

PARENTS DEVELOP LEADERSHIP, SHARE A VISION – THE HAUSSLEIN EARLY INTERVENTION PARENT LEADERSHIP AWARDS

Taking their first steps on a journey of parent leadership, parents from across the state gathered with Department of Public Health staff and other guests in celebration of the seventh annual Hausslein Early Intervention Parent Leadership Awards Ceremony. The awards ceremony, held at the Holiday Inn in Worcester on May 24, recognized the achievements of parents who have created new programs and ideas with funding available from the Hausslein Awards.

Named in honor of one of the most influential parent leaders in Massachusetts, Evelyn Hausslein, the awards encourage families to develop initiatives that expand opportunities for children in Early Intervention and the community. When Evelyn's son was diagnosed with a developmental disability more than 30 years ago, the Early Intervention system did not exist in its present form. In advocating on behalf of her son, Evelyn became a parent pioneer, paving the way for the many families who would come after her.

The Early Intervention Parent Leadership Project, through generous funding from the Massachusetts Department of Public Health, created the Hausslein Awards to give families the opportunity to take leadership roles in creating supports at their Early Intervention programs and within their communities. Four of the main criteria for the awards are as follows:

- They must be parent driven
- They must meet the needs of families in EI
- They must be a new program or a new component of an existing parent-initiated program
- They must demonstrate collaborations between families and other members of the community

This year, nine parent teams from Early Intervention programs throughout Massachusetts received Hausslein Awards of up to \$1000 to implement their projects.

Darla Gundler, Director of the Early Intervention Parent Leadership Project, welcomed parents and Department of Public Health (DPH) staff to the ceremony. Darla then presented Evelyn with a "Good Luck" bamboo plant. In oriental folklore, such plants are given to friends and loved ones in times of celebration. Suzanne Gottlieb, Director of Family Initiatives at DPH, spoke about the importance of parent leadership, saying that "the ideas of parents can carry systems to places we cannot even imagine." In collaborating with Early Intervention and their local communities, parents are able to play a role in improving services and also say "thank you" for the services they have received. Sharing her excitement about the success of the Hausslein Awards, Suzanne pointed to a large banner showcasing the more than 60 projects that have received funding over the past seven years.

Ron Benham, Director of the Division for Perinatal, Early Childhood and Special Health Needs spoke to the gathered parents and staff by cell phone. He praised Evelyn's "career-spanning leadership, and her ability to always include families at the table in meaningful roles." Ron also spoke about the importance of DPH's ongoing commitment to family involvement and the far-reaching effects of the Hausslein Awards. "Small money can make an amazing impact with the dedication and commitment of parents and families."

Then, Evelyn Hausslein welcomed the parent leaders, sharing her own experiences as the parent of child with special needs. Evelyn spoke about the many positive changes that have happened as a result of family involvement in Early Intervention. She encouraged parents to see themselves as leaders, reminding them that, "You can be a parent leader anytime, anyplace. You don't have to be at board meetings or travel long distances. The most important thing is to share your ideas with others."

Evelyn congratulated the parent teams on their achievements. "There is a whole life ahead of you with things you never imagined you could do." Evelyn also shared the "three things I wish someone had told me" in beginning a journey of parent leadership. First, "you must have a vision, a dream. Go beyond your day-to-day life and think what might be possible. Encourage your child to have a vision of his or her own." Second, connect to another system. "Church, community, parent groups, all are opportunities for parent leadership." Third, and most important, Evelyn stressed that parents must "take care of yourselves. Care for the caregiver. Know that it's ok to say 'no' as well as to say 'yes' so you can continue to be a leader for the long-term."

Then, it was time to hear about the projects from the nine teams who received Hausslein Awards.

1. **Room with a View – Family Support EI Program** – This parent team, led by Paul Hebert, created two "Little Rooms" for use by families and providers at the ARC in Danvers. "Little Rooms" were first introduced by Dr. Lilli Nielsen, a woman dedicated to enhancing the potential of children with visual impairments and multiple disabilities. The rooms are created from special materials and toys and other items are hung within reach of the child, allowing the child to explore and discover the world. With funding from the Hausslein Award, this parent group was able to present an in-service training to their local Early Intervention program. Over twenty people attended the training to learn more about the benefits of the "Little Room". The group also used funding to create a Little Room that will be available for providers to use at the ARC. Another Little Room will be available for families to borrow, allowing them to see how their child responds to the activity.
2. **Building Connections through Family Fun – Cape Ann Early Intervention Program** – Inspired by the wonderful parent/provider collaboration at their Early Intervention PAC (Parent Advisory Council) meeting, this project was a joint effort of parents and providers at Cape Ann Early Intervention. The parent team, represented by Miranda Sweet, wanted to focus on creating opportunities for

