On Saturday March 8th the Federation welcomed over 900 attendees to the Seaport World Trade Center in Boston for its annual day-long Visions of Community conference for parents of children with special needs and the professionals who serve them. Participants from around Massachusetts attended workshops, perused the exhibitor’s hall, visited resource tables, and networked with other parents and professionals. This year, the Federation was able to offer workshops in Spanish, Portuguese, Vietnamese, Chinese, and Somali during each of the three sessions in addition to 30 workshops in English. Interpreter services were available for attendees speaking American Sign Language, Cantonese and Mandarin Chinese, Somali, Portuguese, Spanish, and Vietnamese.

The day began in the amphitheater where Federation Executive Director Rich Robison introduced Special Guests and presided over the Community Partnership Award ceremony. Guests included State Rep Tom Sannicandro, Commissioner of the Department of Developmental Services Elin Howe, Commissioner for the Deaf and Hard of Hearing Heidi Reed, Deputy Commissioner at the Department of Mental Health Cliff Robinson, and Department of Public Health Director, Bureau of Family Health and Nutrition Ron Benham.

Representatives from the Department of Elementary and Secondary Education (DESE) included Commissioner Dr. Mitchell Chester, Deputy Commissioner Alan Ingram, Director of Special Education Services Marcia Mittnacht, and Director of the Office of Tiered Systems of Support Madeline Levine.
The Federation Celebrates 40 Year of Helping Families!

Throughout 2014, the Federation is celebrating 40 years of families helping families. The Federation was started in 1974 by a group of Massachusetts parents and advocates, who gathered around a kitchen table to discuss how they could organize to better assist children with special needs. From this modest beginning, the Federation has since grown into a nationally recognized organization serving more than 40,000 Massachusetts families and their children with special needs annually.

So come celebrate with us! Join us for Gala 2014 – Celebrating Every Child on Friday, May 2nd at our new venue, the Westin Boston Waterfront Hotel. This year’s honorees include David M. Bartley, former Massachusetts Speaker of the House, and the chief architect of the passage and implementation of Chapter 766; Eustacia Cutler, autism researcher, lecturer, and noted author of the 2006 book “A Thorn in my Pocket”, which describes raising her daughter Temple Grandin in the “Leave-it-to-Beaver” world of the 50’s; Daniel T.S. Heffernan, Partner, Kotin, Crabtree & Strong, longtime Federation board member, parent of a son with Down syndrome and civil rights attorney. Enjoy a fun filled evening which includes a cocktail reception, silent auction, dinner, and awards. Entertainment will be provided by the Boston Ballet Adaptive Dance Program and noted Boston band Calypso Hurricane!

Can’t attend the Gala? The Federation will hold its second annual family fundraising walk, Walk, Roll, Shobble*, Stroll on Sunday, September 21st on the grounds of the Massachusetts Hospital School in Canton, MA. Last year’s successful event featured a 1.5 mile walk along the beautiful nature trail at Mass Hospital School, family activities, lunch and snacks, entertainment, games music and prizes. Over 100 participants walked, rolled, shobbled* and strolled, networked with Federation staff and other families and all in all helped raise over $13,000 to support the work of the Federation! Registration begins in June 2014. Please plan to join us this year!

*Shobble: “when a shuffle meets a hobble” (Definition by Chelsey Kendig, self-advocate)
From the Executive Director:

Perspectives from Our Founders

On May 2, the Federation is celebrating its 40th anniversary as an advocacy organization that was developed by parents, for parents and is still run by parents. We were formed just as the full implementation of Chapter 766 was beginning in September 1974. Attorney Bob Crabtree of Kotin, Crabtree and Strong recently wrote a blog* entitled “Turning 40 – Are the Purposes of Chapter 766 Being Achieved?” He along with his law partner, Larry Kotin, long time Education Committee staff member Connie Rizoli and others were among the people who shepherded this revolutionary law into being. Crabtree writes that Chapter 766 included a “Purpose Section” to describe the findings and purposes behind the Act. Its key sponsors wanted to clarify the goals of the new law and the reasons for some of the changes it would bring about.

Chapter 766 established that “the policy of the commonwealth (of Massachusetts) is to provide an adequate, publicly supported education to every child”... regardless of the severity of their disability.

In this 40th year, some of the pioneers and founders of that era have offered some insightful comments. Here is a glimpse of their perspectives: Harvey Liebergott was Special Assistant to the Director of the US Bureau of Education (today known as the US Dept. of Education). One of his assignments was to report on the implementation of the new Massachusetts law: “Chapter 766 grew out of model legislation developed by the Council for Exceptional Children, under a grant from the U.S. Bureau of Education for the Handicapped. Because the Massachusetts law was such a success, we had a much easier time winning support for the federal law”.

Harvey continues, “I am convinced, that Chapter 766 would not have been such a success if it had not been for the group of “founding leaders: Michael Daly and David Bartley in the legislature, Greg Anrig and Bob Audette in the Massachusetts Department of Education, and Martha Ziegler, (Founder of the Federation) who is far and away the best parent advocate the country has produced. It was extraordinary that these people were in the positions where they were most needed.”

David Bartley, Former Speaker of the Massachusetts House of Representatives: “Much has been accomplished. I feel much the same as the late Mike Daly, (former Chair of the House Education Committee and Co-Author of the Chapter 766 Legislation) did when he described our collaboration (he in his role as House Chairman of the Education Committee and I as the Speaker) that led to the enactment of Chapter 766 as one of our proudest achievements. Mike and I were both teachers before we entered politics. We were each intimately aware that our public education system – neglected children with disabilities – and it was in the special education reform act (Chapter 766) that we each felt best realized the goals we shared to use the power of our offices to improve that system.”

Martha Ziegler, Founder of the Federation, views it through the eyes of her experience as the parent of Mary Ann. “During the past few months I have thought a lot about our revolutionary Chapter 766. My autistic daughter, Mary Ann, recently celebrated her 50th birthday. As I have thought about this situation, I realize how much our world has changed in the last 40 years. Before 766 (and other changes in state and federal law) most of the people serving Mary Ann in this challenge would have kept social distance from her. Further, they would have had no idea how to communicate with her or me. It would not have occurred to them that Mary Ann should participate in the crucial decisions about her life.”

Barbara C. Cutler, Ed.D, founder & director of the Autism National Committee: “There is no doubt that Chapter 766 was a giant achievement. Have we achieved all we hoped for? Not quite. But, before Chapter 766 the “choices” were institutionalization, stay at home, or if you were lucky and well behaved, a class in a church basement. 766 is a great success and we must be vigilant in our work to keep it moving forward”.

David Bartley: There is much still to be done: While it is apparent to me that the Chapter 766 purposes have been achieved and sustained for many students over the 40 years of its implementation, the inability of parents without means to access the due process system has left a great many of their children behind when their districts short-cut or deny services that they need.

Martha Ziegler: “We (someday will) have fuller understanding of the revolutionary progress the law has brought, first for thousands and thousands of children and families here in Massachusetts but ultimately for millions of children and families across our nation. Speaker Bartley and House Committee Chairman Michael Daly, plus Bob Crabtree, Larry Kotin, Connie Rizoli, and many more hard workers, including parents, achieved a historic victory that must be recognized.

Join us to celebrate the Legacy of 40 years and keep the promise of equal educational opportunity for all!

