On July 17, 2012, 150 advocates of special education gathered at the Massachusetts State House to celebrate the signing of Massachusetts Chapter 766 on July 17, 1972. Chapter 766 was the first comprehensive special education law passed in the United States and became a model for the development of the Federal Law, the Individuals with Disabilities Education Act (94-142) which continues to this day.

Co-sponsored by the Federation for Children with Special Needs and Mass Advocates for Children, the gathering included former Speaker of the House David Bartley, who was a critical leader in this effort. He reminded us that the time was right to remove the barriers of the School House doors and ensure that every student would receive a free public education which was appropriate for their needs. Longtime advocate and member of the Coalition for Special Education, Dr. Barbara Cutler quickly reviewed the 100 year history of abuse and neglect of children with disabilities in our country. Not only were students not allowed to attend public school, the only services available from the state government were provided in state institutions. Also in the 1970’s, the practice of placing children in large institutions came to a halt. The new law provided a “zero reject” policy – every child should be able to go to school.

The new law provided a “zero reject” policy

Mr. Stephen Rosenfeld, member of the Coalition for Special Education who represented the “Task Force for Children Out of School” which later became known as Mass Advocates for Children, recalled the seminal study of children who were prevented from attending school, particularly in Boston. In that era students with behavioral issues, those whose first

Advocates Celebrate 40 Years of Special Education

By Richard J. Robison

From left to right: FCSN staff member Becky Rizoli, Connie Rizoli, Federation Founder Martha Ziegler, Former House Speaker David Bartley, Betsy Anderson, and FCSN staff member Rhea Smith

Advocates Celebrate 40 Years of Special Education continues on page 15
Appeals Court Strikes Down DDS’s Bright Line Ceiling of an IQ of 70 for Eligibility for Services

By Daniel T.S. Heffernan, Esquire

When the entitlement for services from local school districts begins to wind down as students receive their high school diplomas or approach their twenty-second birthdays, many families of the 165,000 Massachusetts students on IEPs look to the Massachusetts Department of Developmental Services (“DDS”), formerly known as the Department of Mental Retardation (“DMR”), to provide services to their adult children with intellectual disabilities. For approximately 32,000 eligible adults, DDS provides specialized services and supports that include day programs, employment supports, residential services, respite and transportation.

One criterion for DDS eligibility is that an individual have mental retardation. Prior to 2006, mental retardation was defined in DDS/DMR regulations as “significantly sub-average intellectual functioning.” Decisions applying this criterion typically relied on such authorities as the American Association for Intellectual and Developmental Disabilities and the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) as defining mental retardation to be present in individuals with significant functional impairments and an IQ score of 70 to 75.

In 2006, DDS/DMR issued a regulation defining “significantly sub-average intellectual functioning” as an IQ of 70 or below. That bright line has long been criticized as having no basis in science, especially in light of the many random conditions that may affect a person’s performance on any given test day. The regulation has been viewed by many as having been arbitrarily imposed simply to reduce DDS/DMR rolls. While it is difficult to quantify, it is believed that the imposition of this ceiling barred a significant number of individuals from becoming eligible for DDS services. It certainly worked a tremendous and capricious hardship on countless individuals and families who desperately needed services from the only agency that could provide them. For want of a single IQ point, individuals with intellectual impairments who heretofore had been receiving extensive supports from school districts, found the only door to even reduced services shut in their face.

On July 23, 2012, the Massachusetts Court of Appeals, in Tartarini v. Department of Mental Retardation, 2012 WL 20447771 (Mass.App.Ct.) struck down this bright line bar. Tartarini had received an IQ score of 71 when she was 18 years old, 69 when she was 40 years old, and 71 when she was 42. The operative IQ score was determined to be the one when she was 18, and as such, barred her eligibility for DDS/DMR services. This determination was upheld by a hearing officer and the Massachusetts Superior Court. The Appeals Court, however, reversed the decision and invalidated the DDS bright line ceiling of an IQ of 70. The Appeals Court held that the DDS regulation of a 70 or below IQ score requirement was inconsistent with the legislation that authorized it, stating that the Massachusetts Legislature “did not give the department [DDS/DMR] unfettered discretion to define mental retardation. The statute requires that the department’s regulations be based on ‘clinical authorities.’”

This decision is welcome news to families in need of adult services from DDS. There is hope that individuals denied eligibility based on the bright line of 70 will be able to reopen their applications or reapply for DDS services. In addition, myriad individuals with intellectual impairments but IQ scores above 70 may now be eligible to receive these crucial services as adults.

