Happy 25th Birthday, EIPLP! Happy 30th Birthday, IDEA!

Leadership from the Perspective of a Mom of a Very Special Child: Celebrating 30 Years of IDEA and 25 Years of EIPLP
By Brenda Allair

“Leadership is not about titles, positions or flowcharts. It is about one life influencing another.” — John C. Maxwell

If someone had met me at the beginning of my journey and asked, “Would you like to become a parent leader?” I would have said a polite but firm, “No thank you.” I didn’t see myself as a leader, and I didn’t know if I had the skills, time, or energy to become one. Busy with the demands of caring for a baby with disabilities and complex health needs, I couldn’t imagine there were ways for me to get involved in leadership or advocacy that fit in with my crazy schedule. Slowly, through meeting with other parents in playgroups and RCP outings, I realized there were small things I could do that could have an impact.

In the early months and years with my daughter, I considered myself a “leadership learner”. I attended workshops on parent leadership, participated in focus groups, wrote letters in support of Early Intervention (EI) funding, and shared our story with other families. As my daughter transitioned from EI to preschool, I built more connections and eventually took on a position with the Early Intervention Parent Leadership Project (EIPLP). My role with the EIPLP gave me the opportunity to support other families on their own journeys, and to learn from them about the numerous ways parents were making a difference in systems at all levels – local, state, and national. While I couldn’t imagine doing what I considered the “big things”, like national projects or research, I became more involved at the level that made sense for me and my family. I also saw that parents who were successful and enthusiastic about leadership were those who became involved in things about which they were very passionate.

Because of all the time we were spending in hospitals and clinics, I was passionate about creating change in those systems that would improve families’ experiences. I joined the Family Advisory Council at our local hospital and

A Mom’s Perspective of a Data Conference!
By Melissa McCarthy

As a parent, I had the honor and privilege of attending the Improving Data; Improving Outcomes Conference sponsored by DaSy Center in New Orleans, Louisiana. The time I spent at the conference taught me about the importance of data for families and providers. It gave me a chance to connect, network, and explore relationships that enriched my learning experience. The most important part for me as a parent was the chance for me to see some of my own personal strengths. I was able to connect to the materials, attendees, and walk away feeling passionate about sharing my experience. I learned how one small detail can truly make a great impact.

As a stay at home mom I focus on all the small details trying to make sure that things go smooth and I work hard to make changes so that things run smoother. My attempts sometimes feel like they do not lead to exactly the results that I was hoping for. After listening to the energetic, exciting, and resources-filled sessions, I now better understand the impact that the application of data, in my own daily goals and tasks, will effectively help set me up for successful outcomes.

I was so grateful for this opportunity to feel connected and able to make a difference for my family and in my community. I know the importance of self-care and respite, and attending this conference supported these needs. This conference gave me the opportunity to feel empowered. I would also like to extend a special thank you to the presenters, organizers, and my mentor through the Department of Public Health, for providing me with this wonderful opportunity and amazing experience.

The DaSy Center is a national technical assistance center funded by the U.S. Department of Education, Office of Special Education Programs (OSEP). DaSy works with states to support IDEA early intervention and early childhood special education state programs in the development or enhancement of coordinated early childhood longitudinal data systems. Learn more about the DaSy Center by visiting www.dasycenter.org/
NCSEAM Family Survey Update

Fall is coming and it is again time to think about receiving and completing the NCSEAM Family Survey. The Survey is given out by Service Coordinators 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 in March 2016 will be getting an Information Flyer, a Survey and a stamped, self-addressed return envelope 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 get your Survey, please complete and return it as soon as you can. For your convenience, there are two ways you can return your completed Survey. Put it in the stamped, self-addressed envelope provided and drop it into any mailbox. Or put into the envelope, seal it, put your initials on the back flap and give it to your Service Coordinator.

Thank you so much for your help. Your input is used to measure the impact of EI services for 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 You Tube video describing the process at http://youtu.be/Gd5nnKOrkI0

Family Survey Frequently Asked Questions

1. My friend has filled out this survey twice and never heard anything about how our program did or how they use the information. What’s up with that?

