

The Parent Leadership Project's *Parent Perspective*

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Early Intervention Information and Resources

June 2008

Paths to Leadership: Becoming a Parent Leader

Parents Put the Pieces Together at MEIC Conference

Families, Early Intervention providers and community partners came together for two days of learning and sharing during the 2008 Massachusetts Early Intervention Consortium (MEIC) Conference. More than 500 people attended each day of the conference, which was held on May 7 and 8 at the Best Western Royal Plaza Hotel in Marlborough.

Attendees were treated to an inspiring keynote address as speaker Elissa Bruno, author, teacher and leader in the early childhood field, encouraged participants to sing, laugh and dance during the first morning. Her shouts of “Are you ready?” energized the group as she spoke to them about partnering with and welcoming change.

Both days of the conference also included a wide variety of workshops, including sessions on feeding issues, legislative advocacy, social and emotional development and many others. The exhibit hall offered books, toys, and numerous resources for families of young children, and parents attending the conference were invited to relax, have a snack, and connect with other families in the Family Hospitality Room sponsored by the EI Parent Leadership Project.

On Wednesday evening, families attending the conference were invited to gather together for a Parent Networking Dinner sponsored by the Early Intervention Parent Leadership Project through the Massachusetts Department of Public Health. The theme for the evening was “Parent Leadership: Putting the Pieces Together”. Suzanne Gottlieb, Director of Family Initiatives at DPH, welcomed families to the dinner. “Just being



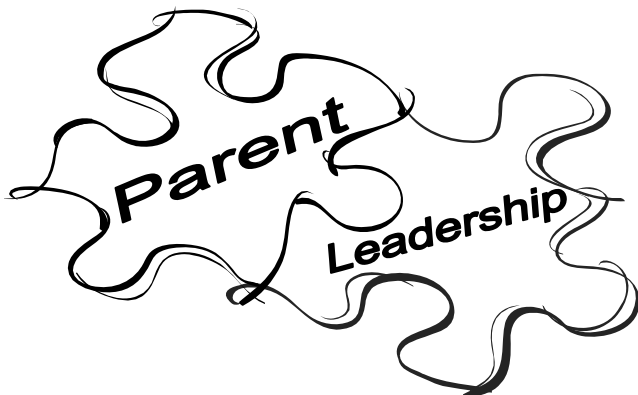
Parents (and baby!) enjoy the opportunity to share a meal and conversation at the Parent Networking Dinner.

here means you are on the path to leadership,” she told families.

A number of special guests shared their experience and words of wisdom with families at the dinner. Evelyn Hausslein, a long-time trainer and mentor to families on their journey to leadership, encouraged families to get involved in the EI system. Rosalie Edes, who was instrumental in the creation of the EI Parent Leadership Project, reminded parents that each of them was already a parent leader and that “your voice will be heard”. Sarah Cullen from the Massachusetts Down Syndrome Congress also spoke about her leadership journey, telling families “life gives you opportunities.”

Darla Gundler, Director of the EI Parent Leadership Project, asked families to think about what parent leadership meant to them. Each parent was given a puzzle piece to write down a word or phrase that represented parent leadership for them.

(Continued on page 5)



NCSEAM Family Survey Update



Families, the Department of Public Health appreciates your willingness to complete and return the NCSEAM Family Surveys. As reported previously, the Family Surveys we received included some excellent information about the impact of Early Intervention services for your child and family.

We have assured the federal Department of Education, Office of Special Education Programs (OSEP), the federal agency that oversees Part C Early Intervention services that we will continue to support families and EI programs to implement the Survey in effective, family-friendly ways. Some of the strategies we will be putting in place include offering more assistance to families in filling out the Survey and creating better tracking of how many Surveys are actually distributed. We are looking forward to reporting even better percentages next year.

Family Survey Frequently Asked Questions

1. I got a Survey, but didn't get around to filling it out.

2. Does one family really make a difference?
You've asked two important questions. It's not too late to complete and return your Survey. Do it today! And yes, every family is important. We want to know how having your child enrolled in Early Intervention has helped you help your child.
3. Can I find out how many families from my program returned the Survey and how our results compare to the state percentages?
Yes you can, each EI program received an individualized report with information about numbers of surveys returned and a comparison to state percentages. Ask your Service Coordinator or Program Director to show you their report.
- Are families still sending back their surveys?
Yes, so far we have received 921 more surveys. Our next report will have a whole year of data, so keep them coming.

