Martha Ziegler, founder and former Executive Director (1974-1997) of the Federation for Children with Special Needs, has played a crucial role in creating the legislation and attitude changes that have considerably enhanced the opportunity for all children with disabilities to live a full life. She developed a model which helped establish parent organizations across the country. As the director of the US Dept of Education’s national parent program, she provided technical assistance to develop similar centers in all of the states, and was among the most respected parent leaders in the country.

In her efforts to achieve quality educational opportunities first for her daughter Mary Ann, Martha furthered a movement that would begin to change forever the life possibilities for children with disabilities in the United States and around the world. At the heart of all of Martha’s advocacy is a vision of respect, dignity, love, and human rights for her daughter and all persons with disabilities. In her book “My Daughter, My Teacher: Mary Ann, Autistic in English and Spanish”, Martha Ziegler shares the experiences that have molded her prolific mark on the disability community.

Martha Ziegler stated, “We (someday will) have fuller understanding of the revolutionary progress the [special education] law has brought, first for thousands and thousands of children and families in Massachusetts but ultimately for millions of children and families across our nation.”

Martha passed from this life just past midnight on September 13, 2014. The Federation was her creation. She inspired the development of many similar organizations across the country. Her legacy is profound and will last into eternity.

“In her efforts to achieve quality educational opportunities first for her daughter Mary Ann, Martha furthered a movement that would begin to change forever the life possibilities for children with disabilities in the United States and around the world. At the heart of all of Martha’s advocacy is a vision of respect, dignity, love, and human rights for her daughter and all persons with disabilities. In her book “My Daughter, My Teacher: Mary Ann, Autistic in English and Spanish”, Martha Ziegler shares the experiences that have molded her prolific mark on the disability community.”


“Martha’s advocacy work planted the seeds of a new generation of people with disabilities – those who had the benefits of education and civil rights. Martha leaves a lasting legacy of respect for all, access for all, and opportunity for all.”

-US Senator Tom Harkin, Iowa
Support the Federation’s Annual Appeal!

What do you get when you support the Federation for Children with Special Needs?

You get a world where individual differences are embraced, and where every child is fully included in school and in the community. At the Federation, we believe that every child deserves the chance to achieve success and live a full and independent life. The support, information and training that we provide to families and to professionals helps make that happen.

Donate online today at www.fcsn.org

or mail your check to:
Federation for Children with Special Needs| The Schrafft Center
529 Main Street, Suite 1M3 | Charlestown MA 02129

Your generous gift makes a world of difference in the lives of children with special needs, and we are most grateful for your support!

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Your generous gift makes a world of difference in the lives of children with special needs, and we are most grateful for your support!
New Projects Strengthen Our Mission

The Federation is proud to announce several important new grant awards that will help us maintain and grow our identity as a parent-run advocacy organization. Through these initiatives, the Federation will steadily increase its multicultural competence, and expand our collaborative partnerships with educational and healthcare professionals at every level; national, state and local, to fulfill its mission in 2015 and beyond.

**Federation becomes a United Way Partner:** We are pleased to announce that we are now a United Way partner agency! Support from the United Way will assist us in ensuring that families who are raising children with special needs have the information, support and training they need to help their children achieve successful outcomes in school and in their communities. Additionally, it will support our work in keeping families of children with special needs informed regarding key issues and topics in the field.

**Parent Training and Information Center for Massachusetts (MA PTIC) receives a new five year award from the Office of Special Education Programs at the US Department of Education.** The MA PTIC at the Federation believes in the potential of all children as echoed in IDEA, and under this award will build on its 40 years of experience supporting families of children with special needs. The MA PTIC will continue to meet the information and training needs of parents and professionals so they can continue as lifelong partners in the education of their children with special needs, and will additionally provide support and training to families and self-advocates in order supporting young adults in their transition to post-secondary education, employment, and independent living.

**The LINK Center: Connecting to Your Future** is one of only six national grants awarded under the Office of Special Education and Rehabilitative Services/US Department of Education. This new project will establish a Parent Training and Information Center on Transition to assist individuals with disabilities and their families to participate more effectively with professionals in meeting the vocational, independent living and rehabilitation needs of individuals with disabilities. The new LINK Center will provide technical assistance and training to help individuals achieve their employment and independent living goals and will work closely with the Federation’s Parent Training and Information Center (PTIC) to provide families with much-needed information about transition, vocational rehabilitation, independent living and other adult services.