Rich Robison

(*Quotes taken from Special Education Today: A Special Education Law Blog from the Attorneys at Kotin, Crabtree & Strong, LLP. www.kesspecialeducationlaw.com)
The Parent Training and Information Center (PTI) is one of the many projects of the Federation. We make our great efforts to reach out to as many families from diverse cultural background as possible. We have established an Outreach Team including bilingual, bicultural staff representing various communities across the state to address the needs of these families.

Parents from diverse communities often have limited access to services in general, due to language barriers, and cultural difference. To meet the needs of these families, it is not simply providing language access, giving a translated packet, or using a compassionate model, so as to say that we know what is best for you and your children. It requires trust and relationship between families and providers.

The language of special education is novel for many culturally diverse families. Because they come from countries where the educational system is different from what they experience here in the US; or where the special education system has not been established. Therefore, many concepts and terms lack an equivalent translation in many of the families’ native languages. In addition, parents from diverse cultural backgrounds often have a deep respect of teachers and school personnel. Parents believe that teachers will do the best for their children with special needs. This respect may prevent parents from asking clarifying questions, requesting different services or challenging a teachers understanding of the child. Parents may fear that their children will be treated badly if parents question a teacher’s actions, training, or motives.

The PTI Outreach Team has collaborated closely with varied community-based groups including faith-based organizations, medical providers, and community health centers to understand better the needs and challenges of the community and learn the best way to address community’s needs. The PTI has successfully addressed some, as follows:

1. Provide Monthly Support Meetings.
2. Held a meeting with DESE’s Policy and Planning Committee to address the issues of language access and translated materials.
3. Modified and adapted its training materials to match the literacy level and language preference of families and ways that people like to learn.
4. Organized and delivered outreach information through local radio and television stations and newspaper articles.
5. Reconfigured its special education trainings in shorter sessions with spelled out terminology, to ensure that families understand the content.
6. Recruited more bilingual partners to present workshops in other languages, and empower these trainers to train parents to be their own children’s advocates.
7. Made referrals to services and supports that take language and culture into consideration during the intake and assistance process.
8. Encouraged referral services to provide adequate language access.
9. Collaborated with other agencies that serve the same populations, in order to be sure scarce resources are fairly shared.
10. Began the long process of addressing systems issues for long-term change.

In 2014, the PTI Outreach team has provided technical support for 83 Spanish speaking families, 64 Portuguese speaking families, 40 Vietnamese speaking families, 11 Chinese speaking families and many other culturally diverse families including Somali, Russia, Haiti, Africa, and Arabic.

Together with PTI Outreach Team, Family TIES of Massachusetts has a Language Line access that allows any non-English family to contact their staff and be connected for appropriate referral resources. Family TIES is another project of the Federation, funded by the Massachusetts Department of Public Health.

The PTI Outreach Team will continuously provide culturally and linguistically appropriate services. We hope to eliminate or reduce disparities and disproportionately distributed resources among culturally diverse families. We understand that all families deserve opportunities to support their children’s special needs.
RTSC Rolls Out Program for Foster, Kinship and Adoptive Parents

By Emily Gaudette, Project Associate - Recruitment Training and Support Center for Special Education Surrogate Parents (FCSN)

The Recruitment, Training and Support Center (RTSC) for Special Education Surrogate Parents (SESPs), is proud to offer a new training program on complex childhood trauma for foster, kinship and adoptive parents. The program is designed to help parents better understand children who have experienced adverse childhood experiences (ACES) and how these events impact learning. This information can empower parents to become more involved with their child’s education and help change their life outcomes for the better.

The term “ACE” was coined by the Centers for Disease Control, based on study results which demonstrated a strong correlation between childhood maltreatment and the risk for negative health conditions. ACEs have a profound impact on the developing brain, and many children in foster care are affected by this condition. Training participants will discuss how childhood trauma affects classwork and social skills. They will also review the trauma-sensitive IEP, and receive support in writing effective goals for social/emotional learning. The curriculum also reviews discipline in schools, including suspension.

RTSC is pleased to collaborate with the MA Department for Children and Families in offering these trainings. For more information on the RTSC’s trainings for foster, kinship and adoptive parents, contact Jane Crecco at jcrecco@fcsn.org or (617) 399-8341. To register for a particular session, contact Emily Gaudette at egaudette@fcsn.org or (617) 399-8342.
Our state is home to many immigrant communities with a rich blend of cultural experiences. Springfield is one of several Massachusetts cities home to refugees from Somalia, a small East African nation. In 2009, the Care Coordination Unit of the Massachusetts Department of Public Health (DPH) invited Family TIES of Massachusetts (FTIES) to meet with a group of 12 newly-arrived Somali families including individuals with special needs. This began a cultural exchange that continues today.

FTIES staff came to recognize the great courage and determination among members of the Springfield-based East Africa Cultural Center (EACC) and its founder Bedel Omar. The EACC engaged FTIES to help its families understand the needs of 13 children. Their special health care needs included complex medical conditions, developmental disability, autism, hearing or vision impairment, and the emotional health concerns of being young refugees. Working with the EACC gave FTIES staff a deeper understanding of the cultural beliefs of its members and the daily challenges facing refugees: learning English, understanding state services and systems of care, securing housing, finding job training and work opportunities, and engaging in their neighborhoods and city.

Through the generosity of the Department of Developmental Services, office space was made available to further the partnership. FTIES staff works with DPH Care Coordinators in the Western Region to engage health care services and identify programs and activities that will enrich the health and lives of Somali children. The Federation’s Parent Training and Information Center (PTI) has worked to address many school-related concerns and improve education in the public schools for the community’s children.

In addition, a Federation intern from the Shriver Center LEND program completed a community scan on behalf of the EACC. This project provided a list of state and community agencies and programs located near the EACC. This is a first step towards collaboration with programs to benefit the EACC’s members and the community at large.

Since 2010, EACC members have attended the Federation’s annual Visions of Community (VOC) conference. The conference offers workshops on the educational and health systems, community engagement, and parent empowerment. Mr. Bedel Omar received the Federation’s Community Partnership Award in 2011 for his efforts within the Somali community. This year the EACC brought a poster to educate attendees about the large number of African states represented in their membership. Family TIES and the Federation are committed to a relationship with the EACC in support of their leadership in the community.
A lot of people have good ideas, but taking an idea to reality is where the rubber meets the road. Like spring in New England, it’s a road filled with bumps and potholes. A good driver learns to avoid obstacles to complete the journey.

Meet Lexington’s Elaine Gabovitch, a parent who had an idea. With her Special Education Parent Advisory Council (SEPAC), Elaine took that idea to the next level. With a son in high school going through transition, Elaine saw the need for a better understanding of how transition planning and services shaping students’ futures between the ages of 14 and 22. Elaine’s response was practical – provide data to the district and shape policy. Using her skills as an instructor and family faculty at UMass Medical School’s E.K. Shriver Center, Elaine developed a needs-assessment survey. She adapted questions from a variety of state and federal sources, including the National Secondary Training and Technical Assistance Center (NSTTAC), the Massachusetts Department of Elementary and Secondary Education (DESE), the University of Kansas, and the Delaware Department of Education. Creating a unique 49 question survey that would educate parents while assessing their knowledge of transition was no easy task. Through the Lexington SEPAC, an email invitation ultimately reached 99 families. 38 successfully completed the entire online survey.