Novedades del Cuestionario de Familia NCSEAM



Familias, el Departamento de Salud Pública aprecia su voluntad de completar y enviar de vuelta las encuestas familiares del Centro Nacional de Supervisión de la Educación Especial (*National Center for Special Education Accountability Monitoring* o NCSEAM).

Como informamos anteriormente, las encuestas familiares que hemos recibido tenían información excelente sobre el efecto de los servicios de Intervención Temprana sobre los niños y sus familias.

Le hemos asegurado a la Oficina de Programas de Educación Especial (OSEP, por sus siglas en inglés) del Departamento de Educación, la agencia federal que supervisa la Parte C de los servicios de Intervención Temprana (IT), que seguiremos apoyando a las familias y a los programas de IT para que administren la encuesta de maneras eficaces y sencillas para las familias. Algunas de las estrategias que pondremos en práctica son ofrecer más ayuda a las familias al completar la encuesta y llevar mejor cuenta de cuántas encuestas se distribuyeron realmente. Esperamos poder informar que se lograron porcentajes de respuesta todavía mejores que los del año pasado.

Preguntas comunes sobre la encuesta familiar

1. Recibí una encuesta, pero nunca llegué a completarla.

2. ¿Puede realmente una sola familia hacer una diferencia importante?
Usted ha hecho dos preguntas importantes. No es demasiado tarde para completar y enviar de vuelta su encuesta. ¡Hágalo hoy mismo! Y sí, todas las familias son muy importantes. Queremos saber cómo le ha ayudado a usted a ayudar a su niño el hecho de tenerlo inscrito en un programa de Intervención Temprana .
3. ¿Puedo averiguar cuántas familias de mi programa enviaron de vuelta la encuesta y cómo se compara nuestro porcentaje de respuesta con el del resto del estado?
Sí, puede averiguarlo. Cada programa de Intervención Temprana recibió un reporte individualizado con información sobre el número de encuestas enviadas de vuelta, comparándolo con el porcentaje a nivel estatal. Pida a su coordinador de servicios o al director de su programa que se lo muestre.
3. ¿Todavía están enviando encuestas las familias?
Sí, hasta el momento hemos recibido 921 encuestas más. Nuestro próximo informe tendrá datos para el año entero, así que no dejen de enviarlas.

The Path to Leadership . . .**Finding Your Way:
The Journey to Leadership**

Over the last year, we have highlighted parents who have become involved in the Early Intervention system in a variety of ways. Each of these parents shared their own experiences as parent leaders and the steps they took on their personal journeys. This month, we share with you their “words of wisdom” and encourage you to start down your own path to leadership!

Getting Started:

Taking the first step on the path to leadership can sometimes be the most challenging part. There are a variety of opportunities for families to become involved, and parents can choose to start small or to jump right in. Here are a few ideas for getting started:

“Start by connecting with other families. Learn about the opportunities that are available and build your knowledge.” -- Joanne Williams, ICC Parent Representative

“Build on your current skills. Families are qualified, have great ideas and can make a difference. Families know how to make things work.” -- Amy Young, ICC Co-Chair

“Attend conferences, trainings and workshops to gather information about your child’s condition. Funds are available to help defray the cost, and the experience can connect you with other parents.” -- Lynn Bopp, parent of a child in Early Intervention

Next Steps:

What do you enjoy doing? What are your personal goals for getting involved? Considering these questions can help you make the most of your time and talents. Take advantage of the many skill-building opportunities available to help you decide where your path should lead.

“Learn about the larger system of Early Intervention. Don’t overlook the personal benefits as well – you’ll learn more about the information and resources available for your child and family!” -- Amy Young, ICC Co-Chair

“Find what you are passionate about. Use your energy and enthusiasm to get involved and find leadership roles.” -- Joanne Williams, ICC Parent Representative

“Create partnerships with providers. Learn to ‘dance’ together!” -- Kim O’Connell, ICC Parent Representative

“Share your experiences with other families” -- Michelle Gaudet, Family TIES Regional Coordinator

Traveling the Path to Leadership:

Once you start down the path, you may realize that there are many ways to be involved. Committees and advisory boards and legislative advocacy – it seems that everywhere you look, there are opportunities to become involved in systems of care. Think about what is important to you and know that you can join with other families or blaze your own trail.