Daniel T.S. Heffernan is a member of the Federation’s Board of Directors and a partner at Kotin, Crabtree & Strong where he practices in the areas of special education, personal injury, and eligibility for adult services. Contact him at dheffernan@kcslegal.com.
From the Executive Director

Measured Treasure

Understanding the needs of families and the well-being of our children is critical to our children making effective progress in school and in their life dreams. This is especially true for children with special needs or special health needs as they often present some of the most challenging circumstances.

The Annie E. Casey Foundation’s 2012 KIDS COUNT Data Book shows both promising progress and discouraging setbacks for the nation’s children: While their academic achievement and health improved in most states, their economic well-being continued to decline. This year’s Data Book uses an updated index of 16 indicators of child well-being, organized into four categories. The new methodology reflects the tremendous advances in child development research since the first KIDS COUNT Data Book in 1990.

The 2012 Kids Count Data Book indicates that Overall Child Well-Being in Massachusetts ranked #2 in the nation. For example, the percent of children without health insurance ranges from 2 percent in Massachusetts and Vermont to 17 percent in Nevada.

The new Book looks at four domains as indicators of well-being: Economic well-being (Mass Rank #11): Percent of children in households that spend more than 30% of their income on housing. Percent of children in poverty (income below $22,113 for a family of two adults and two children in 2010). Percent of teens ages 16 to 19 not attending school and not working. Percent of children living in families where no parent has full-time year-round employment.

Health (Mass Rank #2): Percent of children without health insurance. Percent of teens ages 12 to 17 who abused alcohol or drugs in the past year. Percent low-birthweight babies. Child and Teen death rate (deaths per 100,000 children ages 1 to 19).

Family and Community (Mass Rank #10): Percent of children living in high-poverty areas (census tracts with poverty rates ≥ 30%). Percent of children in families where the household head lacks a high school diploma. Percent of children living in single-parent families. Teen birth rate (births per 1,000 females ages 15 to 19).

While children with special needs are not explicitly broken out in these indicators, they are included. Our task is to highlight gaps and exceptions that occur for smaller groups of children at risk, whether it is due to cultural, language or disability status. The KIDS COUNT index can be found at datacenter.kidscount.org.

Someone once told me that “we treasure what we measure”. Our children are our treasure and our future.

Rich Robison

Update on Health Care Reform: Is health insurance a right, a responsibility or a privilege?

by Patti Hackett-Hunter, M.Ed., Project Director, Mass Family Voices

The debate about these issues has gone on for 75 years. This landmark legislation, known by many names, passed in March 2010. The constitutionality of ACA was argued in the US Supreme Court this spring rendering a favorable 5 to 4 decision to uphold the law and the majority of the provisions (June 28, 2012). While many key aspects of Health Care reform are already in place, other components of the law are being phased in more slowly. See www.healthcare.gov/law/timeline/.

PROVISIONS EFFECTIVE THIS YEAR

• MAYBE A CHECK IS COMING YOUR WAY? By August 1, 2012, insurance companies that didn’t spend at least 85 percent of 2011 premium dollars for large group plans (over 50 employees) on medical care must refund the difference, through refund checks or discounted future premiums (80 percent for individual or small group plans).

• PHYSICIANS ARE BEING PAID BETTER. Primary care physicians treating Medicaid patients must be paid no less than 100 percent of Medicare payment rates.

• PREVENTIVE CARE: On August 1, 2012, a provision requires new insurance plans (plans that begin on or after August 1st) to cover a wide range of preventive services for women without a co-pay. Services such as birth control, well-woman visits, HPV testing, breastfeeding supplies, and domestic violence counseling (among others) will be free through a majority of new plans. To be sure that these preventive services are completely covered under your plan contact your insurance company and ask. See details: http://www.hrsa.gov/womensguidelines/

You can’t educate a child who isn’t healthy, and you can’t keep a child healthy who isn’t educated.”

– M. Jocelyn Elders, MD, former Surgeon General, USA

continues on page 14
Tribunal de Recursos Derruba Teto do Claro Padrão de Competência (Bright Line) do DDS de um QI de 70 para Eligibilidade de Serviços

Por Daniel T.S. Hefferman, Esquire

Quando o direito aos serviços dos distritos locais começa a diminuir por que os estudantes recebem seus diplomas de Segundo Grau ou aproximam-se de seu vigésimo–segundo aniversário, muitas famílias dentre os 165.000 estudantes de Massachusetts, nos Programas de Educação Individual - IEPs, contam com o Departamento de Serviços de Desenvolvimento de Massachusetts (“DDS”), conhecido anteriormente como Departamento de Deficiência Mental (“DMR”), para prestar serviços aos seus filhos adultos com deficiência intelectual. Para aproximadamente 32.000 adultos elegíveis, o DDS presta serviços especializados e apoio que inclui programas diários, ajuda de emprego, serviços residenciais, descanso e transporte.