- parents to come together and have fun with their children while also nurturing the parent-child bond. To meet the needs of the families in their program, the parent team asked program Service Coordinators to bring surveys to the families. Based on the results of the survey, the team put together a series of workshops and creative activities for families to enjoy. A series on “Babies and Books” was followed by “Creative Art Projects”. In this workshop, parents and children worked together to create scrapbooks and puppets. The project is also hosting a “Yoga with Children” series as well as an event at “Kidstop and Kidworks”.
3. **Big Things Can Happen-The Down Syndrome Resource Group of Western Massachusetts** – In the second year of a two-year project, this parent team produced a film titled *Big Things Can Happen*. Evie Hawley, a member of the parent team, filmed children with Down Syndrome and their families living happy, active lives. With the funding from the Hausslein Awards, the group created a DVD to be distributed to new parents through the First Call Program at the Down Syndrome Resource Group of Western Massachusetts. The film will also be given to NICU facilities, teachers, and other public groups to help develop awareness of the “rich, full life” of people with disabilities.
 4. **Aqua Therapy** – After learning the many benefits of aqua therapy, this parent group set out to create a program that would allow children of all abilities to have fun and enjoy the water. Julie Messina, a parent team leader, talked about how the funding from the Hausslein Awards allowed the group to cover the pool fee, swim diapers, and a stipend for childcare for each of the twenty families involved in the “Fun and Movement in the Water” program. The local YMCA provided use of their facilities, and the program was run by licensed Aqua Instructors. As an added benefit, the program was able to raise awareness of Early Intervention by having community participants. Julie was proud to announce that the swim program will now become a permanent part of Cambridge-Somerville Early Intervention group activities.
 5. **TrachCare** – After a successful launching of their support program last year, the TrachCare group received funding to expand their activities. Leslie Gaffney, a parent team member, shared stories and photos from the families who attended the events sponsored by the group. The TrachCare organization held an informational meeting for parents at which Gail Havelick spoke about public benefits and resources available for children with special needs. The group also organized a “Spring Fling” event, a fun outing for families who participated in music and craft activities while also having a chance to learn about community resources. This fall, the group will be participating in a parent panel at “It’s All About Trachs”, a conference sponsored by Children’s Hospital Boston.
 6. **Signing for All** -- When parents find resources for their own child, they often want to share that with other families in Early Intervention. In collaboration with the Western Regional Consultation Program, this parent team was able to allow many other families to experience the educational value of the “Signing Time” videos. Darlene Moser, a parent team member, presented at the awards ceremony. The team used their funding to purchase over 50 of the award-winning videos, which were then distributed to families in their program. The videos were also accompanied by a letter to be sent to the recipients’ local library, encouraging

- the library to consider purchasing the “Signing Time” series. In addition to helping libraries learn about Early Intervention and needed supplies, the letter also allowed families to learn more about the resources their local libraries may already offer, including books, toys and free storytimes.
7. **Complementary Care Fair - Criterion-Stoneham EIP**– Complementary care refers to therapies that may be outside the traditional model of medicine, including acupuncture, reflexology, and massage. After becoming interested in complementary treatments in the course of helping her own child, Kris Levine decided to put together a parent team to help other families and providers learn about these alternative therapies. The parent team received funding from the Hausslein Awards in order to hold a “Complementary Care Fair” at their Early Intervention center. Various community therapists and vendors were available to answer questions from families and staff. The parent team also developed a resource book which described the different types of complementary care.
 8. **Music to Grow By** – With a background in music therapy and a career working with children with special needs, parent team member Lisa Kynvi was excited to share her passion with other families. Together with a group of parents from various EI programs, she wanted to encourage other families to understand the benefits of creating music with their children through singing and using instruments. They also hoped to help others understand how making music contributes to a child’s overall growth and development. Along with Michelle Glidden, a music therapist at Step One EI, Lisa held a music group and training session for parents at Perkins Infant/Toddler Program. Each family was given a set of simple instruments, a DVD of their experiences (including songs to sing with their children), and a written packet of materials. These parents were then able to go back to their own EI programs and share what they had learned. Of the experience, Lisa said, “The Hausslein Awards allowed me to find my leadership role as a parent.”
 9. **Parents Language Development Library – Cape Ann EIP** – This parent team, including Brooke Sanidas, wanted to create a library at their Early Intervention center for parents to learn more about language development. The group purchased materials that focused on helping children develop language and communication skills. The materials, including many books, DVD’s and videos, were made available to families in the Early Intervention program. The group also plans to hold a workshop facilitated by a teacher from the Beverly School for the Deaf to help parents learn more about sign language and language development.

At the end of the presentations, Evelyn Hausslein congratulated the team members for their creativity and dedication to helping other families.

The Hausslein Awards ceremony ended with an inspirational message read by Darla Gundler:

Do You Know Where You're Going?
By Zig Ziglar

One day a traveler in a remote country town, convinced that he was on the wrong road, came to a halt in a village.

Calling one of the villagers to the car window, he said, "Friend, I need help. I am lost."

The villager looked at him for a moment.

"Do you know where you are?" he asked. "Yes," said the traveler. "I saw the name of your town as I entered."

The villager nodded his head.

"Do you know where you want to be?" he asked. "Yes," the traveler replied.

"You're not lost," the villager said. "You just need directions."

Many of us are in the same position as that traveler.

We know where we are – sometimes disappointed, dissatisfied, and experiencing little peace of mind.

And we know where we want to be – at peace, fulfilled, and living life abundantly.

Like the traveler, we are not lost – we just need directions.