



# The Parent Leadership Project's Parent E-Perspective

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**"Plant a Seed, Grow a Leader"**

**September 2011**

Welcome to the first electronic newsletter, created based on feedback from the Early Intervention Parent Leadership Project (EIPLP) newsletter survey. These quick and easy to read e-newsletters will supplement the existing Parent Perspective Newsletter and be released a couple of times a year. Let us know what you think... [eiplp@yahoo.com](mailto:eiplp@yahoo.com)! Simply click on headers to read articles or information in entirety.

## [2011 OSEP Mega Conference](#)

## [WRCP Summer Indoor Picnic](#)



The Office of Special Education Programs (OSEP) held their Leadership Mega Conference themed "Collaboration to Achieve Success from Cradle to Career 2.0" on August 1 - 3 in Arlington, VA. State, agency and parent leaders, from Massachusetts and across the United

States attended this conference.

[Read more](#)

### [2011 OSEP Mega Conference](#)

#### [Parent Perspective:](#)

[Jennifer O'Leary,](#)

#### [Interagency Coordinating Council \(ICC\)](#)

[Co-Chair](#)

August in Washington, D.C. is...hot! But also very informational and full of opportunities to network and make connections. The OSEP (Office of Special Education Programs) Mega Conference on Early Childhood was held the first few days of August, in Washington, D.C.

The conference is designed for participants from all states in the Early Intervention system, such as State Early Intervention Directors and Staff, ICC [Read more](#)

### [2011 OSEP Mega Conference](#)

#### [Parent Perspective:](#)

[Crystal Hebert,](#)

#### [Central Region ICC Parent Representative & ICC Family Leadership Team Chair](#)

This year I was sponsored by the Department of Public Health to attend the OSEP conference in Washington D.C., as an ICC parent. The experience was not only enlightening but eye opening.

Often as parents, we get caught up in our every day lives of taking care of our families and dealing with the needs of our children who might be in Early Intervention or have transitioned into the public schools. [Read more](#)

On August 10, 2011 the Western Regional Consultation Program (WRCP) held their annual Summer Get Together Indoor Picnic. This event coordinated by Karen Cassidy, whose devotion was evident down to the last detail, was held at the beautiful Log Cabin Banquet & Meeting House in Holyoke, MA. All families, past and present, were invited. A diverse mix of families attended and enjoyed the festivities. It was a wonderful opportunity for families whose children have complex medical and health needs, to gather and share information, support each other and simply have fun.

The Early Intervention Parent Leadership Project (EIPLP) was on hand to take family photos and make them into keepsake buttons. Parents remarked how special this gift was since they rarely are able to have their whole family in one picture together. [Read more](#)

Check out photos from this great event...[click here!](#)

## **PARENT OPPORTUNITIES**

(click on header to learn more)

### [Digital Stories](#)

Digital Stories are multimedia stories produced by ordinary people telling stories of their own lives.

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### [It's All About Relationships: A Look At Inclusion & Service Coordination Through the Eyes of a Parent](#)

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### [Federation for Children with Special Needs Workshops & Trainings](#)

Please consider completing our [Newsletter Survey](#)

**NEXT DEADLINE:** We welcome your input and suggestions for resources and articles. The next deadline is **October 20, 2011**. Please call our toll-free number (877) 353-4757 or email the newsletter editor at [kris.levine@state.ma.us](mailto:kris.levine@state.ma.us).



What did you do this summer? Do you have an idea for an article? Email us at [eiplp@yahoo.com](mailto:eiplp@yahoo.com)



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## OSEP Conference Update



The Office of Special Education Programs (OSEP) held their Leadership Mega Conference themed "Collaboration to Achieve Success from Cradle to Career 2.0" on August 1 - 3 in Arlington, VA. State, agency and parent leaders, from Massachusetts and across the United States attended this

conference.