**The Massachusetts Children and Youth with Special Health Care Needs Systems Integration Project.** As a collaborative partner with the Massachusetts Department of Public Health, we will join with state agencies, families, healthcare providers, community organizations and others to increase the number of families who receive integrated health care through a family-centered medical home approach. This partnership will be supported by Massachusetts Family Voices at the Federation, which is the MA chapter of a national network of families and friends speaking on behalf of children with special health care needs to improve access to health care services and supports for families of children with special health care needs.

### Joining Voices Conference 2014

November 6th marks the 12th Annual Mass Family Voices Joining Voices Conference. The conference will be held at the Edwards House Meeting & Retreat Center at the UCC Conference Center in Framingham. We are very excited about this year’s theme: “Partnering with Professionals.”

Whether you are a parent or parent/professional, the relationship you have with the professionals in your home and work life is very important. The goal of Joining Voices 2014 is to give you strategies to strengthen that relationship.

We are happy to welcome Richard Antonelli MD, MS as our keynote speaker. He will be presenting, “Measuring What Matters: Families as Partners in Improving Care Outcomes.” In this session, you will learn how Boston Children’s Hospital is working with families to transform care processes. Dr. Antonelli will highlight some aspects of care coordination and care improvement efforts and speak about the central role of families as partners in care redesign.

In addition to Dr. Antonelli, Joining Voices will include 2 breakout sessions where you can choose from 4 workshops. The workshops will cover: Mental Health, Transition from Pediatric to Adult Medical Care, Guardianship & Adult Family Care, Pediatric Palliative Care, and Medical Home.

We are looking forward to a great conference this year. Come and enjoy meeting and networking with other parents and parent/professionals, learn about some great topics, and enjoy a wonderful lunch! Please email massfv@fcsn.org, visit www.fcsn.org/mfv/, or call 1-800-331-0688 ext. 301 to register.

**Thursday, November 6, 2014**
9:00 AM-3:00 PM
UCC Conference Center - Framingham, MA
The Guild for Human Services is a day and residential school for students with intellectual disabilities and behavioral challenges.

Open 365 days a year, The Guild serves male and female students from age 6 until their 22nd birthday. The Guild specializes in helping students with:

- Intellectual Disabilities (ID),
- Autism Spectrum Disorders,
- Down syndrome and other genetic disorders,
- Students with dual diagnosis (ID and mental health or behavioral challenges).

Applied Behavior Analysis, educational services, residential services, clinical services, vocational services and routine community experiences ensure consistent, effective progress and generalization of newly learned skills to students’ daily lives.

The Guild for Human Services is able to continue assisting students after turning 22 within our new Adult Residential Program.

We are currently accepting referrals. The Guild processes referrals year round. Schedule your tour today.

THE GUILD
for Human Services

411 Waverley Oaks Road, Suite 104, Waltham, MA 02452
Website: www.TheGuildSchool.org
Phone: 781.893.6000 Fax: 781.893.1171
Email: admissions@theguildschool.org
PHD’s (Person, Heart, Determination) for Inclusion not WECHE’s (Wimpy, Enabling, Cool-Hearted, Exclusionists)

By Bill Henderson, Retired Principal, Dr. William W. Henderson K-12 Innovation Inclusion School

There are thousands of different programs, materials, and apps which can be effective in helping students with disabilities learn and succeed in inclusive classrooms. None of these will realize their greatest impact though, unless we demonstrate on a regular basis how we are PHD’s rather than WECHE’s.

P - Focusing on the Person first and his or her capabilities and potential is critical. Too often, at IEP meetings, in the teacher’s room or in workshops, in classrooms or on the playground, or during parent or community meetings, we hear comments by some harping on the deficits or limitations of students with disabilities. Do we speak out and counteract such one-sidedness pointing out strengths or strategies for improvements, or do we Wimp out and remain silent? Do we develop policies which promote ability diversity (prioritize inclusion in mission statements, cite 3 glows before a grow, offer ongoing disability awareness highlighting contributions of persons with disabilities) or do our inactions Enable some to keep lowered expectations and to abrogate responsibility for success?

H - Establishing a positive relationship with a warm Heart is essential. Too often we hear stories of Cool Heartedness toward students with disabilities. Some still resist seriously considering inclusion as the first option thus denying basic civil rights. Some “accept” the students with disabilities in their rooms but don’t interact enthusiastically with them. Some believe that just treating everyone the same is enough and the right thing to do, but they actually limit opportunities by not offering necessary accommodations or specialized services. Do we speak out and counteract such Cool Heartedness, or do we Wimp out and do nothing? Do we develop policies which foster positive relationships (draft job descriptions with explicit expectations for inclusion, model and monitor appropriate interactions, identify and utilize helpful supports), or does our passivity Enable some to treat students with disabilities in ways that make them feel unwelcomed, not good enough, or apart?

