



The Parent Leadership Project's

# Parent Perspective

(877) 35-EI-PLP ♦ www.eiplp.org ♦ eiplp@yahoo.com

Early Intervention Information and Resources

September/October 2004

*Families Finding Their Way: Tools for the Journey*

## PUBLIC BENEFIT PROGRAMS - IS YOUR CHILD ELIGIBLE?

by Gail Havelick

Families who have children with special medical needs may assume that public government benefit programs are only available to those who have an income close to poverty level, or who have no insurance coverage at all. However, a family with a child who has special health care needs that is enrolled in private health insurance may still qualify for public benefit programs that provide additional health coverage, and, at times, a monthly cash benefit.



A family with a child who has a disabling condition, chronic illness and/or blindness may be eligible for the following public benefit programs:

- **SSI (Supplemental Security Income)**

SSI is a federal program of the Social Security Administration (SSA) that provides monthly cash benefits and automatic MassHealth (Medicaid) coverage for a child with special medical needs. To be eligible for SSI, a child must have a medically proven physical or mental condition that results in marked and severe functional limitations, which has lasted, or is expected to last at least 12 months, or is expected to result in death. If the child lives at home, a family with low to moderate income and limited resources (assets) may be eligible for SSI. If the child is hospitalized for more than one calendar month, or is currently living in a residential facility, the parents' income may not count toward eligibility. Families can begin an application by calling SSA at 1-800-772-1213, or their local Social Security office.

- **CommonHealth**

If a child has a chronic illness, disabling condition(s) or blindness, and the family income or resources exceed the limits for SSI and MassHealth Standard, the child may be eligible for CommonHealth. CommonHealth is a state program that may charge a premium for MassHealth through a sliding fee based on income and family size. To receive an application form in the mail, call a MassHealth Enrollment Center at 1-888-665-9993 (TTY: 1-888-665-9997) and ask

for the MBR (Medical Benefit Request) and the Children's Disability Supplement.

- **Kaileigh Mulligan Home Care for Disabled Children**

If a child has a severe medical condition that requires technological dependence and/or skilled nursing care, the child's 'level of care' needs meet the criteria for an acute hospital or pediatric nursing facility, and the family income exceeds the limits for SSI and MassHealth Standard, they may qualify for Kaileigh Mulligan Home Care. If determined eligible, the child is allowed to return or remain at home, with MassHealth coverage for home-based medical care, without the parents' income counting for the Medicaid eligibility. For information or application, call 1-800-408-1253.

### *Opportunity Knocks: Free Training for Parents*

#### **Public Benefits for Children with Special Health Care Needs - October 28th**

Parents and caregivers are invited to come and learn about many of the public benefit programs available for children with special health care needs. Changes are occurring in some of these programs and the training will provide the most up-to-date information.

Gail Havelick, Public Benefits Training and Policy Specialist at the Department of Public Health (DPH) will present the training on Thursday, October 28 from 10 am to 12:30 pm at the DPH Western Regional office at 23 Service Center, Northampton.

The training is sponsored by the DPH Care Coordination Program and the Western Regional Consultation Program

Registration is required as space is limited. To RSVP, please call Karen Cassidy at (413) 783-5500, ext. 16.

*(Continued on page 4)*



## Taking Good Care

### Choosing Shoes For Your Young Walker: Helpful Guidelines for Parents

By Mary-Ellen Langdon, PT

As we all know it's easier and more pleasant to walk in comfortable shoes. We just don't seem to walk with the same ease when the shoes are too big, too heavy, or just uncomfortable. Occasionally we find a pair of shoes that we simply love because they make the feet go "aaah".

It's hard to figure this out with your infant or toddler, whose walking is new or still evolving. Here are some tips to guide you when choosing shoes for your young walker.

- Look for shoes/sneakers with *arch support*. Not all shoes have this. It does create more support and comfort to the whole foot.
- When choosing a child's shoe or sneaker, place it in your hand to feel its weight. Is it heavy or light? Many of the new styles are heavier and it's hard to judge this by sight. Heavier shoes are harder to walk in. *Lighter shoes*

are more comfortable.

