the IDIC 15 conference was so inspirational. During a time of great sadness, we felt and saw a glimpse of hope for our son Tyler and our family. The next scheduled IDIC15 conference is in Indiana in 2009, and I can say "Indiana here we come!!!!"

Richard and Lynne Bopp are the proud parents of two adorable boys. Their first son Aiden (4yrs), was diagnosed with Autism at 18 months. Their son Tyler (16mths), was recently diagnosed with Isodicentric 15 (IDIC15). "We are so proud of both boys. They have accomplished so much in their short lives. They are truly our heroes".



ENCONTRANDO TU MANERA: “El camino de un padre hacia el Liderazgo”

~ Lynn Bopp

Ser padre líder tiene un significado diferente para cada familia. Puede consistir en presidir una reunión grande, dar la opinión sobre una política o programa, o decidir que uno se informará lo más posible sobre el diagnóstico específico de su niño. Lo que tiene en común para todas las familias, sin embargo, es que para convertirse en padre líder hay que transitar un camino. Éste es el relato de cómo una familia dio un paso en esa dirección.

Nos han dicho muchas veces, “¡Tu niño tiene una nariz en forma de botón divina!” Esas palabras quedaron reverberando claramente en nuestras mentes después de que a nuestro hijo Tyler le diagnosticaron el síndrome de duplicación del cromosoma 15q (IDIC 15), un tipo específico de anomalía cromosómica. Este síndrome tiene pocas características físicas, pero uno de los pocos rasgos que sí tiene es la nariz en forma de botón. El diagnóstico fue un golpe tremendo para nosotros.

La explicación de este síndrome puede ser algo complicada porque requiere dar información detallada sobre cromosomas y genes. Ocurre cuando un niño nace con material genético sobrante en el cromosoma 15. Normalmente, las personas tienen 46 cromosomas. Pero los niños que nacen con este síndrome tienen 47. El cromosoma 47 está formado por parte del cromosoma 15. Esta parte de más es la imagen especular de una sección específica del cromosoma 15. Para entender bien este síndrome, recomiendo a todos que visiten esta página web: <http://www.idic15.org/index.php>.

Al poco tiempo de recibir el diagnóstico, comenzamos a participar en un grupo de apoyo por Internet llamado IDEAS. Este grupo brinda apoyo a las familias y promueve la información, la investigación y tratamientos específicos para el síndrome de duplicación del cromosoma 15q. Después de darnos una cálida bienvenida al grupo, nos informaron de inmediato de una conferencia que se iba a celebrar en Boston titulada *Sharing the Journey* (Compartiendo el camino). Se trataba de una conferencia de tres días que iba a cubrir todos los aspectos del IDIC 15. Dudábamos en ir, pero muchos miembros del grupo IDEAS nos alentaron fuertemente a que lo hiciéramos.

Como era de esperarse, la conferencia implicaba gastos difíciles de afrontar para nosotros por las muchas otras cuentas que teníamos y que debíamos pagar de nuestro propio bolsillo. Cuando se lo mencionamos a nuestro proveedor de servicios de Intervención Temprana, nos dio algunos contactos que podían dar apoyo económico para asistir a conferencias. Hicimos muchas llamadas pero no tuvimos éxito por el poco tiempo que quedaba, sólo dos semanas. Entonces nuestro programa de Intervención Temprana se comunicó con el Proyecto Padres Líderes (Parent Leadership Project o PLP) en busca de otras ideas. Tuvimos la gran suerte de que el PLP trabajó con nosotros y nos ayudó a localizar fondos que cubrieron el costo completo de la conferencia. No hay

palabras para describir la dicha que sentimos, porque fue algo positivo en nuestras vidas en un período en el que nos sentíamos descorazonados y solos. El saber que hay gente que se preocupa y desea ayudar significa muchísimo para nosotros.

Cuando entramos a la conferencia, lo primero que pensamos fue “¡HUYAMOS DE AQUÍ!” Porque al principio fue muy abrumador ver a tantos niños con este síndrome. A algunos los afectaba en forma leve y a otros en forma más severa. Pero a los pocos minutos cambiamos de parecer y pensamos, “¡De aquí no me quiero ir *nunca!*” Esta conferencia de IDIC 15 fue una experiencia extraordinaria para nosotros. Se celebra cada dos años en diferentes estados, por todo el país. Tenemos la intención de asistir a todas las conferencias futuras.