*Information that families provide is analyzed and sent back to Massachusetts in two ways. All the data is grouped together to give us our state percentages. You can see our 2015 state percentages below. In addition, each EI program receives a report of their individual percentages and a ranking of the level to which families agree or disagree that the program is meeting their needs. All EI programs are encouraged to share their report with families and any family can ask to see their program’s report. If you want some help understanding what it means ask your program director or service coordinator. Or call the Early Intervention Parent Leadership Project for more information.*

Here’s what we learned from families completing the Survey in 2015.

- **86.2%** feel that EI services helps your family know your rights
- **83.4%** say that EI services helps your family effectively communicate your children’s needs
- **92.4%** feel that EI services helps your family help your children develop and learn

Información sobre la encuesta familiar de NCSEAM

Se acerca el otoño y nuevamente es el momento de pensar en recibir y completar la encuesta para las familias de NCSEAM. Los Coordinadores de Servicio reparten las encuestas en octubre y en marzo.

Las familias con niños inscriptos en el programa Early Intervention (EI) durante al menos seis meses, que no completaron la encuesta para las familias en marzo del 2016, recibirán un folleto informativo, una encuesta y un sobre con dirección y estampilla para mandar la encuesta a principios de octubre.

La encuesta es una herramienta importante para que el Departamento de Salud Pública y el programa Early Intervention (EI) comprendan cuan útiles son para usted y su familia los servicios de EI. Cuando reciba la encuesta, por favor complete y devuélvala lo antes posible. Para su conveniencia, puede devolver la encuesta completa de dos maneras. Puede ponerla en el sobre con dirección y estampilla provisto y ponerla en cualquier buzón de correo. O bien, puede ponerla en el sobre, cerrarlo, colocar sus iniciales en la solapa trasera y entregárse la a su Coordinador de Servicios.

Muchas gracias por su colaboración. Sus aportes se utilizan para medir el impacto que tienen los servicios de EI en las familias y para informar estas mediciones a la Oficina de Servicios de Educación Especial que financia el programa EI.

El Early Intervention Parent Leadership Project (EIPLP) tiene varios recursos para ayudarle a entender esta encuesta y la importancia de completarla. Un recurso que puede ser particularmente útil para usted es un breve video de YouTube que describe el proceso y que se encuentra en: http://youtu.be/Gd5nnKOrkI0.

Preguntas frecuentes sobre la encuesta para las familias

1. Un amigo mío ha completado su encuesta dos veces y nunca supo nada sobre los resultados ni sobre cómo usan la información. ¿Por qué?

*La información que brindan las familias se analiza y envía a Massachusetts de dos maneras. Todos los datos se agrupan para darnos los porcentajes estatales. Puede ver a continuación nuestros porcentajes estatales para el año 2015. Además, cada programa EI recibe un informe de sus porcentajes individuales y una clasificación sobre la medida en la que las familias creen que el programa está satisfaceciendo sus necesidades o no. Se fomenta que todos los programas EI compartan su informe con las familias y cualquier familia puede pedir ver el informe de su programa. Si usted quiere ayuda para comprender lo que significa, pregúntele al director de su programa o coordinador de servicios. O bien, llame al Early Intervention Parent Leadership Project para obtener más información.*
Leadership from the Perspective of a Mom of a Very Special Child: Celebrating 30 Years of IDEA and 25 Years of EIPLP

continued

became deeply involved in projects there. I advocated on behalf of a pediatric emergency room protocol and supported the development of a workshop for residents to learn about children with complex care. Those things made a difference for families, and I was proud of my involvement, but I still didn’t consider myself a “parent leader”. A few years later, I joined the Family Advisory Council at Boston Children’s Hospital, where I am still an active member. I’ve presented at international conferences, been involved in a multi-hospital national project to support family-centered care, and worked alongside researchers to infuse the family voice. Some years I’m able to take on those bigger roles that I hadn’t imagined possible, and some years I stay involved through participation in focus groups, surveys, or conference calls. I’ve learned to value all those things, big and small, as parent leadership, because each of them is a way for me to make a positive impact on the system. More importantly, I’ve learned that we are stronger as parent leaders when we work together, and that when I need to step back to care for my child, another parent is there to step forward.