- Choose shoes/sneakers that fit correctly. Even though children grow out of shoes so quickly it's best to buy the *correct size*, and not a size or two bigger. An incorrect size changes the way a person walks (adult or child).
- Shoes/sneakers that add ankle support (high tops) aren't necessary for all beginning walkers. It's best to talk with your pediatrician and/or motor therapist about whether your child may benefit from high top shoes.
- Lastly, there always seems to be some debate about bare feet versus shoes (for beginner walkers). Infants can benefit from both. Shoes add extra stability and support; bare feet allow strengthening of all the muscles in the toes and foot.

Happy Shopping!

**Mary-Ellen Langdon is a Physical Therapist at the Professional Center for Child Development in North Andover.**

*Taking Good Care is a series that will feature articles on a variety of issues relating to the health and well-being of families with young children. Please send your ideas and submissions to the Newsletter editor at Jocelyn. Woog@state.ma.us or call the Parent Leadership Project toll-free at (877) 35-EI-PLP.*



## Opportunity Knocks

### The Barbara Wilensky Gopen Memorial Fellowship

Barbara Wilensky Gopen was a person with a developmental disability who made a lifetime commitment to advocating on behalf of people with developmental disabilities.

The Barbara Wilensky Gopen Memorial Fellowship is open to any individual with a developmental disability, or family member wishing to enhance his or her knowledge and skills in the developmental disabilities field.

This Fellowship offers a unique opportunity to gain valuable knowledge and experience by working with members of the Massachusetts Developmental Disabilities Network Programs. The one-year award includes a stipend of up to \$20,000, plus fringe benefits. Fellowship activities may include public policy research and analysis as well as grassroots advocacy and leadership development

For more information, please contact David Helm at the Institute for Community Inclusion (ICI) at (617) 355-6209. Information is also posted on the ICI web page at [www.communityinclusion.org](http://www.communityinclusion.org) and the Massachusetts Developmental Disabilities Council web page at [www.state.ma.us/mddc](http://www.state.ma.us/mddc).

Applications for the 2005 Fellowship beginning January 1, 2005 **must be received by October 15, 2004.**

The Barbara Wilensky Gopen Fellowship is co-sponsored by the Massachusetts Developmental Disabilities Council (MDDC); the Institute for Community Inclusion, University Center for Excellence on Developmental Disabilities (ICI); the Eunice Kennedy Shriver Center, University Center for Excellence on Developmental Disabilities; and the Disability Law Center.

## Public Benefits Programs—Is Your Child Eligible?

(Continued from page 1)

- **MassHealth Standard/CommonHealth Premium Assistance (MSCPA)** (Formerly “HIPP”)

Once enrolled in MassHealth through the programs listed above, the child’s family may be additionally helped through MSCPA. This program reimburses the employed parent his/her share of the premium for employer-based private health insurance, or for COBRA benefits through a former employer. This reimbursement for premium payments for the family’s health insurance helps to maintain health coverage for family members who are not covered by MassHealth. The private insurance coverage also remains the primary insurer (first billed) for the child with disabilities. For an application, or more information, contact MSCPA at 1-800-862-4840.

- **Catastrophic Illness in Children Relief Fund (CICRF)**

The CICRF is a last resort for families who face extraordinary out-of-pocket expenses due to a child’s illness. This program provides financial assistance for Massachusetts families who have excessive expenses related to a child’s medical needs that are not covered by any other financial resource including private insurance, federal or state health insurance, or other state programs. To qualify, a family’s related out-of-pocket expenses must exceed 10% of the family gross annual income up to \$100,000 and 15% of any portion of income that exceeds \$100,000. The child must be under 19 years of age and be a Massachusetts resident. To apply, or to obtain further information, call 1-800-882-1435 (TTY: 617-624-5992), or visit the website at [www.state.ma.us/cicrf](http://www.state.ma.us/cicrf) for an application.

**Gail Havelick is a Public Benefits Training & Policy Specialist at the Department of Public Health.**

*For more information...*

### *The Community Support Resource Line - (800) 882-1435*

For more information on these programs and other resources that may be available to children with special health care needs, call the Department of Public Health, Division for Special Health Needs Community Support Resource line at (800) 882-1435 and ask to speak with a Resource Specialist.