“You can’t do everything. Choose which activities are important to you, and choose wisely.” -- Amy Young, ICC Co-Chair

“Contact your state and national legislators to keep the needs of Early Intervention on their minds. Parents and caring professionals can accomplish amazing things from grassroots beginnings!” -- Kim O’Connell, ICC Parent Representative

The skills you’ve developed can lead to paid opportunities as well. Parent and educational advocacy, working for agencies that support families and other opportunities exist. -- Michelle Gaudet, Family TIES Regional Coordinator

The Parent Leadership Project looks forward to supporting your journey with resources, information about skill-building opportunities and opportunities for involvement. From Parent Contact for your EI program to Parent Representative on the ICC, many family opportunities exist. Contact us at 1-877-353-4757 or visit us on the web at www.eiplp.org for more information.



ENCONTRANDO TU MANERA: "El camino hacia el Liderazgo"

Durante el último año, hemos presentado los casos de padres que participaron de maneras diversas en el sistema de Intervención Temprana. Ellos contaron sus experiencias como padres líderes y los pasos que dieron en su travesía personal. Este mes, compartimos con ustedes sus "palabras sabias" y los alentamos a emprender su propio recorrido hacia el liderazgo.

Pasos iniciales:

A veces, lo más difícil puede ser dar el primer paso en el camino al liderazgo. Las familias tienen muchas oportunidades de participar, y los padres tienen la opción de empezar poco a poco o de meterse de lleno desde el principio. A continuación les ofrecemos algunas sugerencias para dar los primeros pasos:

"Empiecen por conectarse con otras familias. Averigüen qué oportunidades tienen a su disposición, infórmense a fondo." — Joanne Williams, Representante de padres en el Consejo Coordinador entre Agencias (*Interagency Coordinating Council* o ICC)

"Aumenten sus habilidades actuales. Las familias son capaces, tienen ideas buenísimas y pueden marcar una gran diferencia. Las familias saben cómo hacer que las cosas funcionen". —Amy Young, Codirectora del ICC

"Asistan a conferencias, sesiones de capacitación y talleres para obtener información sobre el problema de su niño. Hay fondos disponibles para ayudar a cubrir el costo, y la experiencia puede servirle para relacionarse con otros padres." —Lynn Bopp, madre de un niño que está en el programa de Intervención Temprana

Pasos siguientes:

¿Qué le gusta hacer? ¿Qué objetivos personales busca cumplir mediante su participación? Considerar estas preguntas puede ayudarle a aprovechar al máximo su tiempo y sus talentos. Aproveche las muchas oportunidades de desarrollo de habilidades que tiene a su disposición para ayudarle a decidir qué rumbo emprender.

"Infórmese sobre el sistema más amplio de Intervención Temprana. No pierda de vista los beneficios personales. ¡Se enterará más a fondo de la información y los recursos que hay a disposición de su niño y su familia!" —Amy Young, Codirectora del ICC

"Averigüe qué cosas le interesan apasionadamente. Aproveche su energía y su entusiasmo para participar y encontrar funciones de liderazgo." —Joanne Williams, Representante de padres en el ICC

"Forme alianzas con los proveedores. ¡Aprendan a "bailar" juntos!" —Kim O'Connell, Representante de padres en el ICC

"Comparta sus experiencias con otras familias." —Michelle Gaudet, Coordinadora regional de Family TIES

Recorriendo el camino al liderazgo:

Cuando emprenda este camino, tal vez se de cuenta de que hay muchas maneras de participar. Comités, consejos asesores, trabajo con los legisladores... Dondequiera que mire verá oportunidades de participar aun más en los sistemas de provisión de cuidados. Piense en lo que es importante para usted y recuerde que puede unir fuerzas con otras familias o abrir su propio camino.