Um critério para elegibilidade do DDS é o de que um indivíduo tenha deficiência mental. Antes de 2006, a deficiência mental era definida através dos regulamentos do DDS/DMR como sendo “funcionamento cognitivo intelectual significativamente abaixo-da-média”. As decisões para a aplicação deste critério baseavam-se em autoridades tais como a Associação Americana para Deficiência Intelectual e de Desenvolvimento e a Associação Americana de Psiquiatria de Diagnóstico e Manual Estatístico de Distúrbios Mentais da (DSM-IV-TR), que definem a deficiência mental estar presente em indivíduos com incapacidade funcional e uma média de QI de 70 a 75.

Em 2006, o DDS/DMR emitiu um regulamento definindo “funcionamento cognitivo intelectual significativamente abaixo-da-média” como um QI de 70 ou abaixo. Aquele claro padrão de competência (bright line) há muito vem sendo criticado como não tendo nenhuma base científica, especialmente à luz das muitas condições aleatórias que poderão afetar o desempenho de uma pessoa em qualquer dia de determinado teste. A regulamentação foi vista por muitos como tendo sido imposta arbitrariamente, simplesmente para reduzir os papéis do DDS/DMR. Embora seja difícil quantificar, acredita-se que a imposição deste teto impediu um número significante de indivíduos de se tornarem elegíveis para os serviços do DDS. Certamente trouxe uma dificuldade tremenda e negativa para indivíduos e famílias que necessitavam desesperadamente dos serviços da única agência que poderia fornecê-los. Por desejar-se um único ponto de QI, indivíduos com deficiência intelectual que até então estavam recebendo apoio extensivo dos distritos escolares, encontraram a única porta para igualar até mesmo os serviços reduzidos, fechada em seus rostos.

Em 23 de julho de 2012, o Tribunal de Recursos de Massachusetts, no caso Tartarini vs. Departamento de Deficiência Mental, 2012 WL 2047771 (Mass.App.Ct.) derrubou este claro padrão de qualificação de competência (bright line bar). Tartarini tinha recebido uma pontuação de QI de 71 quando ela tinha 18 anos de idade, de 69 quando tinha 40 anos de idade, e de 71 quando tinha 42. A pontuação operacional de QI estava determinada a ser aquela de quando ela tinha 18 anos, e como tal, impediu a sua elegibilidade para os serviços do DDS/DMR. Esta determinação foi apoiada por um Auditor do Tribunal e pelo Tribunal Superior de Massachusetts. Entretanto, o Tribunal de Recursos revertera a decisão e invalidou o teto do claro padrão de competência (bright line) do DDS de um QI de 70. O Tribunal de Recursos considerou que o regulamento do DDS de um requisito de pontuação de QI de 70 ou abaixo, era incompatível com a legislação que o autorizava, afirmando que a Legislatura de Massachusetts “não deu ao departamento [DDS/DMR] livre poder de decisão para definir deficiência mental. O estatuto exige que as regulamentações do departamento estejam baseadas em ‘autoridades clínicas’”.

Esta decisão vem a ser uma boa notícia para as famílias que necessitam de serviços do DDS para adultos. Há esperança de que os indivíduos aos quais lhes foi negado a elegibilidade tendo como base o claro padrão de competência (bright line) de 70, serão capazes de reabrir suas inscrições para os serviços do DDS. Além disso, inúmeros indivíduos com deficiência intelectual mas com pontuação de QI acima de 70, poderão agora ser elegíveis para receber, como adultos, esses serviços de extrema importância.

Daniel T.S. Hefferman é membro da Diretoria da Federação e um sócio de Kotin, Crabtree & Strong, onde pratica nas áreas de educação especial, acidentes pessoais, e serviços de elegibilidade para adultos. Entre em contato no dhefferman@kcslegal.com.

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The children in our community of special needs rely on their parents, whoever serves in that role, to figure out and address their needs. For parents, that is not always so easy, as we are often thrust into a world of complex medical, emotional, social, and educational challenges that are new to us.

At the same time that parents are managing the everyday life of their child and family, they are also expected to learn all about their child’s special needs, identify ways to support them, and seek out any and all resource programs that will help their child to reach their potential. What happens when this is uncomfortable for a parent?