### *Parent Participation Opportunity*

## **Early Intervention Training Center Invites Parents to Trainings**

**By Peggie O’Hare**

**A**s the new director of the Early Intervention Training Center (EITC), I would like to extend an invitation to all families in the early intervention community to get to know us better. We are a program of the Federation of Children with Special Needs which receives funding from the Massachusetts Department of Public Health. Our mission is to help enhance the quality of EI services and supports available to families of infants and toddlers. We do this through training, support and other professional development activities for families, EI personnel and associated early childhood providers.

Some EITC activities which might be of special interest to families are the two-part orientation series called, “Building a Community” and our core courses on Assessment, IFSP Development and Family –Centered Services. These day -long workshops are offered at various locations across the state. They provide early interventionists and families an opportunity to explore the basics that underline the early intervention system here in Massachusetts.

To meet the need of the ever changing and expanding early intervention community, the EITC began offering “Special Sessions” last year. These are half-day workshops on selected topics conducted by experts in their respective fields. These have proven to be very popular and we will be increasing them in the upcoming year. Topics being scheduled for this fall and winter include prematurity, autism, oral motor development, and working with families who are homeless, among others.

How do you find out when and where these educational opportunities are happening? Look in the Calendar Section (page 5) of the *Parent Perspective Newsletter*. Each issue contains information about the EITC training schedule. The training schedule is also available on our Web site, [www.eitrainingcenter.org](http://www.eitrainingcenter.org). To register, please call Heather Tirrell at 800-331-0688 ext. 159. Please be sure to tell her you are a parent involved in early intervention.

Welcome! We look forward to seeing you at the next workshop.

## CONFERENCES AND WORKSHOPS

September 27– **Parent Connection Annual Kick-Off**, 7-9 pm at Soundworks for Children, Topsfield Crossing, Topsfield. The Parent Connection is an organization for families with children who are deaf or hard of hearing. Join other parents to discuss plans for the new school year. Please RSVP to Nancy Williams at (781) 334-6828 or by email at wills0903@comcast.net

September 29– **Basic Rights Workshop**, 7-9 pm, Burlington High School, School Committee Room, Burlington. The Burlington PAC and the Federation for Children with Special Needs presents this course that covers basic information about state and federal laws to assist parents in planning, decision-making and monitoring of their child's special education services. For more information on location or to register, call (800) 331-0688 or online at register@fcsn.org. For other dates locations, please see the Federation Web site for full schedule at www.fcsn.org.

October 2– **Western Massachusetts Buddy Walk –2004**, 10:00 am –4:00 pm, Thorton W. Burgess Middle School, 85 Wilbraham Road, Hampden. The Down Syndrome Resource Group of Western Massachusetts will host this event that includes a two mile walk held in conjunction with the Hampden Fall Festival. Many fun activities are planned including a moon bounce, face and pumpkin painting, Shriner's Clowns, band music and a raffle. Mason Child I.D. kits will be available and the Safe Kids Coalition (Baystate Medical Center) will be there. Come join the fun and help to further education and awareness about Down Syndrome. For more information or to receive a registration form email LHI412@aol.com or call (800) 337-7791.

October 2– **Juvenile Diabetes Walk**, 9:00 am. MDC Hatch Shell, Boston. Walk to raise money to find a cure for juvenile diabetes. Other walks: October 3– 9:00 am at Worcester State College, Worcester; October 17– 9:30 am, Western MA Walk, Six Flags New England in Agawam. For more information, please visit www.jdrf.org.

October 8&9– **Sibshop**, North Shore Children's Hospital, Salem. Don Meyer, Sibling Support Director from the national Arc office, will provide a training on how to run Sibshops. He will also present a Sibshop for children between the ages of 8 and 12 who have a sibling with special needs. Please call Marguerite Roberts at the Family Resource Center at (978) 354 2660 or email mroberts2@partners.org.

October 16– **8th Annual Great Beginnings Conference- "Making the Connections: Integrating Prescriptive Approaches to Developmentally Appropriate Practice"**, Best Western Royal Plaza, Marlborough. This is a conference for those working in the field of early childhood education with typically developing and at-risk children, birth to six, and their families. For full conference workshop descriptions and to register, please visit www.criterionchild.com or call (508) 473-3882.