El comité organizador hizo un trabajo espléndido. En las diferentes sesiones de la conferencia nos explicaron el síndrome en forma detallada. Había muchísimos seminarios para elegir, cada uno dedicado a necesidades específicas de los niños afectados. En ningún otro lugar hubiéramos podido encontrar semejante panel de médicos y oradores o este tipo de presentaciones de diapositivas, folletos y conversaciones. Jamás encontramos este nivel de información en ningún libro, página de Internet o consultorio pediátrico. Después de cada seminario, los médicos se reunían con las familias para contestar preguntas. El panel de profesionales convocados para cubrir cada síntoma de este síndrome era completísimo. La experiencia más maravillosa fue conocer a tantas familias. El simple hecho de saber que no estábamos solos fue una sensación increíble. Las experiencias, lágrimas y triunfos que estas familias compartieron en la conferencia no tienen precio. Al asistir, no sólo aprendimos muchísimo acerca del síndrome, sino que además nos hicimos amigos para toda la vida. Somos parte de una familia asombrosa, ¡la familia del IDIC 15!

Nuestra experiencia en esta conferencia fue una gran fuente de inspiración. Estábamos atravesando un período de gran tristeza pero en la conferencia percibimos y sentimos una chispa de esperanza para nuestro hijo Tyler y nuestra familia. La próxima conferencia de IDIC 15 está programada para el 2009 en Indiana y, puedo decirlo con total certeza, ¡allí estaremos!

Richard y Lynne Bopp son los orgullosos padres de dos muchachos adorables. A su primer hijo, Aiden (de 5 años), se le diagnosticó autismo a los 18 meses de edad. Y a su hijo Tyler (de 16 meses) se le diagnosticó IDIC 15 recientemente. “Estamos tan orgullosos de nuestros dos varones. Han logrado tanto en el poco tiempo que tienen de vida. Son realmente nuestros héroes”.



Family TIES of Massachusetts: *Together In Enhancing Support*

Family TIES of Massachusetts is a network for parents of children with special needs. As parents of children with special needs, we realize that the most powerful source of support is other parents. Sharing information provides family members with knowledge and skills that help to improve our children's opportunities.

Family TIES is pleased to announce that we have several new Regional Coordinators, and we would like to familiarize you with the names of all of our staff. The Regional Coordinators, located in DPH offices across the state, can assist families in finding resources in their community, connect families with Early Intervention programs, and arrange for our "Let's Get Organized" workshops. The Parent-to-Parent Coordinator arranges for parent matches and our "Listening and Learning" workshop, for those who would like to build their listening skills and become trained Support Parents. We hope to hear from you soon!

Regional Coordinators:

Boston: Cassandra Castillo, 617-541-2875
 Metrowest: Michelle Gaudet, 781-774-6602
 Southeast: Miriam Biurci Scrivener, 781-774-6749
 Northeast: Kathie Dell'Arciprete, 978-851-7261 x4018
 Central: Barbara Donati, 508-792-7880 x2337
 West: Gloria Klaesges, 413-586-7525 x1133

Parent-to-Parent Coordinator:

Linea Luck Pearson, 508-792-7880

Program Director:

Mary Castro Summers, 781-774-6736



WORKSHOPS & CONFERENCES

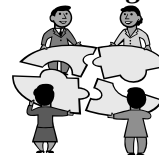
Halloween Skate Party — Oct. 20 from 11am to 2pm at Criterion Valley Early Intervention Program in Milford. This free event is open to all families involved in the Early Intervention Regional Consultation Programs throughout the state. Families are invited to an afternoon of music, food and fun, including a puppet show and trick-or-treat parade (costumes optional). For more information, contact Novlette Wilson at Thom WRCP, 413-783-5500.

Basic Rights — Oct. 22 from 6-8pm at the Chicopee Public Library in Chicopee. This workshop provides families with information about their rights and responsibilities under federal and state special education law. For more information or to register, contact Karen Cassidy, Thom WRCP at 413-783-5500 ext. 16 or email kcassidy@thomchild.org.

Annual Regional Western MA Early Intervention Conference — Oct. 25 from 12 to 4:30 at the Log Cabin in Holyoke. The topic for this year's conference is "The Challenging Young Child". Parents and providers are invited to attend, and lunch will be provided. Registration is required. The conference is free to families enrolled in the Thom Western Regional Consultation Program; there is a fee for other participants. For more information, contact Karen Cassidy at 413-783-5500.