Goals of this event included 'educating participants on legislation, priorities and initiatives within the Department of Education. Focusing on better collaboration of all and alignment of educational requirements. Increasing participants'

understanding of policies and practices that foster achievement across an people's lifespan; strengthen collaboration among states, individuals, and agencies; and promote the use of high quality data to drive program improvement.' (2011 OSEP Leadership Mega Conference, [mega-2011.tadnet.org](http://mega-2011.tadnet.org), Sept 8, 2011.)

Many of the workshops posted their PowerPoint, and in some cases webcast, presentations at <http://mega-2011.tadnet.org>. To view a webcast of Cross Cutting Collaboration to Achieve Success Cradle to Career where each office shared their vision as it contributes to the national agenda for improving outcomes for children with disabilities and their families visit <http://mega-2011.tadnet.org/agenda1>. This webcast speaks to inclusion and goal achievement for all children.

## WRCP Annual Summer Get Together Indoor Picnic

On August 10, 2011 the Western Regional Consultation Program (WRCP) held their annual Summer Get Together Indoor Picnic. This event coordinated by Karen Cassidy, whose devotion was evident down to the last detail, was held at the beautiful Log Cabin Banquet & Meeting House in Holyoke, MA. All families, past and present, were invited. A diverse mix of families attended and enjoyed the festivities. It was a wonderful opportunity for families whose children have complex medical and health needs, to gather and share information, support each other and simply have fun.

The Early Intervention Parent Leadership Project (EIPLP) was on hand to take family photos and make them into keepsake buttons. Parents remarked how special this gift was since they rarely are able to have their whole family in one picture together. They also shared that they collect their "special" buttons and keep them from year to year.

After everyone enjoyed a picnic dinner, parents, children and their siblings made their way to the dance floor to boogie the night away.

This event was an inspiration to all. It was a great way for staff to reconnect with families they may not have seen in a while, to get updates. It set the stage for families to be able to support each other by listening or sharing information. This Indoor Picnic is a much anticipated event every year, for all who work with the WRCP. *Check out photos on page 2.*

**Regional Consultation Programs (RCPs)** provide consultation, family support, and community-wide workshops and training in Massachusetts. Eligible children must be enrolled in a certified Early Intervention Program and meet one or more of the following criteria: the child has extensive medical and/or healthcare needs, complex care needs, or multiple disabilities.

RCP services are funded through the Massachusetts Department of Public Health, Massachusetts Department of Early Education and Care, Medicaid, Health Insurance and Health Maintenance Organizations, and through grants and charitable contributions. (<http://www.thomchild.org/regionalconsultation.htm>, September 6, 2011)

What did you do this summer? Do you have an idea for an article?  
Let us know—this is your newsletter! ...email us at [eiplp@yahoo.com](mailto:eiplp@yahoo.com)  
...we'd love to hear from you and share your thoughts and experiences in this newsletter!



# WRCP Indoor Picnic

August 10, 2011  
Log Cabin Banquet & Meeting House  
in Holyoke, MA



## Parent Opportunities through the Early Intervention Training Center

### Digital Stories

Digital Stories are multimedia stories produced by ordinary people telling stories of their own lives. Digital storytelling may be used in a variety of ways including outreach and awareness campaigns, marketing, training, and recruitment. The EITC in collaboration with the EI Parent Leadership Project has developed several digital stories highlighting family experiences in Early Intervention. To learn more, call 877-353-4757

## Parent Opportunities through the Early Intervention Training Center

### It's All About Relationships: A Look At Inclusion

The foundation for successful inclusion is based on building relationships. This workshop will help the participant identify the challenges one faces regarding inclusion. Participants will strategize about ways to creatively collaborate with partners to ensure that children with disabilities are included in all educational and community settings. This workshop will feature the SpecialQuest approach and the documentary film, Including Samuel. The intent of this workshop is to increase awareness regarding inclusion and to empower providers.