October 23– **"Tying It Together"**, Holy Cross College, Worcester, 10 am-4:30 pm. The Autism Resource Center of Central Massachusetts hosts this annual conference. Early bird registration before October 14. For full workshop descriptions or for more information, please visit www.arcem.org or call (508) 595-9101.

October 27– **"Quirky Kids: Understanding and Helping Your Child who Doesn't Fit In- When to Worry and When Not to Worry"**, 7-8:30 pm, Barry Auditorium, Melrose Middle School, 350 Lynn Fells Parkway, Melrose. Perri Klass, MD and Eileen Costello, MD, authors of *Quirky Kids* will present this workshop. Books are \$20 with proceeds to be used to host an Inclusive Community Dance. For more information, please contact Susan Nadworny at (781) 665-5179 or by email to snadw@aol.com.

November 6– **MDSC Bowl-A-Thon**, Woburn Bowladrome, Woburn. The Massachusetts Down Syndrome Congress (MDSC) sponsors this great family event. Come and bowl while raising funds to support the programs of the MDSC. For more information, please visit www.mdsc.org.

November 18-20– **The Arc National Convention**, Sheraton Prudential Center, Boston. This three day meeting, sponsored by the Greater Boston Arc, will feature a wide range of speakers and topics including future planning, fundraising, abuse prevention, education inclusion, housing, legislative advocacy, siblings, aging caregivers, recreation and leisure, religion, assistive technology and others. For more information and to register, please visit www.thearc.org or call (773) 348-3198

### *What's Happening at the EI Training Center (EITC)*

The EITC presents required trainings for Early Intervention personnel. Trainings are also open to family members of children who receive Early Intervention services. Trainings are free and a stipend is available for parent participants. Upcoming trainings include:

September 30– **Building a Community: An Orientation to Massachusetts Early Intervention**– Part 1, Boston (Home for Little Wanderers) 9:30 am-3:30 pm. Other dates and locations: October 12– North Shore Arc, Danvers; November 10– Department of Public Health Western Office, Northampton. Learn about core values and the evolution of the EI system, operational standards, state and federal laws.

November 9– **Building a Community: An Orientation to Massachusetts Early Intervention**– Part 2, Boston (Home for Little Wanderers) pm. Other dates and locations: December 7– North Shore Arc, Danvers. (See description above)

October 19, **Assessment: Taking a Closer Look**, 9:30 am - 3:30 pm, DPH Western Office, Northampton. Learn about the assessment process including tools and methods.

November 17– **IFSP: Beyond the Nuts and Bolts**. This workshop goes beyond the basics of the IFSP process to focus on how partner with families to create a document that reflects the family's priorities and concerns.

For more information, call the EI Training Center at (800) 331-0688 or visit [www.eitrainingcenter.org](http://www.eitrainingcenter.org).

**For on-going support group information in your area call Family TIES at (800) 905-TIES**

## WORKING TOGETHER

### BOSTON NEWS

**Harbor Area Early Intervention Program (Harbor Area EIP)** is celebrating their 30th Anniversary in September with a wonderful party including music, food, a raffle and other fun activities! Congratulations to all at **Harbor Area EIP** for thirty years of providing services to families in your community. Shine on!

### CENTRAL NEWS

The **Kennedy-Donovan Center-South Central Early Intervention Program (KDC-South Central)** held a yard sale on September 11<sup>th</sup>. Now that fall is here, can Halloween be far behind? KDC-South Central will have a Halloween Party at the Center on October 28 from 3 – 4:30 pm

Parents at **KDC-South Central** are invited to Transition Night on Wednesday, November 10<sup>th</sup>, 6:30 –8:30 pm. Information on transition will be presented for parents whose children will turn three from December 2004-June 2005. Child care is available with advance registration.

**MSPCC-Worcester** held their annual family picnic in August. It was a wonderful opportunity for children, parents and staff to gather and enjoy themselves outdoors in a “no-work-all fun” environment. We send thanks to the many local businesses that donated supplies. There were activities for all abilities including a moon bounce, face painting, water play, arts and crafts, bubbles and food to enjoy! A local fire station arrived with a fire engine and the children could have a turn spraying the water hose. The Worcester Police Department held a finger printing workshop as part of a safety program. Many thanks to all of the volunteers who helped plan this event, including Monique, Susan, Millie, and Mandie.