My professional role has shifted and changed over the years, as well. My passion for Early Intervention led me to a career as a TVI (Teacher of Students with Visual Impairments), and I’m currently the Infant Toddler Coordinator for Perkins School for the Blind, supporting families, teachers, and programs across the state in working with infants and toddlers with vision impairments. I am lucky enough to see new families come through our program every day and to watch those parents find their own paths towards leadership. I’m now happy to call myself a Parent Leader, and I’m enormously grateful for the people who are on this journey with me. Fellow parents, agency staff, program coordinators, doctors, researchers, advocates…each of them continues to play an important role in shaping my journey. I’m excited to see the ways in which parent leadership has been and continues to make a difference. However big or small the steps we take, our paths as parent leaders continue to influence the ways in which families are able to be active and engaged partners in systems of care.

El liderazgo desde la perspectiva de una mamá de un niño muy especial: Celebración de los 30 años de IDEA y los 25 años de EIPLP

Por Brenda Allair

"El liderazgo no se trata de títulos, puestos u organigramas. Se trata de una vida que influye a otra". John C. Maxwell

Si alguien me hubiera conocido al inicio de este camino y me hubiera preguntado: “¿Te gustaría ser una madre líder?” Hubiera respondido “No, gracias” de manera cortés pero con firmeza. No me veía como una líder y no sabía si tenía las aptitudes, el tiempo o la energía para convertirme en líder. Como estaba ocupada con las demandas del cuidado de un bebé con discapacidades y necesidades de salud complejas, no podía imaginar que existieran formas de participar en actividades de liderazgo o apoyo que pudieran ser compatibles con mi alocada agenda. De a poco, al reunirme con otros padres en grupos de juego y salidas de CPR, me fui dando cuenta de que podía hacer pequeñas cosas que podrían tener un impacto.

En los primeros meses y años con mi hija, me consideré una “aprendiz de líder”. Asistí a talleres sobre liderazgo de padres, participé en grupos temáticos, escribí cartas para apoyar la financiación del programa Early Intervention (EI) y compartí nuestra historia con otras familias. Cuando mi hija pasó de EI a la escuela preescolar, generé más conexiones y al final acepté un puesto en el proyecto EIPLP (Early Intervention Parent Leadership Project). Mi rol en el proyecto EIPLP me dio la oportunidad de apoyar a otras familias en sus propias trasvases, y de aprender de ellos acerca de las numerosas formas en que los padres estaban marcando una diferencia en los sistemas en todos los niveles, ya sea local, estatal o nacional. Aunque no me podíaimaginar haciendo lo que consideraba “cosas grandes”, como proyectos o investigaciones nacionales, me fui involucrando cada vez más en el nivel que tenía más sentido para mí y para mi familia. También vi que los padres que tenían éxito como líderes y sentían entusiasmo por el liderazgo eran aquellos que participaban en cosas que les apasionaban.

Debido a que pasábamos mucho tiempo en el hospital y en las clínicas, me apasionaba generar un cambio en los sistemas que mejoraran las experiencias de las familias. Me uní al Consejo Asesor de Familias en nuestro hospital local y comencé a participar mucho en sus proyectos. Promoví la implementación de un protocolo para la sala de emergencias pediátrica y apoyé la creación de un taller para que los residentes conocieran acerca de los niños que requerían cuidados complejos. Esas cosas marcaron una diferencia para las familias y me sentí orgullosa de haber participado, pero todavía no me consideraba una “madre líder”. Unos años más tarde, me uní al Consejo Asesor de Familias en el Boston Children’s Hospital, del cual sigo siendo una miembro activa. He sido presentadora en conferencias internacionales, participé en un proyecto...
El liderazgo desde la perspectiva de una mamá de un niño muy especial: Celebración de los 30 años de IDEA y los 25 años de EIPLP

Continuado

nacional de varios hospitales para apoyar cuidados centrados en la familia y trabajé junto con investigadores para aportar la opinión desde el punto de vista de las familias. Algunos años puedo asumir esos roles más grandes que nunca imaginé que fueran posibles, y otros años participo en grupos temáticos, encuestas o conferencias telefónicas. He aprendido a valorar todas estas cosas, grandes y pequeñas, como madre líder, ya que cada una es una forma de tener un impacto positivo en el sistema. Lo más importante es que he aprendido que somos más fuertes como padres líderes cuando trabajamos juntos, y que cuando tengo que dar un paso al costado para cuidar a mi hijo, otro padre está ahí para dar un paso adelante.