### Service Coordination Through the Eyes of a Parent

This workshop will provide Early Intervention Service Coordinators with insight into what it feels like to be a parent in Early Intervention. It will show how important building a relationship with a family really is, what families need and what they can handle, and look at the best ways to present information and resources to families. Service Coordinators will be able to embed some of the workshop teachings into their everyday interactions with families.

**Questions? Call 877-353-4757** **Dates:** Tuesdays: October 18, 2011, November 15, 2011 and December 13, 2011

## Parent Opportunities through the Federation for Children with Special Needs

### Is your child TURNING THREE and leaving Early Intervention? Want to learn about IEPs or 504s

Check out the FCSN workshops at <http://fcsn.org/pti/workshops/home.php>

*"Plant a Seed; Grow a Leader: One Parent's Perspective"*

### OSEP Mega Conference 2011 - Networking and Connections are Everything

**By Crystal Hebert, Central Region Interagency Coordinating Council (ICC) Parent Representative & ICC Family Leadership Team Chair**

This year I was sponsored by the Department of Public Health to attend the OSEP conference in Washington D.C., as an ICC parent. The experience was not only enlightening but eye opening.

Often as parents, we get caught up in our every day lives of taking care of our families and dealing with the needs of our children who might be in Early Intervention or have transitioned into the public schools.

We fight our own battles tirelessly but rarely get a chance to step back and look at the big picture of what type of involvement the Federal Government has in our child's education.

The conference was an opportunity to see multiple agencies come together to put on one "Mega conference" for parents, educators, Early Intervention leaders and more, from all over the country.

The conference ran from Sunday-Wednesday and almost all presentations contained information on the importance of collecting data to report to the Government. Some of these topics were a little above my head because I live more in the trenches everyday and don't have to worry about the data that is captured or reported. It did however

give me a sense of just how hard the Department of Public Health employees have to work in order to track all the children in Early Intervention.

Massachusetts Medical Director, Dr. Lauren Smith, gave an outstanding presentation about social disparities and how they impact the children coming into Early Intervention. She talked about the need for children in at-risk families and neighborhoods to have access to grocery stores and resources they need in order to support healthy eating and living environments for families. Her presentation was eye opening to everyone in the room and made us all think a little bit differently as to what families need in order to promote a higher quality of life in their communities.

We also heard a wonderful presentation from Jim Johnson, who is the Director of the Urban Investments Strategy Center. He spoke of the changing demographics in the United States and how this shift impacts the children being served in Early Intervention as well as in Public Schools.

The networking at the conference was great! I had time to talk with other families from different states and hear their stories of how their systems worked. What I found was that Massachusetts is unique in the support that they give families.

*"Plant a Seed; Grow a Leader: One Parent's Perspective*

**Continued: OSEP Mega Conference 2011 - Networking and Connections are Everything  
By Crystal Hebert**

So many states were un-represented at this conference and didn't send any parent leaders. I found that Massachusetts gives parents the opportunity to be involved in advocacy and to be a part of the team.

As Chair of the Family Leadership Team for the Inter-agency Coordinating Council, it was a huge honor for me to be at the conference when Ron Benham, the Director of the Bureau of Family Health & Nutrition and Part C Coordinator received the EIFA award for his outstanding support of Massachusetts parents. The FLT nominated Ron for this award and we were so happy that he was chosen as the recipient.

His speech was heart felt and moving and I was so glad that I was able to be there to witness that moment. We truly are lucky to have someone so supportive in all our families' corners.

It was also nice to have interaction with people that represented the Public Schools aspect (Part B). I can honestly say that it is not every day that you are given an opportunity to sit down and have a candid conversation with Marty Mitnacht, who is the Director of Special Education for Massachusetts. Not many families have or will have that opportunity but by attending OSEP I was given the opportunity

to be one of the team with the Department of Public Health.

More than anything, this trip gave me a chance to really get to know the many people with whom I sit on committees throughout the state; the Department of Public Health staff, Early Intervention Training Center staff and so many other wonderful people. It makes you realize that the people you work with everyday are people just like you no matter what title they hold.