"No se puede hacer todo. Elija las actividades que son importantes para usted y elija inteligentemente." — Amy Young, Codirectora del ICC

"Póngase en contacto con sus legisladores estatales y nacionales para que tengan presentes siempre las necesidades de Intervención Temprana. ¡Los padres y los profesionales compasivos pueden lograr cosas asombrosas empezando desde abajo!" —Kim O'Connell, Representante de padres en el ICC

Las habilidades que usted aprenda también pueden llevar a oportunidades de trabajo remunerado. Abogar a favor de los padres y la educación y trabajar para agencias que apoyan a las familias son sólo algunas de las oportunidades. —Michelle Gaudet, Coordinadora regional de Family TIES

El Proyecto Padres Líderes (*Parent Leadership Project* o PLP) está deseoso de apoyarle con recursos e información sobre oportunidades de desarrollo de habilidades y participación. Desde padre de contacto para su programa de Intervención Temprana hasta representante de padres en el Consejo Coordinador entre Agencias, las oportunidades para su familia son muchas. Para más información, llámenos al 1-877-353-4757 o visite nuestra página de Internet: www.eiplp.org.



Family TIES of Massachusetts: *Together in Enhancing Support*

Funding Specialized Medical Equipment for Young Children with Special Healthcare Needs



Family TIES receives many phone calls each year requesting information about funding for specialized equipment. We hope this list of resources will support families in accessing the equipment and supplies their children need.

Parents of young children with special health care needs, disability, or chronic health conditions face a variety of challenges, including finding appropriate equipment for their children. Equipment needs may include bathing equipment, swings, specialty car seats, seating or walking devices.

Families can speak with a pediatrician, specialists, or staff of the Early Intervention program that provides services for the child. These professionals will have the necessary training to articulate specific challenges, potential assistive devices, and vendors for the equipment and can make referrals to a physical therapist to help in the ordering process, if needed. After the equipment is identified, it is necessary to consider possible funding sources. These may include:

- Your private health insurance provider may cover the cost of the equipment under your policy's Durable Medical Equipment benefit. A prescription from the pediatrician or a specialist may be needed. Contact the Customer Service line to inquire about these benefits. Some insurers may be unable to cover the cost but have information sheets on programs that can offer assistance.
- As your primary or secondary health insurance coverage, MassHealth may cover the equipment. Remember to have the vendor seek prior authorization from MassHealth.
- The Regional Consultation Program is funded by the Department of Public Health (DPH) to provide technical assistance and supports to children who are participating in Early Intervention services and have complex medical needs. Your EI provider can make a referral to the RCP in your region.
- Contact the DPH Community Support Line (800-882-1435) to inquire about other resources.
- PASS IT ON is a free program that connects parents with donated durable medical equipment of all kinds. Call 508-477-6966 or 800-267-6768 to make an inquiry or arrange for a donation of equipment that can be shared with others.
- United Way programs may have funding for items such as car seats. Check with the local office in your city or town

for details. **The Family TIES Directory of Resources for Families of Children and Youth with Special Needs** has a listing of local offices, or check a local phone book or the internet.

- Disabled Children's Relief Fund (www.dorf.com) offers assistance for children with a variety of disabilities, especially those children without adequate health insurance.
- Massachusetts Knights of Columbus (ramps for wheelchair vans), Kiwanis, and Lions Club (especially for children with vision impairment) are community organizations that offer assistance to families. Check with your local chapter.
- Other community-based organizations that may be able to provide financial assistance include: United Cerebral Palsy of Metro Boston (617-926-5480), the Genesis Fund (genetic conditions, 781-575-1177), HALO Foundation (neurological impairments, 617-423-4256), Muscular Dystrophy Association, Massachusetts Chapter (any dystrophic conditions, 800-730-0318)
- United Health Care Children's Foundation offers grants for medical needs not covered or not fully covered by a family's health insurance. Payments are made directly to the service provider. (http://www.uhccf.org/apply_applicant.html)
- Catastrophic Illness in Children Relief Fund provides financial assistance for Massachusetts families with children experiencing a medical condition requiring services that are not covered by a private insurer, federal or state assistance, or any other financial source. Families must meet income guidelines. It is a reimbursement-based program that can review expenses for a 12-month period, looking back as far as 24 months. (www.mass.gov/cicrf)
- Reach out to Family TIES of Massachusetts, your local Special Education Parent Advisory Council, or the Mass. Family Voices listserv for resources and ideas.