The survey results were presented to the SEPAC, School Committee and Superintendent in 2012. Key SEPAC members Lisa Baci and Holly Boker provided supporting information on transition mandates and best practices. Parents and School personnel created a Task Force to review the findings. After over a year of meetings, a recommendation was made to establish a Transition Coordinator position within the district. Supported by the Superintendent and School Committee, a position has been funded and a job description is being finalized with input from parents. It was a successful road trip with a positive outcome for all families.

But Elaine and her SEPAC colleagues’ journey did not end there. The passion that led their district on the road to discovery about how transition was working for students and families was too strong to remain idle. This school year, Elaine and Lexington SEPAC members Holly Boker and Marilyn Wong started a transition support group for parents of students aged 14-22. They meet monthly to discuss transition issues and share resources. In March, Elaine facilitated a focus group of parents in reviewing the original survey, suggesting improvements, and developing questions for a follow-up survey that will more closely reflect parents’ needs. The new survey will provide valuable data to help the school district shape transition services under the guidance of the new Coordinator.

Passion for positive change is leading Elaine to her next destination: a model survey tool that SEPACs throughout Massachusetts can use to assess transition services and encourage dialogue within their districts. Her goal of providing data driven information will inform parents and school personnel on how to create a better transition experience.

It has been a long journey with lots of bumps in the road. Sticking to her itinerary, being flexible in her route, and asking for directions along the way, Elaine is showing us a great way to travel. Road trip, anyone?

---

**Practical Passion - A Driving Force**

By Leslie M. Leslie, Project Coordinator - MassPAC (FCSN)

---

**Make a Difference . . . in a Student’s Life. Become a Special Education Surrogate Parent.**

- Are you a parent of a child with special needs?
- Are you an education professional or student looking for a one of a kind experience?
- Do you have experience with the IEP process?
- Can you commit 10-20 hours a year to make a difference in the life of one of our state’s neediest children?

Special Education Surrogate Parents make educational decisions for children in state custody whose parents cannot. To learn more, contact the Recruitment, Training, and Support Center (RTSC) for Special Education Surrogate Parents by calling (617) 236-7210, emailing rtsc@fcsn.org, or check out our website at www.fcsn.org/rtsc.

---

**THE FUN COOKING MAGAZINE FOR FAMILIES**

**CHOPCHOP**

[www.chopchopmag.org](http://www.chopchopmag.org)

Inspire kids to cook and eat real food with their families. Subscribe now and never miss an issue of our award-winning magazine.
An interdisciplinary team works together with a BCBA to develop each student’s individualized behavior plan.

The Guild’s model of integrated staffing ensures consistency and promotes student success.

The complex health care needs of our students are managed by our nursing team and consulting physicians.

Home/school communication and collaboration is an essential program component.

Every student benefits from our on-staff speech/language and occupational therapists.

Guild staff ensures student safety through continual training and professional development.

Using the community as an extension of our learning environment, students are able to use newly learned skills in real world opportunities.

Individual and group therapy sessions are provided by a team of licensed mental health counselors and expressive therapists.

Learning is enhanced for students ages 15+ through paid, meaningful work.

Development of healthy habits is imparted by our nutrition education, healthy food options and adaptive physical activities.
“It Starts with You”: Visions of Community 2014 Conference (continued from page 1)

Community Partnership Awards recognized achievements by Massachusetts parents and professionals in Parent Advocacy and Leadership, Inclusive General and Special Education, Inclusive Recreation, and Self-Advocacy. Awardees included Amber Bobnar (founder of WonderBaby.org), Iraudhias Baez (Federation Parent Consultant for Latino Families), Karen Donovan (Ipswich SEPAC member), Phyllis Jailet (Wachusett Regional School District Teacher), Kate Ahern (Easter Seals Assistive Technology Specialist), Regina Snowden (Executive Director of Partners for Youth with Disabilities, Inc.), and Nicole Tarzia (Ms. Wheelchair Massachusetts 2013). Read more about this year’s awardees on page 11.

The Federation was proud to present a two-part keynote headed off by Michael Yudin, Assistant Secretary for the Office of Special Education and Rehabilitative Services (OSERS) at the Department of Education. Assistant Secretary Yudin’s address focused on fostering high expectations for students with disabilities. Highlighting the core OSERS values of Inclusion, Equity, and Opportunity, Yudin maintained that the goal of full inclusion for youth with disabilities in school and society, “...is more than a moral imperative, this is an economic imperative.” Mr. Yudin’s passionate speech was data-driven but firmly asserted that “Children with special needs are children first,” a sentiment that resonated with conference attendees. He affirmed what parents know from experience, that “…research shows that kids with disabilities do better when they are held to high standards and have access to the general curriculum.” He also made mention of research on how teachers’ expectations directly impact student performance, as well as strategies for inclusion like Principles of Universal Design and Multi-Tiered Systems of Support. Ultimately, Mr. Yudin told the crowd, “We have to change the culture of expectations, and it starts with you. It starts with our parents.”

The second half of the keynote explicitly connected the national strategy with the everyday experiences of parents and children. Delivered by the Executive Director of Parent to Parent Virginia, Dana Yarbrough, and her daughter Brooke using a PowerPoint presentation and assistive iPad technology, the presentation urged parents to raise their expectations and create a vision for their child. Each Yarbrough told the story of pursuing a “Typical life” for Brooke, from a 2 pound premature infant with physical, intellectual, and sensory disabilities to a 19 year-old High School graduate and small business owner. A “typical life is...different for each of us,” said Dana, but for youth with disabilities it can be defined by the realities of the service system. She focused on her belief that families must develop a vision for their child’s future early, stick to it, and not expect that the service system will create a life for a child. She recounted telling IEP teams that Brooke would one day own her own business and being met with the claim that she was “in denial” about Brooke’s reality. The Yarbroughs looked for ways not to say “No,” but “How can we make this possible?” Brooke added, “I live a life of my choosing, not one dictated by the service system.”


Between workshop sessions, attendees browsed resource tables from all of the Federation programs, as well as an extensive display of regional, state-wide, and national resources from Family TIES of Massachusetts. The 84 Exhibitors included advocacy services, support organizations, financial planning, schools and colleges, hospitals, therapy practices, adaptive technology and recreation options, books, and arts and crafts. In addition to exhibitors, there were book signings by Federation founder Martha Ziegler, Federation staff members Becky Rizoli and Ashley Coates, and Judith Canty Graves and Carson Graves.

Both the exhibit hall and the children in conference child-care were excited to receive a visit from the Hearts & Noses Hospital Clown Troupe. The clowns played with children at childcare for over an hour, creating a fun, safe, and empowering space for children and working hard not to overwhelm those less comfortable with clowns.

Upon turning in the conference evaluation, attendees received a copy of “A Family Guide to Transition Services in Massachusetts,” produced jointly by the Federation and the Massachusetts Rehabilitation Commission. Available in Spanish and English, the Guide is available on the Federation website, along with videos and handouts from the conference.

The Federation thanks the more than 100 staff and volunteers who made this year’s conference possible. The joy of the day remains seeing parents connect and inspire one-another. Visions of Community 2015 will be held Saturday March 7, 2015 at the Seaport World Trade Center. Plan now to attend!
Visions of Community 2014 Conference in Pictures...

