On March 8, 2014, the Federation for Children with Special Needs hosted their annual Visions of Community conference at the Seaport World Trade Center in Boston. This year’s conference was kicked off by Rich Robison, Executive Director of the Federation. Representative Tom Sannicandro of 7th Middlesex District; Deputy Commissioner Cliff Robinson from the Department of Mental Health; Commissioner Elin Howe from the Department of Developmental Services; Commissioner Heidi Reed of the Massachusetts Commission for the Deaf and Hard of Hearing; and, Commissioner Mitchell Chester of the Department of Elementary and Secondary Education addressed the over 800 attendees at this year’s conference.

Rich Robison and Dr. William Henderson were joined by Commissioner Chester and Assistant Secretary Michael Yudin, in presenting the 2014 Community Partnership Awards. This recognition celebrated the contributions and commitment of: Self Advocacy Award: Nicole Tarzia, Ms. Wheelchair Massachusetts; Recreation Awards: Regina Snowden, Partners for Youth with Disabilities, Inc., Boston, MA; Inclusive Special Education Teacher Award, Kate Ahern, Easter Seals, Haverhill, MA; Inclusive General Education Teacher Award: Phyllis Jaillet, Wachusett Regional School District, Holden; Parent Advocacy Awards: Amber Bobnar, Founder of WonderBaby.org and Iraudhis Baez, Parent Consultant, Lowell, MA; and, Parent Leadership Award: Karen Donovan, Parent of a child with Autism, Ipswich, MA. Congratulations to all the awardees!

Keynote speaker Assistant Secretary Michael Udin of the Office of Special Education and Rehabilitative Services for the US Department of Education shared that office’s mission “is to ensure access to and excellence in education, employment and community living. And we have a “cradle to career” strategy.”

Interested in what you may have missed or want to revisit it? Visit http://fcsn.org/voc2014/ to view you tubes or download workshop handouts!

The Federation is a center for parents and parent organizations to work together on behalf of children with special needs and their families. Organized in 1975 as a coalition of parent groups representing children with a variety of disabilities, the Federation offers workshops and training, advocacy and resources to parents of children with special needs and the professionals who serve them.

Every year at the Visions of Community conference, I learn something new. Sometimes it’s a conversation with another parent over lunch where we share ideas on working with the school system. Sometimes it’s in the exhibit hall where I discover a new product or program that can help my child and family be more active in our community. This year, it was in keynote speeches and workshops where I was reminded that we have a voice in the policies and decision-making that helps shape the future for our children, and we need to use that voice. Representative Tom Sannicandro urged us to contact our elected officials, saying, “Tell them your stories, and what’s important to you and your families.” (Continued p. 3)
Dear Families,

March was NCSEAM Family Survey month. Hopefully you received one from your Service Coordinator, filled it out and returned it in the stamped, self-addressed envelope provided. You would have been given a Family Survey if:

- your child has been enrolled in Early Intervention for at least six months and,
- you didn’t fill out the Family Survey last October, 2013 since families fill out the Survey only one time per calendar year.

The Family Survey is an important tool for both the Department of Public Health (DPH) and your EI program. The information you provide is used to evaluate and improve the services your family and other families receive from Early Intervention and to report to the federal Office of Special Education Programs (OSEP) about Family Outcomes. Your input is very important. If you got a Survey and haven’t completed and returned it, please do it now and send it in.

**Family Survey Frequently Asked Questions**

1. Why do I have to fill out a long Survey? Can’t I just say, yes, EI is great, or no, there are problems?

The Family Survey was developed to help measure Family Outcomes in three key areas.

**Does help EI families to:**
- know their rights
- communicate their children’s needs
- help their children develop and learn.

Federal and State agencies and your EI program want to know more than if families are satisfied with their services. Answering the questions on the Survey gives us this information.

2. I wish I knew more about this Survey. Where can I get more information?

**Talk to your Service Coordinator and ask for more information and help in understanding the process. You may also contact the Early Intervention Parent Leadership Project toll free at: 877-353-4757 to talk with another parent.**

Estimadas familias:

Marzo fue el mes de la Encuesta Familiar de NCSEAM. Esperamos que su Coordinador de Servicios les haya entregado una y que la hayan completado y enviado de vuelta en el sobre con franqueo y dirección de destino. Deberían haber recibido una encuesta si:

- su niño ha estado inscrito en Intervención Temprana durante al menos seis meses y,
- no completaron la Encuesta Familiar en octubre de 2013, ya que las familias deben responder a la encuesta sólo una vez por año.