D - Demonstrating the Determination to help students with disabilities excel at the highest possible levels is transforming. Too often we witness the limitations caused by lowered expectations or overbearing help. Do we challenge students with intellectual or print disabilities to read, students with physical impairments to exercise, and students with speech and language disorders to interact as much as their nondisabled peers and as independently as possible (albeit sometimes in different ways), or do we Wimp out and flow with a lower status quo? Do we develop policies which actualize rather than give lip service to high levels of determination (set rigorous standards for learning and participation, assess student progress and staff performance, and collaborate and problem solve for continuous improvements), or do we Enable minimal achievements or hovering staff under the guise of misguided “niceness?”

Clearly, students with disabilities who are included need and deserve knowledgeable and skillful teachers and support staff who can identify and implement a range of effective strategies to promote their development. However, unless we can demonstrate our ongoing commitment to be PHD’s, then we will never maximize students’ learning and participation. Instead, even with advanced degrees, we, by default, become “WECHE’s” (Wimpy, Enabling, Cool-Hearted, Exclusionists).

Bill Henderson is the former principal of the Henderson Inclusion School in Boston, Massachusetts, and a sought after speaker at workshops and conferences.
En las aulas inclusivas, hay miles de programas, materiales y aplicaciones que pueden ser útiles para promover el aprendizaje y el éxito de los estudiantes con discapacidades. Pero ninguno dará resultado si no exhibimos continuamente las siguientes cualidades:

Centrarse primero en la persona, sus aptitudes y potencial. Esto es de importancia vital. Con demasiada frecuencia, en las reuniones de los planes educativos individualizados, las salas o talleres de maestros, las aulas o patios de recreo o las reuniones comunitarias o de padres, no faltan quienes insisten en las carencias o limitaciones de los estudiantes con discapacidades. ¿Qué hacemos, denunciamos y combatimos esa visión unilateral subrayando los aspectos positivos y las estrategias para mejorar, o nos acobardamos y callamos? ¿Establecemos políticas que fomenten el respeto a la diversidad de capacidades —priorizando la inclusión en las declaraciones de la misión, mencionando tres características positivas de un estudiante antes de citar algo en que necesita mejorar, fomentando la sensibilización, destacando continuamente las contribuciones de las personas con capacidades diferentes— o dejamos mediante nuestra inacción que se continúe con las expectativas bajas y se renuncie a nuestra responsabilidad con el éxito de los alumnos?

Establecer una relación positiva con un corazón generoso. Esto es fundamental. Demasiado a menudo escuchamos relatos de indiferencia hacia los estudiantes con discapacidades. Algunos aún se resisten a considerar seriamente a la inclusión como opción fundamental y así niegan derechos civiles básicos. “Aceptan” a los alumnos con discapacidades en sus aulas pero no se relacionan con ellos con entusiasmo. Creen que basta con tratar a todo el mundo de la misma manera, pero en realidad, al no ofrecer las adaptaciones o servicios especializados necesarios, limitan las oportunidades. ¿Qué hacemos, denunciamos y combatimos esa indiferencia o nos acobardamos y callamos? ¿Establecemos políticas que promuevan las relaciones positivas —redactando descripciones de puestos de trabajo con expectativas de inclusión expícitas, ejemplificando y supervisando las interacciones apropiadas, identificando y utilizando apoyos útiles— o permitimos con nuestra pasividad que los estudiantes con discapacidades se sientan rechazados, incompetentes o excluidos?

Determinación de ayudar a los estudiantes con discapacidades a destacarse lo más posible. Esto es transformador. Con demasiada frecuencia somos testigos delas limitaciones provocadas por las expectativas bajas o autoritarias. ¿Qué hacemos, desafiamos a los estudiantes con discapacidades intelectuales o de lectura a que, a los que tienen impedimentos físicos a que hagan ejercicio, a los que tienen trastornos del habla a que interactúen con sus compañeros con la mayor independencia posible aunque a veces de maneras diferentes, o nos acobardamos, callamos y conformamos con un status quo inferior? ¿Establecemos políticas efectivas que reflejen niveles de determinación altos —estableciendo normas de aprendizaje y participación rigurosas, evaluando el progreso de los estudiantes y el desempeño del personal, colaborando y resolviendo problema para lograr mejoras continuas— o nos quedamos en la palabrería y nos resignamos a niveles de logros míimos y a personal inútil disfrazado de “amable”?