Massachusetts Families Organizing for Change Statewide Conference "Creating the Possibilities" — Oct. 27 from 8:30am to 3:30pm at the Holiday Inn in Marlboro. This free conference offers families the opportunity to meet, network and learn from other families while learning about how to get involved and advocate for change. For more information or to register, visit www.mfofc.org.

Regional Parent Networking Meetings



The Early Intervention Parent Leadership Project is pleased to present a series of meetings for families to connect, share information, learn about resources and discover opportunities for Parent Leadership.

Meetings will be held this fall at several locations throughout the state.

For more information about meeting dates, times and locations, please contact the Parent Leadership Project
 1-877-353-4757
 E-mail: eiplp@yahoo.com

Next Steps . . . 2007 — Nov. 8&9th at the Holiday Inn/Boxborough Woods Hotel and Conference Center in Boxborough. This conference, hosted by the Deaf and Hard of Hearing Program of Children's Hospital Boston and Gallaudet University Regional Center, offers a forum for making connections and sharing information by bringing together parents and professionals who are experienced in working with children who are deaf and hard of hearing. Family members are encouraged to attend, and a reduced registration fee is available. For more information, visit www.childrenshospital.org/dhnp or call 781-216-2240.

Resources**Family Sign Language Program:
A "Handy" Resource**

Communication is a critical component to a child's overall development. Through interaction with family members and caregivers, children develop a solid foundation of language. For children who are deaf or hard of hearing, access to spoken language may be

hindered through hearing loss. Given access to a visual signed language, children who are deaf or hard of hearing are able to acquire language as successfully as their hearing peers. Through sign language, children who are deaf or hard of hearing are able to develop a solid foundation of language.

Since 1988, the Family Sign Language Program has offered sign language instruction to families across the state. The program, which is part of a larger advocacy effort of the Massachusetts State Association of the Deaf, is funded by the Massachusetts Department of Public Health. Family Sign Language serves families of children who are deaf or hard of hearing from birth to age three and offers classes free of charge to families in the comfort of their own homes. A total of twenty sessions are offered to families through the Family Sign Language curriculum. Teachers instruct families in signing across a variety of topics including: mealtime, bedtime, playtime, family, and illness/safety. Through instruction, families learn how to communicate confidently in sign language, strategies to make their home more 'visually accessible' and how to access available resources.

Who is eligible?

Families of children ages birth to 3 who are deaf or hard of hearing and are enrolled in their area Early Intervention program are eligible to receive services from the Family Sign Language Program.

Family Sign Language Instructors

After an initial contact with the Program Coordinator to assess the family's communication needs, an instructor will be assigned to provide sign language classes. Each instructor has been selected because of his/her experience teaching sign language and/or working with children. The instructors are specially trained to meet the needs of parents, care providers, and other family members as they develop their sign language skills for communication.

Referrals

Parents, schools, Early Intervention programs, hospitals, and other agencies serving children who are deaf or hard of hearing are welcome to make referrals to the program. To make a referral, please contact Fran Conlin, director for the Family Sign Language Program at fslp@msad.org or call (781)388-9114.

About MSAD....

The Family Sign Language Program is coordinated by the Massachusetts State Association of the Deaf (MSAD) through funding from the Massachusetts Department of Public Health.

Spotlight on DPH Programs**MASSTART**

Parents of children with complex medical needs may worry about how their child will stay safe and have their needs met when they are in school or other group settings. Families who have children with complex medical issues and those whose children are assisted by medical technology (feeding tubes, tracheostomy, IV lines, etc.) may need support in helping the school staff understand their child's health care needs.

The MASSTART (Massachusetts Technology Assistance Resource Team) Program, supported through the Massachusetts Department of Public Health is a free program that provides services to children with special health care needs who are assisted by medical technology. MASSTART works with families and school personnel to assist in developing an individual health care plan for the child, provide educational programs about children with special health care needs and resolve issues that may impact the child's health needs during the school day.

MASSTART providers have extensive experience providing health care services to children with a variety of complex medical conditions and technology needs. Providers are located in several regions throughout the state. To find a MASSTART provider, families can contact the Program Coordinator at 508-792-7880. Information is also available by calling the DPH Community Support Line at 1-800-882-1435.



Working Together — Northeast Region

The Criterion-Stoneham Early Intervention Program

hosted its annual summer picnic at Ipswich River Park on August 21. Children and families enrolled in the program enjoyed the wonderful weather and were treated to live music. The PAC (Parent Advisory Council) for the program is currently planning their fall discussion series, which will include talks on menu planning and nutrition, arts and crafts, and sign language. For more information about upcoming events, please contact the program secretary at 781-935-3855.