La encuesta familiar es una herramienta importante tanto para el Departamento de Salud Pública como para su programa de Intervención Temprana. La información que las familias comparten se usa para evaluar y mejorar los servicios de Intervención Temprana y para presentar informes sobre los resultados a la Oficina de Programas de Educación Especial (Office of Special Education Programs, OSEP). Sus opiniones son muy importantes. Si tienen una encuesta y no la han completado y enviado, por favor, háganlo.

**Preguntas comunes sobre la encuesta familiar**

1. ¿Por qué tengo que contestar una encuesta tan larga? ¿No basta con que diga que sí, que la Intervención Temprana es maravillosa y que no hay ningún problema?

La Encuesta Familiar se creó para medir los resultados para las familias en tres puntos clave, saber si la Intervención Temprana ayuda a las familias a:
- Conocer sus derechos
- Comunicar las necesidades de sus hijos
- Apoyar el desarrollo y el aprendizaje de los niños

Las agencias federales y estatales y su programa de Intervención Temprana necesitan saber no sólo si las familias están satisfechas con los servicios. Las respuestas a las preguntas de la encuesta les dan esta información adicional.

2. Me gustaría saber más cerca de esta encuesta. ¿Dónde puedo obtener más información?

Hable con su coordinador de servicios y pidale más información y ayuda para comprender el proceso. Para hablar con otros padres, también puede llamar al Proyecto Padres Líderes de Intervención Temprana al 877-353-4757 (la llamada es gratuita).
It doesn't sound like a lot, but if you do that...each one of you could change the world.” It's a small step to take, and a homework assignment I’m happy to do!

I kept that thought in mind while I was sitting in a workshop on “Encouraging Social and Recreational Connections within Your Community” given by Anna Woods. Anna, a Recreation Therapist, has created an amazing recreational program in her community that includes children of all abilities, including those with significant special needs. Many of the parents in the workshop, including me, immediately began asking what we could do in our cities and towns to support the development of similar programs. And, like Representative Sannicandro, Anna encouraged us to connect with our local officials. “Contact your Parks and Recreation department. Call your Disability Council members. Tell them about your child.”

My take-home message from this year’s conference was that connecting with other parents is one step on this journey, and that the power to create change is a next step I can take. I can share my story, my daughter’s story, with the officials in my town, my region, my state and my government, so that when decisions are made about community opportunities, educational policies, and disability services, our voice counts.

**“Su opinión es importante!”**

**Perspectiva de una madre sobre la Conferencia Visiones de la Comunidad de 2014, de la Federación para Niños con Necesidades Especiales**

Por Brenda Allair

Todos los años aprendo algo nuevo en la conferencia Visiones de la Comunidad. A veces, en una conversación durante el almuerzo con otro padre o madre en la que intercambiamos ideas sobre cómo trabajar con el sistema escolar. Otras veces, descubro un producto o programa nuevo en el salón de exhibiciones que puede ayudar a mi hijo y mi familia a participar más activamente en nuestra comunidad. Este año, los discursos inaugurales y los talleres me recordaron que los padres tenemos voz en las políticas y la toma de decisiones. Eso permite que influyamos en el futuro de nuestros hijos y es algo que tenemos que aprovechar. El diputado Tom Sannicandro nos instó a ponernos en contacto con nuestros funcionarios electos. Nos dijo: “Cuéntenles sus historias y lo que es importante para ustedes y sus familias. No parece gran cosa, pero si lo hacen... pueden ayudar a cambiar el mundo.” Tal vez sea un paso pequeño, pero es una tarea que estoy encantada de asumir.

Con eso en mente asistí a un taller ofrecido por Anna Woods sobre cómo promover las relaciones sociales y recreativas en nuestras comunidades. Anna, una especialista en terapia recreativa, ha organizado un programa increíble en su comunidad que incluye a niños con diferentes capacidades, entre ellos, los que tienen necesidades especiales importantes. Muchos padres, yo entre ellos, inmediatamente preguntamos qué podríamos hacer en nuestro vecindario y ciudades para crear programas similares. Y Anna, al igual que el diputado Sannicandro, nos alentó a ponernos en contacto con nuestros funcionarios públicos locales. “Llaman al Departamento de Parques y Recreación, al Consejo de Discapacidad. Cuéntenles las historias de sus hijos.”