Parents need to be assured of two important facts: your child will enjoy success because of your efforts, and there are resources available to support your child’s needs. You must also be certain that when it comes to your child, you are the expert.

Whether your child’s medical diagnosis or specific learning disability is extremely rare or incredibly common, there is no expert in the medical or educational community who has more relevant experience than you, when it comes to your child’s needs. Develop a few strategies to build your confidence:

1) Investigate your child’s special needs, with careful observation and notes, talking with other parents, and reading everything you can find – to help you understand the basics of the diagnosis.

2) Research and uncover areas where your child would benefit from extra support, focusing on those areas where a little change may make a big difference.

3) Bring to the attention of the medical and educational teams who support your child any and all observations and concerns you have. Your active participation in dialogues assures that your keen observations are included in discussions to identify and support your child.

Jumping into our world of special needs brings a great deal of satisfaction, most parents report, once they understand their children’s needs, potential supports and solutions to improve life circumstances, and realize that their advocacy skills have been sharpened, thanks to their child’s special needs. However, don’t stop when you achieve success on the personal level. Instead, bring your experience to other families (through support communities and school groups), to public agencies that develop programs for families just like yours (such as the Mass. Department of Public Health, through the Family TIES of Massachusetts SHARE YOUR VOICE! Program), and beyond. Our elected officials benefit from hearing your story. Please find your voice-and share it.

STAFFING UPDATE: Please join us in welcoming Debra Candeloro, our new Northeast Regional Coordinator. Families and professionals in the Northeast Region can reach Deb at 978-851-7261 x4018 or dcandeloro@fcsn.org. For those of you in other parts of the state, feel free to reach us through our toll-free line, 800-905-TIES/8437, or visit www.massfamilyties.org.
It’s Time to Get Ready for School! Can You Help Us By Donating $10 Today?

Like many of the families we serve, the Federation looks forward to summer as a time to refresh and rejuvenate. For us, that means working hard to make sure that we are ready to meet the needs of the many families who will contact us for information, training and support once the school year begins. Here’s some of what we’ve accomplished over the summer!

Our A.P.P.L.E. Project staff have utilized program evaluations from last year to improve programming for the coming year. They are ready to continue their work fostering the strong and effective parent-professional collaboration needed to improve results for children under IDEA.

Our Recruitment, Training and Support Center for Special Education Surrogate Parents (SESP’s) has been busy planning a fall conference on Supporting Traumatized Students. Staff are ready to provide the training that volunteer SESP’s need, training that will ensure that children in state custody receive the educational supports necessary to be successful.

Our Parent Training and Information Center provided professional development at the Boston Public Schools High School SPED Transition Summit, and developed additional Planning A Life Transition Conferences for the 2012-2013 school year. We are ready to make sure that both teachers and parents are prepared to help students with special needs achieve better post-school outcomes in the areas of employment, post-secondary education, and independent living.

Family TIES of Massachusetts has revised its Let’s Get Organized workshop, and will welcome 7 new volunteer Support Parents for the Parent-to-Parent Program, including 1 parent who speaks Japanese and 2 Spanish-speaking parents. Family TIES is ready to provide family to family support by sharing strategies and doing outreach to all families, including those facing cultural or linguistic barriers.

Your donation supports this work and so much more. The Federation provides programming that informs, educates and empowers families whose children have special needs, and we serve over 40,000 families each year. Your donation of $10 or more will help us help families during the coming school year.

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Preparing for transition to adulthood with baby steps (that become huge milestones)! It starts with YOU.

By Cristin Lind, Family Leader-Authentic Family Partnerships, Mass Family Voices

Recently my colleagues at the Federation for Children with Special Needs have been talking about the importance of preparing kids for medical transition to adulthood — how parents and caregivers need to deliberately teach kids the skills and build the confidence they will need to be engaged in their own health care as adults.

When the topic came up at first, I was resistant. With so many other skills to teach and care to manage, the thought of adding another task to my long to-do list was overwhelming.

Luckily, my colleague offered one simple suggestion that I felt willing to take on: at our next doctor’s appointment, I would give my kids their health insurance cards, let them walk up to the check-in counter and say that they were there for an appointment. I felt it was something that my nine-year-old son, who has complex medical and developmental needs, and my seven-year-old daughter could handle.

Since our doctor visits are fairly frequent, I was able to try it out soon. My son, who has been practicing social pragmatics like this at school, loved this real world experience. I was also surprised by an unintended consequence: not only did it teach my kids a new skill, it reminded the staff, my kids and me that my child is the patient.