- Acting Asst. Secretary Michael Yudin with DESE Commissioner Mitchell Chester enjoy the opening session.
- FCSN Parent Training and Information Project Director Julie Sinclair greets with Acting Asst. Sec. Michael Yudin.
- FCSN Recruitment Training and Support Center Project Director Paige Parisi with volunteer Tee Thach.
- Our 16th year at the Seaport World Trade Center.
- Lauri Medeiros and Dianne Huggon staff the Massachusetts Families Organizing for Change exhibit table.
- FCSN staff Marilyn Gutierrez and volunteer Isabel Castro provided support for participants at the Interpreters table.
- No one’s too young to enjoy the day.
- Participant Halima Diallo gathers resources in the Exhibit Hall.
- Families from around the state enjoyed a fun day of networking.
- Desi Forte and Cathy Bly provided information at the Easter Seals exhibit table.
- A conference participant peruses the displays on the Family TIES of Massachusetts resource tables.
- Federation Board members Joseph Petner and William Henderson presented a session on inclusive schools and communities.
Congratulations to our Community Partnership Awardees!

Amber Bobnar  
*Parent Advocacy Award*

Originally from Hawaii, Amber Bobnar and her family moved to Watertown to be closer to the Perkins School for the Blind where her son currently attends the Lower School. Amber is founder and editor of WonderBaby.org, a support and information website for parents of children who are blind or visually impaired and also volunteers as president of the Massachusetts Association of Parents of the Visually Impaired (MAPVI).

Phyllis Jaillet  
*Inclusive General Education Teacher Award*

Phyllis Jaillet has been teaching for 32 years. She has taught grades one, three, four, and five, presently Phyllis teaches fourth grade. She has been a reading specialist and a special educator. Phyllis has taught in the Wachusett Regional School District for the past 18 years. Phyllis fosters a true community in her classroom, and sets the bar very high for all of her students.

Kate Ahern  
*Inclusive Special Education Teacher Award*

Kate Ahern is an Easter Seals Assistive Technology Specialist who works in schools with children who have disabilities. She also is well known for her blog, “Teaching Learners with Multiple Special Needs.” Before joining Easter Seals, Ahern was a special education teacher and assistive technology specialist. What drives Kate is her passion. One parent said, “The complexity doesn’t scare her; it challenges her to make our daughter the best she can be.”

Regina Snowden  
*Inclusive Recreation Award*

Regina Snowden, M.S.W., is the founder and Executive Director of Partners for Youth with Disabilities, Inc. She brings a wealth of knowledge regarding youth programming, inclusion, mentoring, and management. Since founding PYD in 1985, she has played a major role in the creation of successful programs and securing funding which has enabled the organization to help Massachusetts youth with disabilities overcome barriers by providing mentoring, education, entrepreneurship, health, recreational and cultural opportunities.

Iraudhis Baez  
*Parent Advocacy Award*

Iraudhis Baez, completed the Parent Consultant Training at FCSN, with her eldest daughter as her inspiration. She is now pursuing a career as a Special Education Advocate, currently working as a Subcontracted Parent Consultant for Latino Families by the Federation through The Jesse Family Advocacy Fund. Iraudhis helps families with children with special needs who are struggling to obtain the appropriate education and services for their children, especially those who face linguistic barriers.

Karen Donovan  
*Parent Leadership Award*

When her child was diagnosed with autism spectrum disorder, Karen Donovan worked countless hours to reach out to parents and educators and tirelessly sought collaboration with the Ipswich Massachusetts Public Schools. Through her leadership of the Ipswich SEPAC, Karen gave Ipswich parents a voice. She has had a tremendous impact on the education and inclusion of Ipswich’s children with special needs.

Nicole Tarzia  
*Self-Advocacy Award*

Nicole Tarzia was chosen as Ms. Wheelchair Massachusetts 2013 on March 2, 2013. Having been diagnosed with quadriplegic spastic cerebral palsy at six months old, Nicole has faced many medical challenges. Despite this, her family always told her that she could do anything and that she would find a way to adapt. She earned degrees from both Bridgewater State University and Simmons College, where she decided that she wanted to guide youths with and without disabilities down successful paths in life. Since being chosen as Ms. Wheelchair Massachusetts, she has used her platform to better educate youths and break down stereotypes concerning physical disabilities. She hopes to teach kids that through education and adaptation, that any dream in life is possible.
It seems like a simple question but for many Massachusetts families it is quite complex. Mass Family Voices hopes to help you get started!

**What is Premium Assistance?**

Premium Assistance is when MassHealth pays part of your private health insurance premium. This could mean a reduced MassHealth premium, no MassHealth premium, or a monthly payment from the state to help defray the cost of your primary insurance. Your result depends on the amount of your MassHealth premium. Premium Assistance payments are available to those eligible for coverage types including MassHealth’s Standard, CommonHealth CarePlus coverage plans, and Kaileigh Mulligan.

Premium Assistance is also available to some adults with private health insurance through their employers. Families with children younger than 19 whose household Modified Adjusted Gross Income is between 150% and 300% of the Federal Poverty Level are eligible through either the Family Assistance program or the MassHealth Small Business Employee Premium Assistance Program.

MassHealth may provide a Premium Assistance payment to an eligible member meeting the following criteria:

- The health insurance coverage meets the Basic Benefit Level (BBL)
- The health insurance policy holder lives with a person eligible for Premium Assistance benefit
- At least one person covered by the health insurance is eligible for MassHealth benefits and the health-insurance policy meets the criteria of MassHealth coverage for Premium Assistance benefits

Eligibility is determined by the coverage type and the type of private health insurance the person has or has access to. There are two types of health insurance that are eligible for Premium Assistance: Employer-Sponsored Insurance 50% Plans and Other Group Insurance Plans.

For Other Group Insurance Plans where the employer contributes less than 50% of the monthly premium, COBRA, and other group health insurance, MassHealth will provide Premium Assistance to enroll in plans purchased directly for children under 21. All plans must meet a Basic Benefit Level. In addition, MassHealth may provide Premium Assistance for individuals with unsubsidized insurance.

It cannot be stressed enough that after submitting quote/insurance information to Premium Assistance, it is a good idea to follow-up with a phone call to confirm that it was received and that they have everything they need.

When you find out you are eligible, MassHealth Premium Assistance will then submit payments directly to the HealthConnector or to the applicant’s insurance company.

**MassHealth Premium Assistance contacts are:**

Lekecia Powell-Watkins at 617-886-8263/Lekecia.Powell-Watkins@Umassmed.edu or Samantha Laskey at 617-886-8058/Samantha.Laskey@Umassmed.edu.

Faxes can be sent to their attention at 617-886-8400.

It is very important to note that while Health Connector Plans are available for children under 21, families who are in Standard or CommonHealth and are seeking coverage for services not covered by MassHealth, such as ABA services, are not eligible.

MassHealth will not pay premium assistance for a Health Connector Plan if the child has access to the needed services through an Employer Sponsored Insurance, even if outside the open enrollment period for that plan.

Any questions about the process for enrolling children in a Health Connector Plan can be answered by calling 1-877-MA-ENROLL (877-623-6765). Be sure to let the customer service representative know that you are only interested in purchasing an unsubsidized Connector Plan for your child.
Changes to the Application for MassHealth

By Darcy Rubino, Information Specialist - Mass Family Voices (FCSN)

If you recently applied for MassHealth or have been following the big changes in healthcare this year, you may have noticed that the MassHealth application has changed. The biggest change is in the title. The form is no longer called “Member Benefit Request (MBR)”. Instead, the name matches the federal form and is called “Application for Health Coverage and Help Paying Costs.”

The form is also longer, growing from 6 to 18 pages. Basics like household income and job information remain but each section has more detailed questions.