Después de la conferencia de este año, mi conclusión es que uno de los pasos de este recorrido es relacionarme con otros padres, y el siguiente es aprovechar nuestro poder para generar cambios. Puedo compartir la historia de mi hija y la mía con los funcionarios públicos de mi pueblo, región, estado y gobierno, para que cuando se tomen decisiones sobre oportunidades en la comunidad, políticas educativas y servicios a discapacitados, nuestra voz cuente.

**“Your Voice Counts!”**

**Helena’s Perspective of the Federation for Children with Special Needs, Vision of Community 2014 Conference**

By Helena Liedtke

Every time I participate in a conference, I take home valuable information for caring for my child, for myself and advocating for children with special needs in general.

The Federation for Children with Special Needs, Visions of Community 2014 Conference was not an exception. It was very well organized, offered a variety of high quality workshops and provided a platform to network. (Continued p. 4)
The presenters were knowledgeable and it was another opportunity for me to broaden my horizon, to learn about new opportunities, maintaining old and establishing new connections.

After my daughter was diagnosed with a genetic progressive condition I tried to hang on to my old life as much as possible. With time I realized I needed to let go; especially as my passion for helping and improving lives of families with disabilities was growing.

Conferences like VOC 2014 not only improve my knowledge about a variety of conditions and means of support; they also teach me how to advocate and spread awareness myself, by watching the presenters and organizers and learning from them.

Once again leaving the conference I felt empowered and reassured.

Many thanks to the Federation for Children with Special Needs for offering such a meaningful source of information for families and providers, to help improve the lives of our special children.

“Your Voice Counts!”

Helena’s Perspective of the Federation for Children with Special Needs,
Vision of Community 2014 Conference
continued

The Early Intervention Training Center (EITC) at the Department of Public Health (DPH) provides support and professional development to the Massachusetts Early Intervention (EI) community. The EITC has some great trainings that may be interesting to families and staff! Parents are welcome to register and attend any trainings! Visit the eitrainingcenter.org and click on the Calendar/Registration link to learn more! Titles include:

The Process of Developing an IFSP
Infant Brain Development
Early Intervention: An Overview
With the implementation of the federal Affordable Care Act (ACA) in Massachusetts, parents of children and youth with special health needs (CYSHN) may think big changes have taken place regarding public health insurance coverage for their child. However, for a child who has special health care needs, some things DO remain the same...

There are still certain avenues for families of CYSHN to obtain public insurance coverage (MassHealth) that may pick up costs for medical services that private insurance may not cover (i.e. therapies, durable medical equipment, PCA services, etc.).

As a reminder to families of CYSHN, even if you have primary family health insurance coverage through an employer, you may want to consider the following programs:

**SSI (Supplemental Security Income)** is a federal income benefits program of the Social Security Administration which can be available to families of children with a chronic illness, disabling conditions or blindness. To qualify for SSI, the child needs to be eligible under the disability criteria, meet certain citizen or non-citizen and residency requirements, and the family has low to moderate income and resources (assets). A person who qualifies for SSI is automatically eligible for MassHealth. To apply for SSI, contact a local SSA office, or call the national teleservice line toll-free at 1-800-772-1213. For the SSI Child Disability Starter Kit, visit the Social Security website at www.ssa.gov/disability/disability_starter_kits_child_eng.htm.

If the family income or resources exceed the limits for SSI, or exceed the income limits for MassHealth Standard, **CommonHealth** is a state program to purchase MassHealth coverage through a monthly premium based on a sliding scale of income and family size. To qualify, a child must also meet certain disability criteria. To obtain an application form (along with a request for the Children’s Disability Supplement), call MassHealth Customer Service at 1-800-841-2900 (TTY: 1-800-497-4648), or call a MassHealth Enrollment Center, toll free at 1-888-665-9993 (TTY: 1-888-665-9997). For more information and an application form, visit the MassHealth website at www.mass.gov/masshealth and under ‘Publications’, click ‘Applications and Member Forms.’