Es evidente que los alumnos con discapacidades que son incluidos necesitan y merecen personal de apoyo y maestros ilustrados y habilidosos que puedan identificar y poner en práctica una variedad de estrategias eficaces para promover su desarrollo. Pero a menos que podamos personificar un compromiso continuo con estas tres cualidades, jamas podremos maximizar el aprendizaje y la participación de los estudiantes. En lugar de ser campeones de la inclusión, seremos profesionales mediocres: débiles, permisivos, indiferentes y excluyentes.

Bill Henderson es ex director de la Henderson Inclusion School en Boston, Massachusetts, y ponente en seminarios y conferencias.
On September 21, 2014, the Federation for Children with Special Needs hosted our second annual fundraising “Walk, Roll, Shobble*, Stroll”! Held on the grounds of the Massachusetts Hospital School in Canton, the event drew over 60 participants and raised $11,000 for the Federation!

Participants enjoyed tunes spun by DJ Kevin Sullivan, who got everyone on the floor dancing the Cha-Cha, the Electric Slide, and the Hokey Pokey; and playing Freeze Dance. The morning’s activities included face painting, arts and crafts projects, balloon animals and hats, and much more. Families were provided with snacks and drinks courtesy of the wonderful donors listed below.

Executive Director Rich Robison welcomed participants, thanked them for coming, and introduced the guest of honor, Ms. Wheelchair Massachusetts 2014, Rosa Angelica Colon. Ms. Colon urged kids and families not to be defined by disability, but by the strength and possibility they have inside. Last year’s guest of honor, Ms. Wheelchair Massachusetts 2013, Nicole Tarzia, was also in attendance.

At 1pm, Colon and Tarzia led participants on a trek around the nature trail, where they were encouraged to search for playful scavenger hunt items that had been hidden by volunteers from Boston University.

The weather was hot, with some showers at the beginning of the event. Luckily the rain held off for the walk and the party afterwards!

Following the walk, families and children returned to the outdoor pavilion, where they enjoyed ice cream and more activities. Awards were given to the individuals and teams who had raised the most money for the Federation.

Federation staff extended their gratitude to all the volunteers, especially the students from Boston University who generously gave their time to help at the walk.

The second annual Walk, Roll, Shobble*, Stroll was a great success that would not have been possible without all the hard work of participants, donors, volunteers, and Federation staff! We hope to see you at next year’s Third Annual event!

Many thanks to the Massachusetts Hospital School for the use of their facilities and to all our wonderful sponsors and donors who helped make the event a success:

• Whole Foods • Utz • Frito-Lay • Sunny Delight
• Crystal Springs • Eastern Bank • Millennium Nails
• Marathon Sports-Brookline • The Leslie Family
• Bob and Patricia Schram • Boston Parents’ Paper

*where a shuffle meets a hobble
News came recently that Martha Ziegler has passed. No matter that Martha lived a long and robust 84 years, the loss is, as our friend Julia Landau at the Mass. Advocates for Children put it, “stunning” – to think that our world will now be without her “vibrancy, passion, and vision.”

Martha was a major civil rights leader for children with disabilities. She arrived in Massachusetts in the early 1970’s, thinking, as she loved to say, that she would now be able to set aside the advocacy work she had done in Pennsylvania and devote her energies fully to family and friends, only to find herself immediately and completely immersed in organizing a coalition to help carry a new special education reform initiative – “Chapter 766” – into law.

As she saw it, the victory Martha and her coalition celebrated in the signing of Chapter 766 was not enough by any means. She well understood that without an ongoing reliable organization to educate and train parents and professionals over the long haul and to monitor and advance the promises of our special education reform act, it would be all too easy for the law to become dead letter. She turned her energies accordingly toward the creation of what became the Federation for Children with Special Needs – an agency that all who work in our field know as the gold standard of parent training and advocacy. Along with that, she dedicated countless hours to advancing the principles and many of the solutions built into Chapter 766 at the federal level, developing bonds with leaders in Congress that contributed greatly to the eventual enactment of the Education of All Handicapped Children Act (now the Individuals With Disabilities Education Act, or “IDEA”).