For example, the old section entitled Working Income only asked if you were offered health insurance through your employer within the last 6 months. The new application renames this section, calling it Part 3: Current Job and Information. MassHealth still wants to know if your employer offers insurance, how much it is, how often you pay premiums, and if it meets the Minimum Value.

In Part 3, most applicants’ eligibility for MassHealth and Qualified Health Plan credits/subsidies is now based on an income counting method called MAGI (Modified Adjusted Gross Income). MAGI is used in federal income tax calculations and makes it easier to determine financial eligibility. Now that MAGI is used, changes will occur in the way certain types of income are reported. Child support, non-taxable veterans’ payments, and SSI are not counted as income.

Part 6: Rights and Responsibilities and Signature Page has a new section that asks specific questions regarding the collection of income data. MassHealth wants permission to take information from your federal tax returns to determine income level. This is part of the MAGI calculation. You can authorize MassHealth to use this data for 1-5 years. You can also opt out and not permit the use of federal data to renew eligibility. If you opt out, you will need to provide income information during your recertification period.

Another change to the application is the name of the section formerly entitled Absent Parent. The new name of this section is more aptly titled Non-Custodial Parent Section.

With the passage of the Affordable Care Act, there are definitely many changes other than those to the MassHealth application. When you need questions answered, we at Mass Family Voices hope to be your go-to call. Please call us at 1-800-331-0688 ext. 301.

---

**Crystalsprings**

New Abilities for a Better Tomorrow

Crystal Springs provides individualized programs for children and adults with developmental disabilities while embracing and nurturing each person’s pursuit of growth, independence, dignity, and choice.

**Who We Serve**

Children and adolescents with cognitive impairments and/or physical disabilities, medical complexities and behavioral challenges.

- Autism Spectrum Disorder
- Severe Disorders
- Medically Involved
- Behavioral Challenges
- Cognitive Disabilities

- Non-Verbal
- Multiple Diagnosis
- Orthopedic Disabilities
- Visual and Auditory Impairments

**Schedule a Tour Today • Rolling Admissions**

38 Narrows Road, P.O. Box 372, Assonet, MA 02702 • Phone: 508.546.7101 • www.crystalspringsinc.org

---

**Strengthening Our Family Supports**

Family Support Centers are Your “Go To” Resource

The Family Support Centers of Seven Hills Family Services are the “Go-To” Centers for all children with disabilities and their families seeking support tailored to their needs. At the Centers, families can network with other families; access real-time information; explore avenues to community inclusion; and receive unique, individualized supports while navigating the social services system. Family Support Specialists respond to each family’s needs with a planned course of action. Drop-ins are welcome, or call for a personalized appointment.

**Seven Hills Family Services**

An Affiliate of Seven Hills Foundation

799 West Boylston Street, Worcester, 508.796.1850
1460 John Fitch Highway, Fitchburg, 978.632.4322
128 Main Street, Sturbridge, 508.796.1950 • www.sevenhills.org
“Comienza con usted”: Conferencia Visiones de la Comunidad 2014

Por Roisin Foley, Asistente Ejecutiva - FCSN

El sábado 8 de marzo, la Federación dio la bienvenida en el Seaport World Trade Center de Boston a más de 900 concurrentes a la conferencia anual Visiones de la comunidad, para padres de niños con necesidades especiales y profesionales que les brindan servicios. Participantes de todo Massachusetts asistieron a talleres, visitaron el salón de exhibiciones y las mesas de recursos y se relacionaron con otros padres y profesionales. Este año, la Federación ofreció en cada una de las tres sesiones talleres en chino, español, portugués, vietnamita y somalí, además de 30 talleres en inglés. Hubo intérpretes de cantonés, español, idioma de señas estadounidense, mandarín, portugués, somalí y vietnamita.

La jornada comenzó en el anfiteatro, donde Rich Robison, director ejecutivo de la Federación, presentó a los invitados especiales y presidió la ceremonia de entrega de premios a los asociados en la comunidad. Algunos de los invitados fueron Tom Sannicandro, diputado estatal; Elin Howe, comisionado del Departamento de Servicios del Desarrollo; Heidi Reed, comisionado de la Comisión de Massachusetts para Personas Sordas y con Dificultades Auditivas; y Cliff Robinson, comisionado del Departamento de Salud Mental. Como representantes del Departamento de Educación Primaria y Secundaria, participaron el Dr. Mitchell Chester, comisionado; Alan Ingram, comisionado adjunto; Marcia Mittnacht, directora de Servicios de Educación Especial; y Madeline Levine, directora de la Oficina de Sistemas Escalonados de Apoyo.

Los premios a los asociados en la comunidad reconocieron los logros de los padres y profesionales de Massachusetts en las categorías de apoyo, defensa y liderazgo; educación general y especial inclusiva; recreación inclusiva; y abogar a favor de uno mismo. Se entregaron premios a Amber Bobnar, fundadora de WonderBaby.org; Iraudhis Báez, madre consultora de la Federación en lo relacionado con familias latinas; Karen Donovan, miembro del SEPAC de Ipswich; Phyllis Jaiilet, maestra del distrito escolar regional de Wachusett; Kate Ahern, especialista en tecnología adaptada de Easter Seals; Regina Snowden, directora ejecutiva de Partners for Youth with Disabilities, Inc.; y Nicole Tarzia, Miss Silla de Ruedas 2013 de Massachusetts.

La Federación se complació en presentar un discurso inaugural de dos partes encabezado por Michael Yudin, secretario adjunto de la Oficina de Servicios de Educación Especial y Rehabilitación (OSERS, por su sigla en inglés) del Departamento de Educación, que se centró en la importancia de plantear metas ambiciosas para los estudiantes con discapacidades. Yudin destacó los valores centrales de OSERS de inclusión, equidad y oportunidad, y sostuvo que el objetivo de la inclusión plena de los jóvenes con discapacidades en la escuela y en la sociedad, “...es más que un imperativo moral, es un imperativo económico”. La apasionada intervención estuvo respaldada por datos pero declaró firmemente que “los niños con necesidades especiales son ante todo niños”, un sentimiento que resonó entre los asistentes. Yudin afirmó que los padres saben por experiencia propia lo que la investigación ha demostrado...”que los niños con discapacidades prosperan cuando se espera que rindan y se los mide con estándares altos y cuando tienen acceso al plan de estudios general”. También citó investigación sobre la forma en que las expectativas de los maestros influyen directamente en el rendimiento de los estudiantes, y acerca de estrategias de inclusión como los principios de diseño universal y los sistemas de apoyo a múltiples niveles. Por último, dijo que “tenemos que cambiar la cultura de las expectativas, y eso es algo empieza con cada uno de ustedes, los padres”. La segunda mitad del discurso inaugural vinculó explícitamente la estrategia nacional con las experiencias cotidianas de padres e hijos. Fue presentado por Dana Yarbrough, directora ejecutiva de la rama de Virginia de Parent to Parent, y su hija, Brooke, mediante una presentación en PowerPoint y tecnología adaptada para iPad. Exhortaron a los padres a elevar sus expectativas y a crear una visión para sus hijos. Contaron la historia de cómo buscaron una vida “normal” para Brooke, que nació prematura, pesando sólo dos libras, con discapacidades físicas, intelectuales y sensoriales, y hoy es una joven de 19 años que se ha graduado de la escuela secundaria y es dueña de una empresa pequeña. “Una vida normal es algo diferente para cada uno de nosotros”, explicó Dana, pero para los jóvenes con discapacidades pueden estar definido por las realidades del sistema de servicios. Se centró en su creencia de que las familias tienen que desarrollar desde temprano una visión de futuro para sus hijos, deben perseverar y no deben esperar que el sistema de servicios haga esto por ellos. Relató cómo, cuando les decía a los equipos de los planes educativos individualizados (IEP) que Brooke un día sería la dueña de su propio negocio, le contestaban que no estaba negando a aceptar la realidad de su hija. La familia Yarbrough, en lugar de decir, “No es posible”, se preguntó “¿Cómo podemos convertir esto en realidad?”. Y Brooke añadió: “Tuve la vida que yo escogí, no la que me podría haber impuesto el sistema de servicios”.