Mi rol profesional ha variado y cambiado en estos años también. Mi pasión por Early Intervention me llevó a estudiar la carrera de TVI (maestra de estudiantes con impedimentos visuales), y actualmente soy la Coordinadora de Bebés y Niños Pequeños para la Escuela Perkins para Ciegos, donde apoyo a familias, programas y maestros que están trabajando con niños pequeños con problemas de vista en todo el estado. Tengo la fortuna de ver cómo llegan familias nuevas a nuestro programa todos los días y de observar cómo esos padres encuentran sus propios caminos hacia el liderazgo.

Ahora estoy feliz de poder llamarme una Madre Líder y enormemente agradecida por las personas que me acompañan en este camino. Otros padres, miembros del personal de las agencias, coordinadores de programas, médicos, investigadores, defensores... cada uno de ellos sigue teniendo un rol importante en darle forma a mi travesía. Me apasiona ver las maneras en las que el liderazgo de los padres ha marcado la diferencia. Sin importar lo grande o pequeño que sean los pasos que tomamos, nuestro recorrido como padres líderes sigue influyendo la manera en la que las familias pueden participar activamente en los sistemas de cuidados.

La perspectiva de una mamá sobre la Conferencia de Datos

Por Melissa McCarthy

Como mamá, tuve el honor y el privilegio de asistir a la Conferencia “Improving Data; Improving Outcomes” patrocinada por DaSy Center en Nueva Orleans, Luisiana. El tiempo que pasé en la conferencia me enseñó acerca de la importancia de los datos para las familias y los proveedores. Me dio la oportunidad de conectarme, conocer a otras personas y generar relaciones que enriquecieron mi experiencia de aprendizaje. La parte más importante para mí como mamá fue la oportunidad de ver algunas de mis propias fortalezas. Pude conectarme con los materiales, los asistentes y salir sintiendo un deseo vehemente por compartir mi experiencia. Aprendí de qué manera un pequeño detalle puede verdaderamente generar un impacto enorme.

Como mamá de tiempo completo, me centro en todos los pequeños detalles e intento asegurarme de que no haya inconvenientes, y trabajo arduamente para implementar cambios para que las cosas funcionen aún mejor. A veces parece que mis intentos no producen exactamente los resultados que esperaba. Después de asistir a sesiones apasionantes, llenas de energía y recursos, ahora comprendo mejor el impacto que tiene la aplicación de datos en mis propios objetivos y tareas diarias, y cómo me ayudará a prepararme para conseguir buenos resultados.

Estoy muy agradecida por esta oportunidad de conectarme y poder marcar una diferencia en mi familia y en mi comunidad. Conozco acerca de la importancia del cuidado propio y de atención temporal (“respite”), y el hecho de asistir a esta conferencia me dio herramientas para cubrir estas necesidades y sentirme fortalecida. También me gustaría extender un agradecimiento especial a los presentadores, organizadores y a mi mentor del Departamento de Salud Pública, por brindarme esta maravillosa oportunidad e increíble experiencia.

El DaSy Center es un centro de asistencia técnica nacional financiado por la Oficina de Programas de Educación Especial (OSEP) del Departamento de Educación. El DaSy Center trabaja con los estados para colaborar con los programas estatales de educación especial para la infancia temprana e intervención temprana conforme a la ley IDEA en el desarrollo o la mejora de los sistemas coordinados de datos longitudinales sobre infancia temprana. Puede conocer más sobre el DaSy Center visitando www.dasycenter.org/.
When asked to tell a Part C story, I immediately thought it needed to be a story in which I have been an active participant, but more importantly it needed to be framed as a collective response. I have had the experience of working with early intervention services in Massachusetts prior to P.L. 99-457, and the journey has never been dull! While, Massachusetts had a well-articulated early intervention system prior to the Individuals with Disabilities Education Act (IDEA) legislation, its passage and ultimate creation of a system of care without waiting lists created unique opportunities for very young children and their families.