It was a very interesting environment to attend for the first time. So many people just like me, fighting for the same thing...to give people with disabilities the best quality intervention and education that they deserve.

For me, I grew as a person. It was the first time I had ever left my family and did something so big. Being away from them for 5 days was one of the hardest things I have ever had to do, but in the long run it gave me a clear direction to come home to. It made me appreciate the things I have more and empowered me to fight harder for my boys every day.

I can't thank the Department of Public Health enough for seeing the parent leader inside of me and giving me this amazing opportunity.

*"Plant a Seed; Grow a Leader:" One Parent's Perspective*

**OSEP Mega Conference 2011 - Networking and Connections are Everything  
By Jennifer O'Leary, Interagency Coordinating Council (ICC) Co-Chair**

August in Washington, D.C. is...hot! But also very informational and full of opportunities to network and make connections. The OSEP (Office of Special Education Programs) Mega Conference on Early Childhood was held the first few days of August, in Washington, D.C.

The conference is designed for participants from all states in the Early Intervention system, including State Early Intervention Directors and Staff, families, ICC members and other Early Intervention and early childhood professionals.

This year two parents from Massachusetts were supported to attend the conference; myself and Crystal Hebert, the Central Region ICC Parent Representative and Family Leadership Team Committee Chair. Parents are encouraged to attend the conference and bring what they learn back to Massachusetts to share with the ICC and other families.

We attended large audience sessions and smaller workshops throughout the 4 days of the conference. In addition, we had the opportunity to network with a variety of people from various agencies both at state and federal levels. It has been my experience that attending a conference for the knowledge is only half of what you get out of it;

networking and making connections with influential people is the other half.

During the conference, I had the opportunity to meet and have a conversation with Marcia Mitnacht, the Director of Special Education for Massachusetts. I also had conversations with Julie Sinclair and Rich Robison. Mr. Robison, the Executive Director of the Federation for Children with Special Needs, gave verbal testimony on IDEA (Individuals with Disabilities Education Act) Part D (Discretionary funds) regarding improvements that the federal government could make in IDEA discretionary funds. In addition I met the Massachusetts Department of Public Health Medical Director Lauren Smith; had conversations with the two national advocates for Early Intervention, Sharon Walsh and Maureen Greer; and met with several board members of the only EI advocacy organization for parents at the national level, EIFA (Early Intervention Family Alliance), including Darla Gundler, Maureen Casey, Roxanne Romanick, Mark Smith, and Talina Jones, family members who represent EIFA in 5 states (visit [www.eifamilyalliance.org](http://www.eifamilyalliance.org) for more information on joining EIFA).

*"Plant a Seed; Grow a Leader: One Parent's Perspective"*

**Continued: OSEP Mega Conference 2011 - Networking and Connections are Everything**

**By Jennifer O'Leary**

One day of the Conference was especially for ICC parents and members. The day was full of parent networking, resource sharing, and discussions among like-minded families from across the country. These parents are as passionate about the importance of Early Intervention for our children, as I am. Exchanging emails and phone numbers was standard fare during this day.

Ron Benham was nominated for a national award promoting parent involvement in Early Intervention by the MA Family Leadership Team of the ICC. Ron is the Director of the Bureau of Family Health & Nutrition and Part C Coordinator at

the Department of Public Health which is the lead agency for Early Intervention in Massachusetts. I was present to witness Ron receive this national award given out by EIFA.

Four days of the conference gave me so much information to digest from the various speakers I'd heard and the workshops I'd attended. The opportunity to meet and connect with so many influential and committed people made it an incredibly worthwhile experience for me. I can't thank the Parent Leadership Project enough for providing these opportunities to me.

**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.

**EI Parent Leadership Project Team**

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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. If you would like to be removed from this mailing list, please contact [eiplp@yahoo.com](mailto:eiplp@yahoo.com)