El tema de las expectativas altas para los jóvenes con discapacidades continuó en la primera sesión con una mesa redonda titulada “Transiciones exitosas: Cómo cumplir nuestros sueños”; moderada por Michael Yudin, con la participación de Dana y Brooke Yarbrough; Becky Rizoli, empleada de la Federación; Nicole Tarzia; y Laura Surprenant. Cada joven habló de sus experiencias con el sistema de educación especial y la transición a una vida independiente. Otros talleres favoritos de los participantes fueron una conversación interactiva con el personal del DESE titulada, “Cómo mejorar el formulario del IEP: Qué cosas funcionan y no funcionan; y Cómo mejorar el formulario del IEP: Qué cosas funcionan y no funcionan...”

Continúa en la siguiente página
“Comienza con usted”: Conferencia Visiones de la Comunidad 2014

(continuado de la página anterior)

Cuáles no?”, una exploración del viaje emocional y las necesidades de autocuidado de los padres de niños con necesidades especiales, “Cambiado por un niño: El viaje emocional”, “Cómo apoyar el aprendizaje de los niños traumatizados: Crear y abogar a favor de escuelas sensibles al trauma”, “Manejo de la conducta en las discapacidades del desarrollo: Guía para entender y lidiar con los comportamientos desafiantes”, “La Ley de Atención Médica Asequible: ¿Qué está cambiando para las familias de Massachusetts?”, “Cómo ayudar a los niños con ansiedad” y “Trabajando juntos: Cómo promover cambios positivos en su distrito escolar”.

Entre las diferentes sesiones, los asistentes tuvieron oportunidad de visitar las mesas de los diferentes programas de la Federación, así como una exhibición amplia de recursos a nivel regional, estatal y nacional presentada por Family TIES de Massachusetts. Entre los 84 expositores había representados servicios de apoyo y defensa, organizaciones de asistencia y planificación financiera, escuelas, universidades, hospitales, prácticas de terapia, tecnología y opciones recreativas adaptadas, libros y artes y manualidades. Además, autografiaron libros Martha Ziegler, fundadora de la Federación, y miembros de su personal como Becky Rizoli, Ashley Coates, Judith Canty Graves y Carson Graves.

Tanto la sala de exhibiciones como los niños cuidados en la guardería recibieron con entusiasmo la visita de la compañía de payasos Hearts & Noses Hospital Clown Troupe, quienes jugaron con los pequeños durante más de una hora creando un espacio divertido, seguro y fortificante, y procurando no abrumar a los que se sentían menos cómodos con payasos.

Este año, los participantes que entregaron formularios de evaluación de la conferencia recibieron una copia de la “Guía de los servicios de transición en Massachusetts para las familias”, preparada conjuntamente por la Federación y la Comisión de Rehabilitación de nuestro estado y disponible en español y en inglés en el sitio web de la Federación.

Esta conferencia fue posible gracias al trabajo de más de 100 empleados y voluntarios de la Federación, entre ellos, trabajadores de la guardería, intérpretes, presentadores de talleres y todas las personas que ayudaron a armar y luego limpiar todo. La Federación agradece a todos por sus esfuerzos para que todo marchara sobre ruedas. La verdadera alegría de la jornada sigue siendo ver los rostros de los padres y cómo se relacionan e inspiran mutuamente compartiendo historias, recursos y apoyo. La próxima conferencia Visiones de la comunidad se celebrará el sábado 7 de marzo de 2015, nuevamente en el Seaport World Trade Center. ¡Anótelo ya mismo en su calendario!
“Começa com Vocês”: Conferência sobre as Visões da Comunidade 2014

Por Roisin Foley, Executive Assistant - FCSN

No sábado, dia 8 de março, a Federação acolheu acima de 900 participantes no Seaport World Trade Center em Boston para a sua conferência sobre as Visões da Comunidade, de um dia de duração, para os pais de crianças com necessidades especiais e para os profissionais que lhes prestam assistência. Os participantes de todo Massachusetts participaram de oficinas, examinaram o salão dos exibidores, visitaram as mesas de recursos, e trabalharam em rede com outros pais e profissionais. Este ano, a Federação foi capaz de oferecer oficinas em espanhol, português, vietnamita, chinês e somali durante cada destas três sessões, além de 30 oficinas em inglês. Serviços de interpretação estavam disponíveis para os participantes que usam a Linguagem Americana de Sinais, chinês cantoñones e mandarim, somali, português, espanhol e vietnamita.

O dia iniciou-se no anfiteatro, onde o Diretor Executivo da Federação Rich Robison introduziu Convidados Especiais e presidiu a cerimônia de Prêmio de Parceria Comunitária. Entre os convidados encontravam-se o Comissário do Estado Tom Sannicandro, o Comissário dos Serviços de Desenvolvimento Elin Howe, o Comissário dos Surdos e Deficientes Auditivos Heidi Reed, e o Comissário Adjunto do Departamento de Saúde Mental Cliff Robinson. Os Comissários do Departamento de Educação Elementar e Secundária (DESE) incluindo o Comissário Dr. Mitchell Chester, Comissário Adjunto Alan Ingram, a Diretora dos Serviços de Educação Especial Marcia Mittnacht, e a Diretora do Escritório dos Sistemas Interligados de Apoio Madeline Levine.

A Federação orgulhou-se em apresentar uma palestra importante, consistida de duas partes, encabeçada por Michael Yudin, Subsecretário do Escritório dos Serviços de Educação Especial e de Reabilitação (OSERS) no Departamento de Educação. O discurso do Subsecretário Yudin tratou de concentrar-se na promoção de altas expectativas para os estudantes com deficiências. Destacando os valores principais de Inclusão, Equivalência e Oportunidade, do OSERS, o Sr. Yudin afirmou que o objetivo da inclusão integral para os jovens com deficiências na escola e na sociedade, “...é mais do que um imperativo moral, isto é um imperativo econômico.” O discurso apaixonado do Sr. Yudin foi orientado por dados que um imperativo moral, isto é um imperativo econômico.

A Federação acolheu acima de 900 participantes no Seaport World Trade Center em Boston para a sua conferência sobre as Visões da Comunidade, de um dia de duração, para os pais de crianças com necessidades especiais e para os profissionais que lhes prestam assistência. Os participantes de todo Massachusetts participaram de oficinas, examinaram o salão dos exibidores, visitaram as mesas de recursos, e trabalharam em rede com outros pais e profissionais. Este ano, a Federação foi capaz de oferecer oficinas em espanhol, português, vietnamita, chinês e somali durante cada destas três sessões, além de 30 oficinas em inglês. Serviços de interpretação estavam disponíveis para os participantes que usam a Linguagem Americana de Sinais, chinês cantoñones e mandarim, somali, português, espanhol e vietnamita.