We hope the length of this list is reassuring to parents, to know that there are many options available. The Family TIES Regional Coordinators may also have knowledge of local efforts. Our Parent-to-Parent Program may be useful in connecting a parent with another family who has experience in this area, too. Please feel free to reach us through our toll-free line, **800-905-TIES (8437)**.

Working Together—Metrowest Region

Cambridge-Somerville Early Intervention has completed its first year of partnership with *Raising a Reader Massachusetts*. The mission of *Raising a Reader* is “to give all children an equal opportunity for achievement by engaging their parents in a routine of daily book sharing from birth to age five, fostering healthy brain development, parent-child bonding, and the early literacy skills essential for school success.” Eighty families have been involved in the book lending program since last spring, and red book bags fly in and out of our site as books are rotated to families. On March 13, Cambridge-Somerville EI program staff hosted over 100 children, parents, grandparents and siblings at our second annual Family Fun Night. Families enjoyed singing and dancing, playing, decorating sippy cups and eating dinner together. Door prizes and treat bags added to the excitement!

The **Thom Neponset Valley Early Intervention** program has just finished celebrating its first year with Thom Child & Family Services. The program is still at the same location on Vanderbilt Ave. in Norwood with most of our long-term staff and some terrific new therapists on our team!

Thom Neponset Valley offers a quarterly meeting with all the local preschool coordinators and Special Education Directors for the twelve towns served by the Early Intervention program. The meetings have been held for the last 7 years, and this year family attendance has been on the increase. Representatives from the towns attended the meetings to discuss not only the transition process but also to share information about the Department of Early Education and Care and the Department of Education. This has been a positive opportunity to discuss family needs as they transition to the public schools and to build relationships between agencies.

Thom Neponset Valley's monthly newsletter continues to keep families informed about trainings available in the area, program needs, children's birthdays and timely topics, including “Autism Events in April” and an annual “Parent Survey” distributed with the May newsletter.

Thom Mystic Valley Early Intervention is continuing to host a monthly get-together at the center for families of children with Down syndrome. Currently enrolled families and alumni have been able to share information, stories and support while the children and siblings play. Saturday morning sessions have been popular and often allow the whole family to attend!

A group of parents at **Thom Mystic Valley** are working together to create a “Parent-to-Parent” information packet for families whose children have been diagnosed as being on the autism spectrum. The families met at a parent group and began

brainstorming ideas about books, information and support opportunities and websites they had found helpful. The idea of the information packet grew from that discussion. Thom Mystic Valley is excited about having this perspective to share with other parents.

Thom Mystic Valley has also recently developed a relationship with the owner of a sparkling new play space, “Together in Motion”, in Arlington. This relationship has led to the creation of two new music and movement groups. The groups, named “Movin’ Groovin’ Tots”, are fun for children aged 12 months to three years.

The United Way of Massachusetts Bay recently selected **Thom Charles River Early Intervention** as a Venture Partner with the goal of making Greater Boston “the best place for children in the country.” The grant will support staff to continue to enhance their ability to respond to children's social and emotional needs and to promote “partnering with parents”... building on their strengths to foster their children's healthy development. It is an exciting opportunity for the EI staff in what has been a very busy year.

“Improving Access to Early Intervention by Asian and South Asian Families” was the focus of a CHNA Mini Grant awarded to **Thom Charles River EI** this year. A wonderful Advisory Group of parents representing five countries guided the outreach efforts of the project throughout Greater Boston. The outreach of our liaison extended beyond our catchment area to Boston, Brighton and beyond.

Thom Charles River EI just completed our second 2008 Transition Workshop for parents... this one in Spanish! We appreciated the support of the Federation of Children with Special Needs and the Greater Boston Regional Consultation Program. It was well attended by families and community members.



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.

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IN THIS ISSUE

Parent Leadership p.3,4
English and Español

NCSEAM Survey p.2

Training Opportunities p.5

Family TIES News p.6

Working Together p.7

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

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