Some years ago, when my now-retired partner, Larry Kotin, and I stood as co-recipients of the Martha Ziegler Founder’s Award from the Federation, I turned to Martha during my remarks and said: “Without your enormous energy and indomitable spirit, your great humor, your organizing skill among warring factions, and your pragmatic political savvy in 1972, Chapter 766 might never have come into being, and without your formation and leadership of this great organization for so many years, there would quite certainly have been no Federation for Children with Special Needs.”

There is so much more to say to and about Martha as advocates in our field begin to mourn her loss. As for me, I feel the loss not only of a powerful and sophisticated colleague in advocacy, but of a true and loving friend for more than forty years. Rest in peace, old friend.

Robert Crabtree is a partner in the Special Education & Disability Rights practice group at Kotin, Crabtree & Strong, LLP in Boston, Massachusetts.
A Trail Blazer For Many:
Tributes to Martha Ziegler from across the country

“Her vision and willingness to blaze a trail to make things as they should be is an inspiration to all who believe in social justice.”
- US Senator Ed Markey, Massachusetts

“She was a trail blazer for many.”
- Mary Eddy, ProParents of South Carolina

“A fine lady and real force for everything championed by the Federation.”
- Steven Popper, Needham, MA

“She was a force to be reckoned with—so full of life and determination. Her will and her spirit moved the world for all of us.”
- Jerry Mogul, Executive Director, Mass Advocates for Children

“I attended a workshop that Martha was conducting for parents where I saw parents with tears of joy because their children were going to be allowed to go to school. We owe a lot to her.”
- James V. Major, Executive Director, Massachusetts Association of 766 Approved Private Schools (MAAPS)

“Her story, which is our story, is of a leader of a movement that continues to transform the lives and experiences of so many families and children with disabilities.”
- Debra Jennings, SPAN New Jersey

“Martha was a great visionary leader. She helped create centers that could focus on working with diverse parents.”
- Virginia Richardson, PTI Director, PACER

“She certainly led the way for families in Massachusetts”
- Jane Buckley, Massachusetts Rehabilitation Commission

“What a tremendous feeling of gratitude for all she did.”
- Dan Heffernan, Kotin, Crabtree & Strong

“Mary Anne Ziegler with mom, Martha

“Hard to imagine this world without Martha's vibrancy, passion, and vision.”
- Julia Landau, Senior Project Director, Mass Advocates for Children

“She was a leader with great vision, wonderful integrity and compassion for all.”
- Carla B. Jentz, Executive Director, The Massachusetts Administrators for Special Education (ASE)

“An amazing woman who paved the way.”
- Barbara Buswell, Founder and Executive Director, PEAK, CO.
Parent Consultant Training Institute (PCTI)

By Laura Yellick, Statewide Training Coordinator - Parent, Training and Information Center (FCSN)

Are you interested in learning more about special education law and process? Have you ever thought about how you can brush up on your special education advocacy skills? The Federation for Children with Special Needs will be offering several sessions of its popular Parent Consultant Training Institute program during this upcoming school year. This program is an 8 week course that covers a wide range of special education related topics including special education law and process, understanding the IEP form, writing measurable IEP goals, assessments and evaluations, 504 plans, school discipline, CBHI services, supporting students with complex healthcare needs, basic advocacy skills, dispute resolution options and more!

Workshops are presented by Federation staff members, distinguished attorneys and other professionals, representatives from the Massachusetts Department of Elementary and Secondary Education (DESE) and the Bureau of Special Education Appeals (BSEA). If you are interested in learning more about this exciting opportunity you can visit the Federation’s website at www.fcsn.org/pti/advocacy/become_a_parent_consultant.php or contact Laura Yellick at lyellick@fcsn.org. Session dates are as follows:

**Winter 2015 - Boston**

**Location:** Federation for Children with Special Needs
529 Main Street, Suite 1M3
Boston, MA 02129

**Time:** 9:30 - 3:30 each day

**Session Dates:** Tuesdays
(January 27th, February 3rd, 10th, 24th, March 3rd, 10th, 17th and 24th)

**Spring 2015 - Western MA**

**Location:** TBA

**Time:** TBA

**Session Dates:** Tuesdays
(April 7th, 14th, 28th, May 5th, 12th, 19th, 26th and June 2nd)

**Summer 2015**

**Location:** TBA

**Time:** 8:30 - 4:30 each day

**Session Dates:** Monday - Friday
(June 22nd, 23rd, 24th, 25th and 26th)
Parents of children with special needs face a variety of challenges in their efforts to meet the health, educational, social, and emotional needs of their child. Imagine the complexity of these efforts for families who are new to our country, adjusting to a whole new way of life, far from their former homes and without the nearby support of family and friends?