OK, I thought. I get it. This doesn’t have to be a big deal. As with most things we want our kids to know, we need to give them lots and lots of tiny opportunities to practice, not one big lecture a couple of days before they reach adulthood. I realized I could do this.

A couple of weeks later, a patient satisfaction survey came addressed to my daughter. Rather than fill it out myself or toss it, I gave it to her. To my surprise she had a lot to say, both good and bad. “I love Lorraine*,” she wrote about the medical assistant. She wrote earnestly: “The waiting room is really boring.” I was taken aback by the strength of her experience and her ability to articulate it. I chuckled thinking about what the person opening the envelope would think when they read the results.

Last week, she had her eight-year well visit. With minimal effort, I handed her not only her insurance card but also the card I use to pay her co-pay. I told her that she’d be fine checking herself in. As we went through the process, a woman sitting nearby with four boys, all clearly older than my daughter, remarked at how independent she was. They had already checked in, but next time, she said, she’d get them to do it themselves. Then a young man came in and checked himself in, and I reflected on how my daughter would have his ease with just a little more practice.

Unfortunatley, there wasn’t any way to pass along the lesson I learned to her mom, but I can pay it forward to you. Preparing our kids to become adult patients doesn’t have to be complicated. Just start giving them lots of tiny chances to practice, and they’ll surprise you. Before you know it, adulthood will be here, and they’ll be ready. Even if we’re not!

*not her real name

Cristin Lind is a Family Leader and CHIPRA Project Associate with Mass Family Voices, a project of the Federation for Children with Special Needs, and a Patient Lead at the Cambridge Health Alliance, helping primary care practices include patients in their medical home transformation teams. She blogs at www.durgastoolbox.com.

Is your organization interested in an onsite workshop or want a customized webinar about preparing for health care transition? Let us know: Email Mass Family Voices at the Federation for Children with Special Needs at massfv@fcsn.org

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On May 4, 2012, over 340 people gathered at the Seaport Hotel in Boston for the Federation for Children with Special Needs’ annual fundraising event “Gala 2012, Celebrating Every Child”.

Upon arriving at the event, attendees were treated to the smooth jazz sounds of the Blake Newman Trio as they had a chance to greet new and old friends and bid on a fabulous selection of silent auction items ranging from original artwork, to Red Sox-Yankees tickets, to a week’s stay on the Cape!

The festivities continued in the ballroom, where the evening’s program was emceed by Bianca de la Garza, Emmy-award winning newscaster and anchor of NewsCenter 5’s EyeOpener, who graciously thanked everyone for coming and introduced comedian Tony V, who entertained the crowd throughout the evening, and kept all of the attendees apprised of the status of the bidding on the various silent auction items.

Folk singer Randall Kromm then took the stage to perform two original songs. The first was an appropriately seasonal song about spring, called “We Can Do No Wrong.” It was followed by “I Wouldn’t Have Thought It Possible,” a song Kromm wrote earlier this year about being the father of a child with developmental disabilities. As he played the song, a slideshow of pictures of his daughter appeared on the screen behind the stage. The song carried a powerful message of how being a parent made him a stronger person, which resonated with all of the parents in attendance.

Following Kromm’s performance, the Federation’s Executive Director Rich Robison took to the stage. Displaying a photo taken at the signing of Massachusetts Chapter 766 of the Acts of 1972 into law, Robison noted that this year marks the 40th anniversary of Chapter 766. This law, which guaranteed all children with or without disabilities a free appropriate public education in the least restrictive environment, later served as the model for the Federal law known as IDEA (Individuals with Disabilities Education Act). Robison thanked all those who made this legislation a reality, and explained that two years after the passage of Chapter 766, Federation co-founders Martha Ziegler and Betsy Anderson, along with several other parents formed the Federation for Children with Special Needs, in order to support families so that the law’s benefits could be fully realized.

As the main course was served, the Federation’s latest PSA was shown. This three and a half minute video was produced by Redtree Productions, and casting services were provided by Boston Casting. The piece is narrated by Marianne Leone Cooper, and features the music of Susan Werner. Other contributors include John Doucette Film & Video, Video Express and Accomplice Edit. Over 30 local children and their families participated in the making of this PSA! If you have not yet had the pleasure of seeing this amazing, uplifting production, you can view it on the Federation’s Web site at fcsn.org.