Reflecting over time, it is humbling to acknowledge the numerous parties that have continuously moved this system forward. This includes the Office of Special Education Programs, governors, legislative supporters, public health commissioners, budget staff, provider organizations, the pediatric medical community, health plans, higher education, state Part C staff, and most importantly the voices of families. Without the combined commitment of these individuals and organizations it is highly doubtful that the current system in Massachusetts, in its scope and scale, would exist.

As we know from research and grandmotherly wisdom, it’s all about relationships. With young children and their families, and all those mentioned above, the journey of Part C has been about a collective vision of inclusion, positive developmental outcomes for young children and a commitment to full participation of families in the development of policies of how services are delivered.

I am pleased to have been a part of this evolution and salute all those whose commitment and voices have continuously moved this system forward. It has not always been easy but it reflects a system that has tried to always keep the eye on the prize, assisting families in caring for their children and allowing all to have dreams of a brighter future. If we continue to share an inclusive vision with our other Early Childhood partners and act in the best interests of families, we can continue building a comprehensive, broad based system of early education and care.

In closing, I will paraphrase a Beatles lyric and simply say it’s been fun, challenging, exhilarating, and extremely meaningful to be on “the long and winding road” with families, sharing in their lives.

HAPPY ANNIVERSARY!
RCP Fun...
Regional Consultation Programs

Southwick Zoo

WRCP Indoor Summer Picnic

Fenway Park

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
When children with a disability or developmental delay are young, parents often focus on questions they do not ask about their typically developing child. Questions such as; Why my child? What is this? What will this mean for my child’s future? With so many questions filling their minds, it can be difficult to focus on today, to enjoy the present and milestones as they happen, when they happen.

The root of this uncertainty lies in our wishes for only the best for our children. Consider that term, “the best” and remember that it can mean many different things. Parents cannot script a future for their newborn child. They must accept that whatever comes. They will manage – because of the deep and enduring love they have for their child. Be confident in that one thought.

Be sure, too, that you are not alone in your challenges. Even if you do not yet know one person who is caring for a child with similar special needs, there are parents out there who can share emotional support, guidance in ways they have supported their own child, and a great deal of admiration – for all that you are able to do with and for your child.

Contact Family TIES of Massachusetts to find those other parents. Our Regional Coordinators maintain active lists of support groups where parents come together periodically, to talk about their experiences, their emotions, and their lives. Staff can also tell you about the Family TIES Parent-to-Parent Program, which can offer you a one-to-one connection with a parent who is familiar with that one aspect of special needs parenting that rises to the top of your list of important issues. When you send your Match Request Form, the Parent-to-Parent Coordinator will call and start you on the way to finding a Match among our trained volunteer Support Parents. Also remember that no matter where you live in Massachusetts, calling Family TIES will immediately put you in touch with another parent of a child with special needs. We understand. We are, like you, parents, too. We look forward to your call. Anytime. We will help to relieve your concerns, and give back the energy to enjoy today with your child.

Family TIES 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. Family TIES of Massachusetts is a project of the Federation for Children with Special Needs, with funding from and in collaboration with the Massachusetts Department of Public Health, Division for Children & Youth with Special Health Needs.

HELP us meet our goal of “750 likes!”
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.

EI Parent Leadership Project Team
Darla Gundler
413-586-7525 Ext. 5863157
darla.gundler@state.ma.us
Faith Bombardier
413-586-7525 Ext. 5863119
faith.bombardier@state.ma.us
Kris Martone-Levine
978-851-7261 Ext. 1994057
kris.levine@state.ma.us
Liz Cox
413-586-7525 Ext. 5863116
liz.cox@state.ma.us

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

Want information “hot off the press?”
E-mail your name and e-mail address to:
eiplp@live.com
We'll add you to our email list!

IN THIS ISSUE
Leadership from the Perspective of a Mom of a Very Special Child ..................1, 3, 4
English and Español
A Mom’s Perspective of a Data Conference 1, 4
English and Español
NCSEAM Survey Update ............... 2, 3
English and Español
Ron Benham and Tiffany Gundler—Early Learning Making a Difference (Blog reprint) .5
RCP Fun. ..............................6
Family TIES, Children with Special Health Care Needs Program ............... .7

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 January 10, 2017. 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 three 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.