O dia iniciou-se no anfiteatro, onde o Diretor Executivo da Federação Rich Robison introduziu Convidados Especiais e presidiu a cerimônia de Prêmio de Parceria Comunitária. Entre os convidados encontravam-se o Comissário do Estado Tom Sannicandro, o Comissário dos Serviços de Desenvolvimento Elin Howe, o Comissário dos Surdos e Deficientes Auditivos Heidi Reed, e o Comissário Adjunto do Departamento de Saúde Mental Cliff Robinson. Os Comissários do Departamento de Educação Elementar e Secundária (DESE) incluindo o Comissário Dr. Mitchell Chester, Comissário Adjunto Alan Ingram, a Diretora dos Serviços de Educação Especial Marcia Mittnacht, e a Diretora do Escritório dos Sistemas Interligados de Apoio Madeline Levine.

A Federação orgulhou-se em apresentar uma palestra importante, consistida de duas partes, encabeçada por Michael Yudin, Subsecretário do Escritório dos Serviços de Educação Especial e de Reabilitação (OSERS) no Departamento de Educação. O discurso do Subsecretário Yudin tratou de concentrar-se na promoção de altas expectativas para os estudantes com deficiências. Destacando os valores principais de Inclusão, Equivalência e Oportunidade, do OSERS, o Sr. Yudin afirmou que o objetivo da inclusão integral para os jovens com deficiências na escola e na sociedade, “...é mais do que um imperativo moral, isto é um imperativo econômico.” O discurso apaixonado do Sr. Yudin foi orientado por dados que um imperativo moral, isto é um imperativo econômico.

O dia iniciou-se no anfiteatro, onde o Diretor Executivo da Federação Rich Robison introduziu Convidados Especiais e presidiu a cerimônia de Prêmio de Parceria Comunitária. Entre os convidados encontravam-se o Comissário do Estado Tom Sannicandro, o Comissário dos Serviços de Desenvolvimento Elin Howe, o Comissário dos Surdos e Deficientes Auditivos Heidi Reed, e o Comissário Adjunto do Departamento de Saúde Mental Cliff Robinson. Os Comissários do Departamento de Educação Elementar e Secundária (DESE) incluindo o Comissário Dr. Mitchell Chester, Comissário Adjunto Alan Ingram, a Diretora dos Serviços de Educação Especial Marcia Mittnacht, e a Diretora do Escritório dos Sistemas Interligados de Apoio Madeline Levine.

A Federação orgulhou-se em apresentar uma palestra importante, consistida de duas partes, encabeçada por Michael Yudin, Subsecretário do Escritório dos Serviços de Educação Especial e de Reabilitação (OSERS) no Departamento de Educação. O discurso do Subsecretário Yudin tratou de concentrar-se na promoção de altas expectativas para os estudantes com deficiências. Destacando os valores principais de Inclusão, Equivalência e Oportunidade, do OSERS, o Sr. Yudin afirmou que o objetivo da inclusão integral para os jovens com deficiências na escola e na sociedade, “...é mais do que um imperativo moral, isto é um imperativo econômico.” O discurso apaixonado do Sr. Yudin foi orientado por dados que um imperativo moral, isto é um imperativo econômico.

Tweet Us: #1familyatatime

By Sarah Stevenson, Communications Coordinator - FCSN

Over the last four decades, The Federation for Children with Special Needs has listened to and learned from families like yours, helping us grow into a well-respected and highly regarded organization helping 40,000 Massachusetts families each year! Through exceptional programming, we provide education, advocacy and critical networking opportunities to the most vulnerable families. One parent commented, “I would like to express my gratitude to the Federation for their hard work, dedication and guidance. People like you are the ones that make this planet better, one family at a time.” As we move into our next 40 years, we are dedicated to making life better for all children—one family at a time.

Please help us celebrate this year by sharing your family’s story. Has the Federation made life better for your family? We’d love to hear how. Did you attend the Parent Consultant Training Institute and become an advocate for your child? Have you joined a support group through Family TIES of Massachusetts? Or maybe we helped you find the answer to a health or education question. Join Chris and Marianne Cooper, “Blades” the Bruins mascot, and Susan Arndt, parent of a child with special needs by tweeting your photo, like the ones you see here, @FCSN with the hashtag #1familyatatime.

“Começa com Vocês”: Conferência sobre as Visões da Comunidade 2014

(Finalização da página anterior)

Federação, bem como em uma extensa exposição de recursos regionais, estaduais e nacionais do LAÇOS da Família, Family TIES de Massachusetts. Os 84 Exibidores incluídos os dos serviços de defensoria, organizações de apoio, planos de financiamento, escolas e faculdades, hospitais, práticas terapêuticas, tecnologia de adaptação e opções recreativas, livros, e arte e artesanato. Além dos exibidores, houve autógrafo de livros pela fundadora da Federação, Martha Ziegler, pelos membros do pessoal da Federação Becky Rizoli e Ashley Coates, e Judith Canty Graves e Carson Graves.

Tanto o salão de exibição bem como as crianças sendo cuidadas pela creche da conferência ficaram entusiasmados em receber a visita da Trupe de Palhaços do Hospital Corações & Narizes, Hearts & Noses Hospital Clown Troupe. Os palhaços brincaram com as crianças por mais de uma hora, criando um espaço divertido, seguro e energético para as crianças, trabalhando intensamente para não oprimir aqueles que se sentem menos confortáveis diante de palhaços.

Este ano, os participantes que entregaram os seus Formulários de Avaliação da Conferência receberam uma cópia do “Um Guia da Família para os Serviços de Transição em Massachusetts,” produzido em conjunto pela Federação e pela Comissão de Reabilitação de Massachusetts. Disponível em espanhol e inglês, o Guia também pode ser encontrado no Website da Federação.

Mais de 100 funcionários da Federação e bem como voluntários tornaram com que esta conferência fosse possível este ano, desde os funcionários que dão cuidados às crianças, intérpretes, dirigentes das oficinas, até cada um que ajudou na organização e na limpeza. A Federação agradece a cada um deles por seus esforços em proporcionar que o dia corresse com tranqüilidade. A verdadeira alegria do dia continua sendo a de ter visto os rostos dos pais e observá-los conectando-se e inspirando uns aos outros ao compartilhar histórias, recursos, e apoio. A próxima Conferência Visões da Comunidade acontecerá no dia 7 de março de 2015 no Seaport World Trade Center. Planeje agora a sua participação!
“You’re weird, Bryce,” a kid recently told my brother. “Everyone says you’re special.”

Following his dual diagnosis of Tourette’s Syndrome and ADHD, and after the neighborhood boys took note of him being in the “special” classroom, Bryce defected to my parents’ iPad for fun. He continued attending Math Club and Boy Scouts with other fourth graders, but without structured social events, he was lonely.

One day at recess, Bryce overheard older boys talking about a game called Minecraft. They were frustrated because someone on another team had snuck onto their server the night before and stolen some of their minerals. The game sounded awesome, like Legos but better. Bryce found Minecraft after school on the iPad. A few hours later, my mom came into the living room when she heard raised voices. She was surprised to see Bryce speaking to the iPad, using his finger to drag blocks on top of other blocks. She asked, “Who’re you talking to?”

“My friend. He’s in Taiwan,” Bryce said, frustrated at the interruption. “We have to do it together!” The boy on the other end of the game agreed, and they used their tools to continue building.