Following dinner, the President of the Federation’s Board of Directors, Jim Whalen, took the stage to announce this year’s honorees. The first honoree and recipient of the President’s Award was Peter Brennan, former treasurer of the Board of Directors and partner at PricewaterhouseCoopers. The President’s Award is given to individuals who have made outstanding contributions to furthering the work of the Federation. Brennan, who helped the Federation through challenging fiscal times, thanked Federation staff, and his friends and family for supporting his work on the Board. In particular, he thanked his niece, Mary, who was born with Down syndrome, stating that “through my relationship with Mary, I have...
The next award given was the Patricia Blake Advocacy Award. Named after former Associate Executive Director Pat Blake, this award is given to an individual whose work exemplifies Pat’s belief in the potential of all children with disabilities to achieve. The award was presented to Joe Petner, the recently retired principal of the Haggerty School in Cambridge. During his time as principal, Petner successfully helped develop inclusion classrooms for each grade level. After accepting the award, Petner shared his belief that we must model the values we wish to teach our children, and encouraged people to tell their stories to inspire others.

The final award of the evening was the Martha Ziegler Founders Award, named after the co-founder and former Executive Director of the Federation. As Ziegler presented the award, she wished the crowd “Happy Anniversary,” referring to the 40th anniversary of Chapter 766. She also thanked Robison for his work in carrying out the Federation’s mission after her retirement in 1997.

The Founders Award recognizes individuals who continue to educate, advocate and inspire, and was presented to Shonda Schilling. Although Schilling is perhaps best known as the wife of former Red Sox pitcher Curt Schilling, she received the award for sharing her experiences in parenting a child with Asperger’s Syndrome through her book The Best Kind of Different, which details the Schilling family’s journey in identifying and accepting their son Grant’s diagnosis of Asperger’s Syndrome. In accepting the award, Schilling described how grateful she was to the Federation for all that they do, and also thanked Bob Crabtree, Larry Kotin, and Connie Rizoli; the key staff who worked on Chapter 766. He also said that his wife’s award meant more than any World Series ring or trophy in the Schilling house.

After the awards ceremony, the crowd enjoyed a hilarious comedy routine from Tony V. The Boston native had the crowd laughing out loud at his jokes about getting older, dieting, spam (the meat, not junk mail), marriage, parenting, traffic, and fashion.

The evening concluded with a long-standing Gala tradition as Amy Robison took the stage to announce the winners of the raffle and to wish everyone a good night.

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Catamount Ski Resort  
Celebrities For Charity Foundation, Inc.  
Charles River Canoe and Kayak  
Children’s Museum & Theatre of Maine  
Clayroom  
Robert Crabbree  
Cranmore Mountain Resort  
Custom Crystal Rings  
Darilynn’s  
Edward DeNoble  
Married Photography, Inc.  
Edwin Case Comfort Shoes  
Jane Ernstoff  
Fast Frame  
FEI Theatres  
James Fort  
Wilson Gouvea  
Gregg Workman Photographic Art  
Harvard University Art Museums  
Joyce A. Haun  
Gwen Healey  
Healthworks Fitness Centers for Women  
Henry Bear’s Park  
Highland Kitchen  
Huntington Theatre Company  
International Tennis Hall of Fame  
Isabella Stewart Gardner Museum  
Jeffrey Salon Boston  
Andrew J. Jerz  
John E. Jerz  
JessiArts  
Jillian’s Billiard Club  
John F. Kennedy Library and Museum  
Joseph Gann Jewelers  
L’Andana  
Legal Sea Foods  
Longfellow Sports Club  
Lucia Borges Art Studio  
LunaRik Fashions  
M.Y. Salon & Day Spa  
Magic Beans  
Mahoney’s Garden Center  
Maine Narrow Gauge Railroad  
Party Favors  
Massachusetts Bay Lines  
Massachusetts Museum of Contemporary Arts  
Sandra Mazur  
Millennium Nails  
Molhegan Sun  
Mount Sunapee Ski Resort  
Mystic Seaport  
MZ Skin Care  
National Amusement Theaters  
New England Aquarium  
New England Comics  
New England Patriots Charitable Foundation  
New Repertory Theatre  
Party Needs-itzaparty  
Peabody Essex Museum  
Peace Love Studios  
Piloth Plantation  
Providences Children’s Museum  
Puppet Showplace Theatre  
Redbones  
Regina Pizzeria  
Rota Portrait Design  
Sadhana Yoga  
Patricia Schram  
Seaport Hotel  
Shan Hair  
Simons Shoes  
Six Gun City & Fort  
Splash Water Park  
Sky Zone Indoor Trampoline Park  
South Boston Yoga  
Betsy J. Sowers  
Star Market  
Sterling Golf Management  
Story Land  
Susan Shulman Interiors  
Rhea Tavares Smith  
The Benchmark Company  
The Charles Hotel  
The Coolidge Corner Theatre Foundation  
The Doug Flutie, Jr. Foundation for Autism, Inc.  
The Fireplace Restaurant  
The Hall At Patriots Place  
The Institute Of Contemporary Art  
The Land Of Witches & Pirates  
The Liberty Hotel  
The Pear Tree Of Brookline  
The Preservation Society of  
Newport County  
The Red Lion Inn  
The Red Sox Foundation  
The Ritz-Carlton, Boston Common  
The Sports Museum  
The Turtle Lane Playhouse  
Union Bar and grille  
Walter’s Jewelry  
WB Mason  
WCVB Boston  
Wellesley Booksmith  
Westport Rivers, Inc.  
James Whalen  
Wheelock Family Theater  
Martha Ziegler
How to Save $4 Billion: Young Adults Transitioning from Foster Care