The **Lipton Early Intervention (Lipton EI)** Parent Advisory Council (PAC) sponsored its 12<sup>th</sup> annual Summer Picnic/EI Family day at Mirror Lake in Devens in July. Many families enjoyed lots of good food, beautiful weather and swimming in the lake. The PAC provided the burgers, hot dogs and drinks for the picnic.

The PAC is also sponsoring many activities for the fall including a trip to Davis Farmland in Sterling in September, and a Red Cross Infant/Toddler CPR course. On October 2, the PAC will sponsor Apple Picking at Sholan Farms in Leominster. Families are also invited to the Fall Celebration on November 6<sup>th</sup>.

Families from the **Criterion Child Enrichment Early Intervention Program in Milford (Criterion-Milford)** enjoyed an old fashioned ice cream social recently. Parents, siblings, grandparents and friends came to a local park for a picnic lunch

and ice cream treats. The children also enjoyed playing on the playground, bubbles, face painting, and the parachute. In September, **Criterion-Milford** will be hosting a “Turning Three” workshop in collaboration with the Federation for Children with Special Needs. Please visit the Federation website for full details at [www.fcsn.org](http://www.fcsn.org).

### METROWEST NEWS

Riverside Community Care has recently purchased a building which will be the new home of **Riverside Early Intervention at Needham (Riverside-Needham)**, currently located at 460 Hillside Avenue in Needham. Several other Riverside programs will also share the new location with the Early Intervention program. **Riverside** has recently wrapped up the building permit and architectural plans and begun construction/renovations. Riverside is pleased that the building has a modern elevator and that they had a chance to participate in the design of our new home! A late October or early November move is planned. **Riverside** will hold an open house to show off the new building when the move is complete.

### NORTHEAST NEWS

The **Professional Center for Child Development in Andover (PCCD)** was pleased to reunite Early Intervention graduates who are 5 to 7 years old for a very successful summer literacy group. The “Book Club” created by Christeen Brown, M.Ed featured familiar favorites including Dr. Seuss books, “If You Give A Pig a Pancake”, Curious George, Peter Rabbit Tales and Frog and Toad. The children learned pre-reading and reading skills through a variety of activities including art, circle time, and cooking. The children enjoyed making and eating pancakes, green eggs and ham and cutting vegetables from Mr. MacGregor’s garden.. These activities helped the stories come alive and the Early Intervention grads learned valuable lessons while recognizing words in print and identifying authors and titles.

October is a busy month at **PCCD**. On October 3, please join us for the 12<sup>th</sup> Annual “Trot for Special Tots” 5K Road Race. Families will enjoy a barbeque and prizes for the top winners. For more information including forms, please visit [www.TheProfessionalCenter.org](http://www.TheProfessionalCenter.org).

On October 19<sup>th</sup>, **PCCD** will present “What to Look for in a Preschool for your Child”, a workshop for parents who may be considering a preschool placement for their child. The workshop facilitator will be Melanie Shipon,, M.Ed., who is **PCCD**’s community playgroup coordinator.

The **Criterion-Medford Early Intervention Program (Criterion-Medford)** and parents are hosting their annual Family Picnic in mid-September at the Five Banks River Park in Malden. Several playgroups are available for parents and chil-

## FAMILY & EI PROGRAM COLLABORATION

dren—Babble and Banter, a speech focused playgroup for 2 year olds; Toddler Time, a toddler playgroup; and Baby and Me! For crawlers and walkers. **Criterion-Medford** looks forward to starting a parent support group in the fall.

### SOUTHEASTERN NEWS

**The Kennedy-Donovan Center in Attleboro (KDC-Attleboro)** recently sponsored “A Victorian Tea” performed by Kandi Carle, a professional artist, dancer and singer at the Florence Sweet House in Attleboro. **KDC** EI program staff helped to bake goodies for the event, staffed the tables and helped to clean up. Funds raised from this event will go towards the annual “Rodman Ride for Kids”. **KDC-Attleboro** will participate again in this event, a one day cycling tour to be held on October 2. Two teams of riders, including friends, staff members, family of staff, alumni parents and a KDC board member, will ride to raise money for the program.