In certain cases, when a child has a severe medical condition that requires technological dependence and/or skilled nursing care, the child’s level of care needs may meet criteria for an acute hospital or pediatric nursing facility. This may qualify the child for the **Kaileigh Mulligan Home Care for Disabled Children Program**. The Kaileigh Mulligan Program is a home and community-based waiver program in Massachusetts that does not count parent income for SSI/MassHealth eligibility. It allows the child to return or remain home with MassHealth coverage for home-based medical care (with no premium charged to the family). To apply, call 1-800-408-1253 and ask for Kaileigh Mulligan intake.

**Additional Programs for Families of a Child with Special Health Care Needs:**
Once a child is enrolled in MassHealth through one of the programs listed above, the child’s family may additionally be helped through the **MassHealth Standard/CommonHealth Premium Assistance (MSCPA) program**. 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 primary health insurance helps to maintain coverage for family members who are not covered by MassHealth. The private insurance coverage also remains the primary insurer (first billed) for the child in the family who has MassHealth. For an application, or more information call MSCPA at 1-800-862-4840 or 1-800-462-1120.

**The Catastrophic Illness in Children Relief Fund (CICRF)** is a last resort for families who face extraordinary out-of-pocket expenses due to a child’s illness or special health needs. 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 22 years of age and be a Massachusetts resident. To apply, or obtain further information, call 1-800-882-1435 (TTY: 617-624-5992), or visit the website at www.state.ma.us/cicrf for an application.

For more information on these programs and other resources that may be available to children with special health care needs, call the DPH Division for Children and Youth with Special Health Needs (DCYSHN) Community Support Line at 1-800-882-1435 and ask for a Resource Specialist.

*Gail Havelick is the SSI/Public Benefits Training and Policy Specialist of the DCYSHN. She provides public benefits training presentations for agencies, organizations or parent groups. If you wish to host a training session, and want to schedule a date and time at your location, Gail can be contacted at 1-800-882-1435, 617-624-5961, or at gail.havelick@state.ma.us. A training session is approximately 1.5 – 2.5 hours (weekdays/daytime preferred).*
Turning Three—This workshop, highlights the difference between Early Intervention and publicly funded pre-school for children with disabilities.

Basic Rights—This workshop provides families with an introduction to their rights and responsibilities under state and federal special education laws.

Project Play at Northeastern University

Project Play is a research project at Northeastern University focused on developments in play, given the importance of play activities for young children.

Play is an important and natural activity that young children use to learn about their world. Children with delays and disabilities often have delays in play; they have difficulty learning, and they have difficulty learning to play. The Developmental Play Assessment-Professional (DPA-P) was created to measure how young children are developing in their play activities to help teachers and service providers select activities that will help children learn to play more and at more advanced levels. We can see a lot about what children know by evaluating their play activities, and we can help them learn through their play activities. Our project is focused on finding out the details of how children learn to play and then use this information for supporting the development of children with delays and disabilities.

We are recruiting children from 8 months to 60 months of age – children who are developing with delays and children who are developing typically – and their parents or caregivers. Team members conduct the observations in the home or at the children’s day program or school. Observations consist of a 30-minute sample of the child playing with our toys, which is videotaped for later analysis. Observations include an evaluation of the child’s developmental level, using brief screening tests, in addition to some questions about the child, family, and activities at home.

We also are recruiting individuals who work with young children to take our online training program about children’s play. These personnel will learn to use the DPA-P for determining a child’s progress in play, and they will work with team members to collect play observations using the DPA-P.

Please see our website for further details or to sign up! https://www.northeastern.edu/projectplay/.

FAMILY TIES of Massachusetts

Sometimes You Have to Build It

A family from Western Massachusetts contacted Family TIES of Massachusetts last fall, asking for help to address the emotional needs of their older children (ages 3-9) upon learning that their newborn baby has complex medical needs. This is not an unusual request, but where it has gone is exciting.

Have you heard of SibShops®, workshops designed for brothers and sisters of children who have disabilities? First implemented by Don Meyer twenty years ago, the program is designed to provide children opportunities to learn from each other, as they express their needs and emotions within the safe environment of other children facing similar circumstances. Most sessions are geared toward children ages 7-12 or 13-17, focusing on the varied needs of these age groups.