By Jane Crecco, Training & Support Specialist, Recruitment, Training & Support Center for Special Education Surrogate Parents (RTSC)

$4 billion. That’s how much is estimated to be spent by the criminal justice system over the lifetime of each cohort of youth aging out of foster care each year. That’s a lot of money to keep kids locked up in jails.

Recently, there has been a new focus on kids aging out of foster care, either from foster homes, group homes, residential programs, or short-term residential placement services. In Massachusetts, approximately 800 foster youth turn 18 every year and have the option of leaving the Department of Children and Families (DCF). They must quickly face the challenges of addressing basic needs (housing and/or medical care), which become even more critical if they have been diagnosed with an emotional disability. As the result of many disruptions such as multiple placements, school changes, and placements in institutional settings, foster youth are often disconnected from family and social networks. They lack the supports that can help them through the hardships of transitioning to adulthood. These young adults are far more likely than their peers to be homeless, less likely to have completed high school, at risk of becoming the victims of crime, and struggle with mental health issues. And they are disproportionately more likely to end up in the criminal justice system.

The wonderful news is that Massachusetts is at the forefront of confronting these issues in unique and creative ways. In 2008, Congress passed the Fostering Connections to Success and Increasing Adoptions Act. Fostering Connections gives states the option of taking federal matching funds to support foster youth who remain in the care of the child welfare department past their 18th birthday. The acceptance of matching funds and making the Juvenile Court and DCF practices compliant with federal law was signed by the Governor and became effective in January, 2011.

The funds are used for young adults between the ages of 18 and 22 who sign a voluntary agreement to stay in the care of DCF. They are their own guardians, but they maintain a right to counsel. They have the ability to receive a copy of their service plan, and must have a court-approved transition plan at least 90 days prior to their case termination (which must include a plan for stable housing and employment). Generous educational funds for public and private colleges and vocational training are offered, along with funded options for independent living. The focus of DCF planning, from the day a child enters their custody, is called “permanency planning.” Hopefully, the outcome of this planning is family reunification or adoption. Unfortunately, for the 800 kids aging out, this has not occurred, and there remains a disconnect with supportive adult role models.

In school, if a child has met eligibility for special education, transition plans and services must begin by the age of 14 in Massachusetts. These services include post-secondary preparation for education, employment, community experiences, and post school adult living. Many foster children are deemed eligible for services due to an emotional disability as a result of their complex childhood trauma.

The Department of Children and Families and the Department of Elementary and Secondary Education have started to collaborate on data gathering for foster kids, sharing statistics on drop-outs, truancy, and school refusal. Transition services under Individuals with Disabilities Education Act (IDEA) and Fostering Connections are complimentary and have the potential to strengthen one another when combined. Best practice would dictate that planning processes be coordinated when planning for the transition of foster youth with disabilities. An IEP Team made up of the foster child (as involved as possible, as early as possible), educators, adults who have a relational history with the young adult and may be able to provide ongoing emotional support, DCF Adolescent Workers, and community connections, would be an absolute step forward in the right direction. And a potential savings of $4 billion.

Quality of Life is at the Center of Our Family Supports

- Family Support Specialists
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- Comprehensive Education
- Training Library
- Respite Care
- Monthly schedule of events
- Drop-ins welcome

For a person or loved one with a disability, the Family Support Centers of Seven Hills Family Services make a measurable difference in the quality of life for your entire family. Seven Hills Family Support Centers are located in Worcester, Fitchburg, and Sturbridge, MA, and provide all the programs and services you or your loved one needs to live full and rewarding lives.