The face of the United States is changing, as immigrants and refugees from around the world arrive and start a new chapter in their lives. Between 2000 and 2011, the number of immigrants living in the US grew from 31.1 million to 40.04 million, an increase of 30% in just 11 years. Further, there is great diversity among newly arrived immigrants. This helps to explain the exciting changes we see in communities across the nation, including our own state and the opportunities we have to learn more about diverse cultures of the world as we support our new neighbors.

In 2012, Massachusetts had 948,061 immigrants, 34% of whom have been residents for less than 10 years1. Thus, our state, too, has a great number of newly arrived residents from a variety of countries around the world, with unique cultural customs and beliefs and languages.

Recognize the many cultural shifts for these families. Many of their countries of origin offer only limited (and often expensive) healthcare services, few opportunities for children with special needs to attend school, and limited venues for peer support to address the emotional challenges of caring for their families. Upon arriving in the United States, many parents face new challenges as they seek to address their children’s needs. For example, the majority of services are offered primarily in English, thus there may be a significant language barrier for our new neighbors.

The Federation, through each of its projects has initiated strategies to identify and address some of the challenges for these new families. Federation staff introduce families to the wide array of educational and health-related services and community-based programs for children with special needs and their families for which they may qualify. The Federation has established an Outreach Committee which includes representatives of each project and meets monthly. Members include the PTI Outreach Team: Oanh Bui, Vietnamese community; Norma Casaya and Marilyn Gutierrez, Latino community; Susan Ou, Chinese community; and Rhea Tavares Smith, Portuguese community as well as additional members including Cathy Hickey of Mass. Family Voices; Paige Parisi, RTSC; Roxanne Hoke-Chandler, Family and Community Engagement Team (FACET); and Mary Castro Summers, Miriam Biurci Scrivener, and Sara Asmerom from Family TIES of Massachusetts. The primary focus of the work of the Outreach Committee is to identify strategies to provide families facing cultural and linguistic barriers with adequate information and support, to enhance the lives of their children and families. Some activities include (1) building cultural awareness in our own staff, as the first step in understanding similarities and differences between cultural groups and to serve as cultural brokers; (2) identifying community-based organizations that serve various immigrant communities, to broaden knowledge and understanding of the needs of newly arrived immigrants, to raise awareness among immigrant families of resources and services for their families; and (3) cultivating awareness among all partners of the varied customs and needs of families in an effort to assure access to services and maximize outcomes for children and families.

Federation outreach staff team members
Norma Casaya, Oanh Bui, and Marilyn Gutierrez

Life Planning for Children & Adults with Special Needs
By Joseph Mastrangelo, brother of an adult sister with special needs, and parent of a child with special needs

As actors have roles in a play, parents of children and adults with special needs have their roles as well in “Life Planning” for their child. It’s a lifetime of various roles that have a direct effect on the daily and future quality of life of their children. As both a parent and a sibling of adults with special needs, I am quite familiar with the many roles I have played and continue to play. One of my most important roles is that of a “planner”. By putting together my daughter’s and sister’s “Life Plans”, I addressed their current and future personal, legal and financial needs.

Create a Personal Plan Diagnosis: Finding out and understanding your child’s diagnosis and needs are paramount in planning for your child’s current and future needs. My wife and I developed our own understanding of our daughter’s diagnosis which we use as a reference point for making decisions on treatments, therapies or medications. We also keep an open mind in assessing the options because we know that it is a life long process building on small incremental goals being reached over time.

Education Plan: During her school years, we found ways to work with the school system to meet many of her needs. We had our daughter evaluated and developed her Individual Education Plan (IEP). We established an amicable and supportive relationship with the educators through close communication. Any initiative or strategy whether at home or in school that had a positive effect or influence was communicated back and forth and supported by us and the school.

Social Plan: Concurrent with the IEP, we developed a Social Plan which was based on structured extra curricular activities and socialization. Activities for my daughter included a “Dog Biscuit” business and a “Jewelry” business as well as participation in Art programs. In order to address my daughter’s socialization needs, given her autism issues and her limited social skills, we installed a swimming pool which allowed us to provide a supportive environment by having her social network visit her. My sister’s, extra-curricular activities were therapeutic horseback riding and weekly dances organized through her day program. She attended an overnight camp during the summer and then moved into a group living situation which enabled her to blossom into an independent woman.