Thom Anne Sullivan Early Intervention Program will be very busy with plenty of activities and events in the next few months. “Itsy Bitsy Yoga”, co-sponsored by Family Foundations Network, will be presented by Donna Gorman. On October 17, babies 8 months to 24 months old are invited, along with a parent, to participate in the program. On November 7, the yoga group will be available to toddlers ages 24 months to three years and a parent. “Introduction to Sign Language”, a six-week program for parents and staff to learn to sign with infants and toddlers, will be held at Thom Anne Sullivan program from October 4 through November 8. The Early Intervention program will also be hosting an Open House on November 15 from 4:30-6:30pm. This is a wonderful opportunity for families to visit the center and meet other families and staff. Refreshments will be available, and children will have play

room activities and a musical guest to entertain them for the evening. Parents who are interested in learning more about any of the workshops or events can contact Karen Kane at 978-453-8331 ext. 256 or email pac@asc.thomchild.org.

The Professional Center for Child Development (PCCD)

will host information evenings for parents of children in Early Intervention who may be moving on to special education in the public school systems. PCCD and the Northeast Regional Consultation Program invite families to attend “Turning Three & Basic Rights Workshop” on October 18 from 7-9pm to learn more about the transition process. The workshop is offered through the Federation for Children with Special Needs. The program will also offer an “IEP Workshop” on November 8 from 7-9pm. This workshop will provide families with information about developing an IEP (Individualized Education Program) for their child. To register for these workshops, contact Ellen at 978-475-3806 or email Ellen@TheProfessionalCenter.org.



Focused Monitoring: Family Involvement

By Faith Piaggi

The Focused Monitoring process allows DPH to target regional resources to programs to promote core values, and ensure compliance with federal and state requirements through training, technical assistance and monitoring.

Parents are a crucial part of the Focused Monitoring process. Parent Team Members are trained to work as part of a team with EI Regional Specialists to complete onsite visits at Early Intervention programs around the state. Parents choose to participate in the Focused Monitoring process for many different reasons.

Bette Surette is one of the parents who decided to become involved as a Focused Monitoring parent team member. Bette is the mother of two young children; her daughter was referred to Early Intervention after being born prematurely and was enrolled in the program for one year. She was transitioned out of the program after having met appropriate developmental milestones. As her daughter grew, Bette had additional concerns about her child’s speech. Bette requested another evaluation from Early Intervention, and her daughter again started EI and graduated at age 3. Now her daughter loves to talk to her brother and the rest of the family!

Bette was extremely grateful to her EI program for working with her daughter and family and answering all of her questions. After her daughter graduated from EI, Bette saw a *Parent Perspective* newsletter article about a training for parents who wanted to be involved in Focused Monitoring. With previous work experience as a quality control inspector in the engineering field, Bette felt she could take her talents and apply them to the experiences she had in EI. She was also looking for the opportunity to get involved without having to be away from her children for long periods of time. Since the Focused Monitoring visits take place over two days, her husband is able to take time off if she cannot find other childcare, which works well for their family.

Bette also enjoys the opportunity to use her skills and energy as well as her experiences in EI to work with others. One of Bette’s favorite parts about participating in Focused Monitoring is the opportunity to visit different programs to facilitate parent groups and meet other program staff. Bette says she finds it interesting that “each local EI program works very differently for a common goal of providing services to children and families.”

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/Training Coordinator and Collaboration and Outreach Coordinator. Please feel free to contact any of them with your thoughts, suggestions, and concerns.

Statewide Director:

Darla Gundler
Toll-Free 877-35-EI-PLP
800-445-1255 Ext. 1157
Darla.gundler@state.ma.us

Communications Coordinator

Brenda Allair
413-586-7525 Ext. 1162
Brenda.allair@state.ma.us

Education/Training Coordinator

Lynn Taylor
781-774-6622
Lynn.taylor@state.ma.us

Contact Us:

Toll-Free: 877-35-EI-PLP
Email: eiplp@yahoo.com
On the web: www.eiplp.org

EI Focused Monitoring Parent Coordinator

Faith Piaggi
413-663-3610
faithp1@verizon.net

Collaboration and Outreach Coordinator

Jada Carlson
978-851-7261 Ext. 4058
Jada.carlson@state.ma.us



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NEXT DEADLINE: We welcome your input and suggestions for resources and articles. The next deadline is **November 16**. Please call our toll-free number (877) 353-4757 or the email the newsletter editor at Brenda.allair@state.ma.us.

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