Since that first night, my mom has virtually met the parents of each child on Bryce’s team, wiping her hands on a dishcloth after dinner while waving shyly to a woman in Korea as she gets her kids for the morning. They shrug at each other as their boys resume play, almost addicted to the game’s endless possibility.

Eric Klopfer of MIT’s Scheller Teacher Education Program says, “When they play Minecraft, kids think about establishing rules for society.” While Bryce has difficulty negotiating in person, due in part to the stigma around his special education program, on Minecraft he’s just another user with a good track record for building.

Bryce feels for his team; they mourn the loss together when their world is attacked by rivals. They discuss when a team player is absent, asking her if she’s okay the next time she logs on, all the while dragging and dropping items into each other’s inventories. Sometimes his team votes him the “boss”, and other times he completes his labor in the workspace as another player oversees the projects. He cries when night zombies attack and he devises plans for repairs.

As a child with ADHD, one of Bryce’s challenges is battling his lack of impulse control. Eric Klopfer says the cadence of Minecraft’s game play forces players to reflect on their actions. “If a kid blows up another kid’s house online,” Klopfer says, “they have time to think about how they’re going to deal with it and how to confront the player.”

Of course, Bryce doesn’t care that Minecraft won the KIPi Award for “Best Virtual World for Children,” and he doesn’t care that the United Nations uses Minecraft to reimagine rundown areas, helping people around the world picture what their environments could look like with ample funding. All he knows is that the game is fun, and that wearing his Minecraft shirt to school gets him nods from older boys on the playground. Limiting his time in front of a screen is important, but Minecraft has given Bryce a shared vocabulary with kids in his peer group, most of whom have a similar experience online.

“If you had told me a computer game would make Bryce more social,” my mother says, “I wouldn’t have believed you.”

---

Canary Partnership Announcement:
Support the Federation and De-clutter Your House! A Win/Win Partnership!

The Federation is proud to announce a new partnership with Canary, a local Boston-area startup. Canary helps people buy and sell online locally. 60% stays with item’s owner and 12% benefits the Federation for Children with Special Needs through a tax deductible donation in your name! If you have extra stuff sitting around the house, Canary will do all the work selling it for you- from taking pictures to researching prices to finding credible buyers. They’ll sell anything worth over $150, from furniture to appliances, gazebos, swing sets, even cars! If you have extra stuff cluttering up your house, let Canary take care of everything, and support the Federation while you’re at it. Check them out at gocanary.com, or contact them at chirp@gocanary.com or 617-366-2787.
**Book Reviews**

**How to Make and Keep Friends: Helping Your Child Achieve Social Success**
(originally published as How to Make & Keep Friends: Coaching Children for Social Success)
Donna Shea and Nadine Briggs,

Reviewed by Dorothy Robison, Parent of three young adults, two of whom have Intellectual Disabilities.

*How to Make and Keep Friends: Helping Your Child Achieve Social Success* is a guide for parents or caregivers of children with challenges making and keeping friends. The book is full of suggestions and examples for children with special needs who find it hard to progress socially. All parents want to experience the joy of seeing their child playing with a pal in the neighborhood, or watching them go off to play at the home of a friend from school. Unfortunately, this is a difficult area of growth for many children.

*How to Make & Keep Friends* includes examples of children with social challenges. This is followed by clear ideas for talking children through these issues and reaching the goal of meaningful social interaction. The authors describe a child who is shy and how this presents a "barrier" to friendship. A simple explanation of why shyness is so difficult for a child is followed by "coaching suggestions." Shea and Briggs suggest it is important to reassure the child that they will not be forced to participate until they are ready. The authors list common feelings extremely shy children experience in stressful social situations: "lump in throat," "stomachache," "dizziness," "nauseous." This reminds the reader it is important to pause before asking a child to enter a social situation they find uncomfortable.

The book addresses topics such as, "Preparing for Playdates, Social Events & Life Changes," "Playdate Reciprocation (or lack thereof)," and, "When a Child is Excluded." Included is a "Real Friends Checklist," which can be used to figure out if a relationship is a true friendship. Strategies include how adults can talk to a child about improving his or her voice modulation, dealing with feeling left out, and expressing feelings so they can be an independent voice on the playground. No matter how many ideas parents have to help their child, more is always useful. How to Make & Keep Friends is loaded with information parents can turn to daily and can be hugely helpful no matter what the age of the child.

Editor’s Note: *How to Make and Keep Friends: Coaching Children for Social Success is being renamed How to Make and Keep Friends: Helping Your Child Achieve Social Success and will be available for purchase on Amazon.com in the coming weeks.*

**Lucky Dogs, Lost Hats, and Dating Don’ts**
Thomas Fish, Ph.D. & Jillian Ober, M.A., CRC,

Reviewed by Amanda McClafferty*

The book *Lucky Dogs, Lost Hats, and Dating Don’ts* by Thomas Fish Ph. D and Jillian Ober M.A. is a book with 12 short stories about people with and without disabilities. I really like this book as it is easy to read and comprehend. In my opinion it is a brilliant and spectacular piece of literature that provides motivation for people with physical ailments, learning disorders, social emotional disabilities, and a broad range of people on the Autism spectrum.

My favorite story in this book is "Adventures in Camping". The story is about four people on a camping trip. Two people on the trip have Down Syndrome. The reason I like this story so much is because it portrays people with Down Syndrome to be just like any other person. The four main characters are Hank, Holly, Jessica, and John. Hank and Holly are both twenty-one years old and have been dating since high school. Jessica is a twenty-two year old woman, and John is twenty-one. They both have Down Syndrome. Jessica and John met at a park while participating in a walk to raise money for Down Syndrome. They exchanged phone numbers two days after the walk, and Jessica soon asked John if he wanted to go feed the ducks at the park, what time they should go, and if he would be her boyfriend!

I also enjoyed another story entitled "Road Trip." Out of all the stories in the book, I could relate to this story the most. The story was about two brothers named Damon (21), and Marcus (22). They were going to New York City to visit friends. On the way to New York City, Marcus who has diabetes, had gotten a headache, which then turned into a seizure. (I have had seizures before). Damon got really scared and called 911. The 911 Operator reassured Damon that Marcus would be okay. The ambulance came quickly, and brought Marcus to the hospital. Luckily, he recovered quickly, and Damon promised that he would get Marcus back to New York City soon.

Overall, I could really relate to most of the stories in this book. It made me think about my own disabilities and how I could benefit from learning and understanding the fact that there are people in this world that have it worse that I do, and that I should be more accepting of others as well as myself.

*Amanda McClafferty is a 17 year old girl from Massachusetts. She enjoys reading, writing, music, movies, joke telling, and spending time with her family. Amanda has hydrocephalus, left sided hemiplegia, low vision, depression, seizure disorder, ADHD, and NVLD - but she thinks that the first sentence of this author description is the most important part.*
Federation for Children with Special Needs

Gala 2014
Celebrating Every Child

Friday, May 2nd, 2014
6:00 PM – 10:00 PM

40th Anniversary

Join us at our new location, the Westin Boston Waterfront Hotel
Purchase Tickets online at www.fcsn.org/gala14

Honorees:

Martha H. Ziegler
Founders Award

David M. Bartley
Former Speaker of the Massachusetts House

Patricia Blake Parent Advocacy Award
Eustacia Cutler
Author and mother of Temple Grandin

President’s Award
Daniel T.S. Heffernan
Past Board President
Partner, Kotin, Crabtree & Strong