Shifting the Emotional Gears: As parents and caregivers, we came to a point when we mentally needed to move to a different level of acceptance with respect to our child and my sister. We saw our own denial as a kind of wishful thinking based on an expectation that they will out-grow their disabilities or get better. We found that this mind set delayed our ability to make the difficult planning decisions. When we accepted that our family members will need long term support and care, we could move into an acceptance mode which allowed us to act, plan and implement strategies ensuring our their future quality of life.

Living in Parallel Time: As family members of individuals with special needs, we live simultaneously in the present and future time frames. Given the constant concerns of the present, it may seem unfair that we are also concerned about the unknowns of the future with regard to the residence, care and quality of life of our child or sister. This is where making legal and financial plans, plays such an important role in addressing and alleviating these concerns and unknowns.

Your Child’s/Family Member’s Time Line: It is easy for parents and caregivers to get focused at particular points along your child’s life time line and lose sight of the overall picture. Whether its formulating and updating the “Individual Education Plans” (ages 3-22), planning for transition to adult living, employment and/or post- secondary education, or applying for and securing “Public Benefits” at age 22-, parents still must be aware of the “Long Term” view. Many services, especially those outside the school system, are often outside our sphere of control and depend largely on the financial resources and political commitment of the state and federal governments for the care of your child.

When properly constructed and even modestly funded, creating a “Life Plan” can supplement these resources and enhance your family member’s quality of life.

When should parents construct and fund their child’s long term Life Plan? Ask yourself what would happen to your child if you and your spouse were suddenly out of the picture. Where would your child live? Who would take care of them? How would they be financially supported? If there are no legal and financial plans in place, others or the state will be required to make all those decisions.

The first step is to make your own Personal Plan, then to start working with an Attorney and/or Financial Planner who are experienced working with families of children with special needs. They can assist you in developing the Legal and Financial Plans necessary to complete your child’s Life Plan. You will enjoy the peace of mind in knowing that the quality of life you expect for your child is securely in place for the rest of their life.

Joseph Mastrangelo is a partner at Secure Horizons Financial, LLC
www.securehorizonsfinancial.com
Book Review: “Journal of an ADHD Kid”
Reviewed by Rebecca Rizoli, Program Specialist, FCSN

Having ADHD can be a struggle. In addition to the frustration of dealing with the symptoms of the disorder, people with ADHD often feel alone and like a misfit. Being “different” can be especially frustrating for children and adolescents, who are trying so desperately to fit in and find their place.

Fortunately for these young people, there’s “Journal of an ADHD Kid,” by Tobias Stumpf, a middle school student who was diagnosed with ADHD in the second grade. This book consists of a series of diary entries penned by Stumpf, who chronicles his thoughts, feelings, and challenges about having ADHD. Following each entry, Stumpf poses a set of questions for the reader, such as “When and why did people start to wonder if you had ADHD? Did you ever feel like something was ‘different’ about you?”

Any reader with ADHD will feel a connection with Stumpf and his story. I have ADHD, and I saw my own struggles and challenges in the pages of his book. On page 5, he writes, “ADHD makes me feel not so normal. You see, sometimes I get off track. I was just writing in this journal and then a big noise happened and I forgot what I was doing.” When I read this, I smiled and nodded, as I could completely relate to Stumpf. Like him, when I am writing or engaging in any activity that requires total concentration and I hear an unexpected noise, I often get distracted and lose my train of thought to the point that I have to start all over again.

Stumpf also demonstrates the creativity and humor that is present in so many people with ADHD. He likens ADHD to what he calls a “magnet mind,” because so many thoughts cling to his brain, just as paper clips will cling to a magnet. He also refers to the “volcano in his locker” that has an “eruption” when he’s trying to find a particular book or folder.

This book is a must read for all young people with ADHD who need to be reassured that they are not alone!
Parents of children with disabilities can now obtain advice from experts in the field by watching an informative show entitled, “You’re Not Alone, Surviving Your Child’s Disability.” This local cable program was created to inform and support parents overwhelmed with the task of raising a child with special needs. The show strives to share helpful knowledge and give parents the concepts and ideas that can answer unresolved questions.

“You’re Not Alone, Surviving Your Child’s Disability,” introduces pertinent issues with its guests in a half hour format. Topics covered have included guardianship, special needs financial planning, respite care, and the IEP team meeting. Previous guests include Barbara Jackins, an Attorney with the Special Needs Law Group, Cynthia Haddad, Director of Shepherd Financial Partners, Dafna Krouk-Gordon, President and Founder of TILL, and Barbara Donati, Family Ties of Massachusetts. All guests have embraced the show as an excellent resource for anyone involved with the care of children with disabilities.