In researching SibShops®, in Western Mass., Family TIES learned that at present, there were no active sibling groups. That left only one solution: build one! Conversations were set into motion among collaborating agencies in the area. Jericho of Holyoke and the Jewish Community Center of Springfield became the leaders of SENSA-TIONAL SIBS.

After three months of planning, four sessions have been scheduled. The first session was held in March, and the turnout was fantastic! In all, 8 children (ages 8-12) and 10 teens (ages 13-16) attended the first session, and all committed to the next three Spring sessions. This group is designed to meet the needs of our large geographic area, so the location will rotate.

Another difference from many SibShops is that Sensational Sibs is led by older Sibling Mentors. Participants will focus on team building as they play games, enjoy outdoor adventures, and develop friendships in a natural and safe setting with the guarantee of laughter and having loads of fun! Sensational Sibs hopes to expand to additional sites in Western MA in the future.

Would your family benefit from a program like Sensational Sibs or SibShops®? To learn more about Sensational Sibs, contact Maggie Wurm, Western Regional Coordinator: 413-586-7525, Ext. 3178 or mwurm@fcsn.org.

Family TIES of Massachusetts 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 an Alliance Member of Parent to Parent USA, a national organization that provides technical assistance to parent-to-parent programs across the country. For more information, call 800-905-TIES (8437) or visit www.massfamilyties.org.
Transition (Reprint from Spring 2013)
By Sue Murray, DPH Early Intervention Regional Specialist

What comes to mind when you hear the word transition? Leaving one thing, and going to another. We all do that all the time.

Some transitions are big and some are small. A new job, moving to a new home, having a family...those are some pretty big “life transitions.”

We transition from being in the car to going into the store. Might be a small transition for some but if you are a parent with a child who has a harder time transitioning, this could be a huge one.

Transition means different things, at different times, to different people, but we all experience transitions.

It is a word we use a lot in Early Intervention (EI).

Think back to your first IFSP – remember that time? Perhaps you wondered, why in the world your EI person would be talking about transition and leaving when you hadn’t even started yet?

One of the roles an EI provider takes on is to help offer supports to families and children through the many transitions encountered while in EI. We know that although some families might be enrolled in the program for a year or less, and others stay for almost three years, there is a time when your EI services will end (perhaps one of those bigger “life transitions”). Regardless of how that happens or where you are going after, part of the job is to offer some supports that may help you through the big transition of leaving EI.

Supports may include getting information about other community settings, maybe visiting one or two together. It could be hearing about a workshop or other training opportunities to learn more about transition and what to do after EI. Some families want to talk to other parents who are going or who have already gone through the transition, learning about their experiences and knowing they are not alone.

Many children may continue on to services with their local schools after they turn three. If you decide to explore this as an option, your EI provider can help you.

Over the past few years, the Departments of Early Education and Care, Elementary and Secondary Education and Early Intervention have been hosting trainings across the state for public school districts and their local EI partners to come together and discuss how to better work together to support seamless transition practices. These transition forums provide an opportunity for staff to learn about the Federal Part C (EI) and Part B (public schools) transition requirements and share best practices. The goal is to focus on collaboration and communication to be better able to support you and your child in your transition out of Early Intervention.


ACRYNMS DEMYSTIFIED...

| DD  | Developmental Disability |
| ECO | Early Childhood Outcomes |
| MEIC | MA Early Intervention Consortium |
| IEE | Independent Education Evaluation |
| LEA | Local Education Agency (school system) |
| LD | Learning Disability |
| LDA | Learning Disability Association |
| PTO | Parent Teacher Organization |
| RFP | Request for Proposal |
| SSP | Speciality Service Provider |

EIPLP

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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 Statewide Director, a Media Coordinator, a Communications Coordinator, an EI Program Focused Monitoring Parent Coordinator and an Education Coordinator. Please feel free to contact any of them with your thoughts, suggestions, and concerns.

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NEXT DEADLINE: We welcome your input, suggestions for resources and articles. The next deadline is June 15, 2014. Please call our toll-free number (877) 353-4757 or email the newsletter editor at kris.levine@state.ma.us.

To receive the Parent Perspective Newsletter, a free publication, published four 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

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