The **KDC-Attleboro** PAC will meet on September 28 to discuss ideas for future workshops and social events.

### WESTERN NEWS

The **Western Regional Consultation Program (WRCP)** is planning a sign language series in the fall for families in Belchertown and Pittsfield. Please call Karen Cassidy at (413) 783-5500, if you are interested in attending this series.

The **WRCP** will be having parent groups in September, October and November at Holyoke Community College. A CPR training for families and respite providers will be held in October.

Another big event is planned for September 23—the Family Support Fair at the Best Western Hotel in West Springfield from 10 am to 1 pm, featuring a variety of resources in Western Massachusetts.

The **WRCP** has several workshops planned in the fall. On September 29, October 6 & 20, Sign Language for Infants and Toddlers will be held at Westfield Head Start. Parents are invited to a workshop entitled “Social Books, Social Pages... Let’s Interact: using personalized photos and pictures for communication skills and interactions” on November 4th.

Get rolling with other families from the **WRCP**—the annual Skating Party will be held on November 14th at Interskate 91. For more information on any of these events, please call Karen Cassidy at (413) 783-5500.

**REACH** Early Intervention Program (**REACH EIP**) recently held a Family Picnic at Look Park in Northampton. Graduate families, as well as families who are currently receiving services enjoyed meeting each other and having fun at this event.

## Haussein Early Intervention Parent Leadership Awards Applications Now Available!



**D**o you have a bright idea for a project that would benefit families at your Early Intervention program or in your community?

The Haussein Awards, named for influential parent leader, Evelyn Haussein, were created to give families an opportunity to take leadership roles in creating supports at their Early Intervention program and in their communities. Awards up to \$1000 are granted to parent teams to implement innovative projects.

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 to an existing parent-initiated program;

- They must demonstrate collaborations between families and other members of the community.

For the past five years, parents from EI programs throughout the state have used Haussein funds to put their ideas into action! Read about some of their projects on our website at [www.eiplp.org](http://www.eiplp.org). Click on Haussein Award Archives

The application for the 2004-2005 Haussein Awards is now available to download from our website at [www.eiplp.org](http://www.eiplp.org). To receive a copy by mail or for more information, please call the Parent Leadership Project, toll-free at (877) 35-EI-PLP.

**Remember, the application deadline is October 15th**

# 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 Re-certification Parent Coordinator, an Outreach and Collaboration Coordinator and a Training Coordinator. Please feel free to contact any of them with your thoughts, suggestions, and concerns.

## STATEWIDE DIRECTOR

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## The Early Intervention Parent Leadership Project NEWS

**Welcome aboard Erin!** The Parent Leadership Project is pleased to welcome Erin Ward as Collaboration and Outreach Coordinator. Erin will also serve as the Parent Leadership Project representative for EI programs in the Northeast region.

Erin is the mother of William, a three-year-old, beautiful boy who has significant medical and overall developmental needs. William received EI services through the Professional Center for Child Development in Andover, where Erin served as the Parent Contact for two years. She also attended the annual conference for the Massachusetts Early Intervention Consortium (MEIC) for the past three years. William has recently transitioned into an integrated preschool program in Methuen, where Erin, husband Mark, and William live.

Formerly, Erin was a school counselor and has a Masters degree in Education. Erin has found that her past professional experiences in child and family advocacy have strengthened her ability to advocate for her son's needs. She has first-hand knowledge of how to effectively navigate public benefits programs, how to work collaboratively within the Early Intervention system, how to successfully transition to the Special Education system, and how to connect with statewide child and family resources. Erin is looking forward to her new position and expanding the opportunities for parent involvement in the Early Intervention system.

**NEXT DEADLINE:** We welcome your input and suggestions for resources and articles. The next deadline is **November 10th**. Please email the newsletter editor at [Jocelyn.Woog@state.ma.us](mailto:Jocelyn.Woog@state.ma.us) or call the Parent Leadership Project toll-free at (877) 35-EI-PLP.

The *Parent Perspective* newsletter is a free publication, produced six times a year by the Early Intervention Parent Leadership Project, through funding from the Massachusetts Department of Public Health.