The show is produced and hosted by Susan Cauley, mother of two daughters with autism. Cauley has dealt with professionals involved with their care for over 20 years. Utilizing the knowledge she has gained, Susan recently became a Special Education Surrogate Parent representing homeless or foster children in the IEP process. In addition, she participates in a family support and advocacy group at the Edinberg Center for parents of children with mental/developmental disabilities. Susan has a Bachelor of Arts degree in English/Communications and has worked in advertising for 25 years.

A production of the Woburn Public Media Center, the show is currently aired on local cable TV channels in the towns of Woburn, Bedford and Burlington. Program content is announced on Facebook.com/ynadis prior to the show’s airing. All taped shows appear on YouTube at YouTube.com/You’re Not Alone Susan Cauley.

For more information or questions regarding future shows or projects, contact Susan by e-mail at scauleyyna@gmail.com.

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The Autism Omnibus Bill: What It Means for Your Child and Their Healthcare

On August 6, 2014 Governor Deval Patrick signed the Autism Omnibus Bill. The bill attempts to address the unmet needs of people with Autism in Massachusetts.

Key parts of the bill include:

- A requirement that MassHealth cover medically necessary treatments for children with ASD who are under 21 years old. They must cover ABA therapies as well as dedicated and non-dedicated AAC devices.

- An extension of Department of Developmental Services (DDS) eligibility to many persons with Autism, Prader Willi Syndrome and Smith-Magenis syndrome. DDS will no longer solely rely on IQ test results. They will be required to use the federal definition of a “developmental disability.”

- The creation of an Autism Endorsement for special education teachers to help them gain in-depth knowledge about the complexities of educating students with ASD

- The creation of tax-free saving accounts (called “Achieving a Better Life Experience” or ABLE) to help families cover disability-related expenses for individuals with ASD and other physical and developmental disabilities

- A requirement that the Departments of Mental Health and Developmental Services develop and implement a plan to provide services for individuals with both a mental illness and a developmental disability

- The establishment of the Autism Commission as a permanent entity.

What does this mean for our Mass Family Voices Community? The biggest victory is the requirement that MassHealth cover medically necessary ABA services. Before this bill, MassHealth did not cover ABA at all. It is important to note that this piece of the bill may not actually go into effect with the rest of the bill on November 3, 2014. It depends on the availability of federal funds. We are waiting to see if federal funds are available to the state for this provision.

The F2F Health Information Center will inform the community as more information comes out related to MassHealth ABA coverage.

Campeões, não Adversários da Inclusão (continuação da página anterior)

formador. Muito frequentemente nós testemunhamos as limitações causadas pelas baixas expectativas ou cruciante ajuda. Nós desafiamos os estudantes com deficiência para a leitura cognitiva ou impressa, e estudantes com deficiência de fala, estudantes com incapacidade físcia para a prática de exercícios, e estudantes com distúrbios de fala e linguagem a interagirem tanto quanto os seus companheiros não deficientes e de forma tão independente quanto possível (embora algumas vezes de maneiras diferentes), ou nós nos Acovardamos e seguimos conformando-nos com um status quo inferior? Nós desenvolvemos políticas que atualizem em vez de falarmos demasiado sobre altos níveis de determinação (estabelecer padrões rigorosos para o aprendizado e a participação, avaliar o progresso do estudante e o desempenho do pessoal da escola e colaborar e resolver o problema para melhorias contínuas), ou nós Capaci-

Ittamos as conquistas mínimas ou deixamos o pessoal pairar sob o disfarce de uma equivocada “amabilidade”?

Evidentemente, os estudantes com deficiência que são incluídos precisam e merecem professores experientes e habilidosos e pessoal de apoio que possam identificar e implementar uma série de estratégias eficazes para promover o seu desenvolvimento. No entanto, a menos que possamos demonstrar com o nosso compromisso contínuo com estas três qualidades, jamais iremos maximizar o aprendizado e a participação dos estudantes. Em vez de profissionais competentes, nós tornaremos mediócres: débeis, permissivos, indiferentes e exclusivistas.

Bill Henderson é ex-diretor da Henderson Inclusion School em Boston, Massachusetts, e um orador em oficinas e conferências.
Visions of Community
Visiones de la Comunidad
Visões da Comunidade
Viễn Ảnh Cộng Đồng
年度社區展望

A Conference for Families of Children with Special Needs and the Professionals Who Serve Them

March 7, 2015 | 7:30 am-5:00 pm
Seaport World Trade Center, Boston, MA