For more information, please contact Robin Foley at 508.796.1850.
The SEPAC Action Plan; a Back-to-School Necessity

By Barbara Popper, Senior Policy Analyst and Leslie M. Leslie, MassPAC Coordinator

Back to school means new backpacks, notebooks, pencils and most important; a new schedule with classes organized by time and place. Special Education Parent Advisory Councils (SEPACs) would also benefit from such a defined schedule; a plan of action for the new year with set deadlines and responsibilities. Getting the time to organize, strategize and develop relationships to create this type of plan though, is getting harder and harder with our hectic lives.

The Federation’s answer for busy districts is the A.P.P.L.E Institute. Held each May, the Institute brings SEPAC leaders and their Special Education Administrators together for three days to work on creating an action plan to engage families. The Institute is free of charge for school districts, supported by a grant from MA Dept. of Elementary and Secondary Education (Mass Focus Academy). This year, the A.P.P.L.E Project held a successful Institute at the new Conference Center at the Federation for Children with Special Needs in Charlestown. Districts from Marlborough, Malden, Medway, Newburyport and Weston had the opportunity to work as district teams with a facilitator to prepare an action plan for their SEPAC. Each team designed a vision statement – what their SEPAC aimed to achieve in the next two years. They then considered current realities, possible groups not represented on their SEPAC, and what specific actions they would take to make their vision a reality. The action plans created will provide direction for the SEPAC while strengthening the relationship between Administrators and parent leaders.

Feedback from this year’s participants was very encouraging:

- I thought it was an excellent 3 days. Very well facilitated & meaningful content. I believe our PAC will move forward much more effectively now that we’ve had the benefit of this workshop.
- I felt energized & engaged throughout but to have permission to talk, listen & share with critical stakeholders like SEPAC families was a privilege, especially to do it around topics over a focused meaningful extended period of time.
- Absolutely wonderful conversation, support & discussion, a remarkable growing experience.
- Lasting relationships were built, action plans were identified, common visions & timelines were identified

The Federation A.P.P.L.E Staff works closely with MassPAC to assist districts that are looking for more support and skill building around leadership. SEPACs should consider taking the time (three days!) to refocus themselves and create an action plan. Going back to school without a schedule may cause you to lose your way – don’t be without a SEPAC Action Plan, an essential back to school item.

For more information about the A.P.P.L.E Institute on May 15-17, 2013, contact Marilyn Guttierrez at marilyng@fcsn.org or 617-236-7210, x351.

El Tribunal de Apelaciones revoca el límite del DDS de un cociente intelectual de 70 como criterio de elegibilidad para recibir servicios

By Daniel T.S. Heffernan, Esquire

Cuando los estudiantes reciben sus diplomas de high school o están por cumplir 22 años y su derecho a recibir servicios de los distritos escolares locales empieza a acabarse, muchas familias de los 165.000 estudiantes de Massachusetts con planes educativos individualizados acuden al Massachusetts Department of Developmental Services (DDS, Departamento de Servicios del Desarrollo de Massachusetts), anteriormente conocido como Department of Mental Retardation (DMR, Departamento de Retraso Mental), en busca de servicios para sus hijos adultos con discapacidades intelectuales. El DDS ofrece programas y apoyos especializados tales como asistencia con el empleo, servicios residenciales, cuidado de relevo y transporte a aproximadamente 32.000 adultos.

Uno de los criterios de elegibilidad del DDS es que la persona tenga retraso mental. Antes de 2006, el retraso mental se definía en los reglamentos del DDS/DMR como un funcionamiento intelectual “significativamente por debajo del promedio”. Cuando se aplicaba este criterio, las decisiones se basaban generalmente en autoridades como la Asociación Estadounidense para las Discapacidades Intelectuales y del Desarrollo (American Association for Intellectual and Developmental Disabilities) y el Manual diagnóstico y estadístico de los trastornos mentales (conocido en inglés como DSM-IV-TR) de la Asociación Psiquiátrica Estadounidense. Según ellos, existe retraso mental cuando una persona tiene deficiencias funcionales importantes y un cociente intelectual de 70 a 75.

En 2006, el DDS/DMR anunció una nueva regla que definía como criterio de funcionamiento intelectual “significativamente por debajo del promedio” tener un cociente intelectual de 70 o menos. Ese límite ha sido muy criticado por no tener una base científica, especialmente teniendo en cuenta que hay muchos factores imprevisibles que pueden afectar el rendimiento de una
El Tribunal de Apelaciones revoca el límite del DDS de un cociente intelectual de 70 como criterio de elegibilidad para recibir servicios (continued from page 12)

persona el día de la prueba. Muchos consideran que esta regla se impuso en forma arbitraria simplemente para reducir el número de personas que reciben servicios del DDS/DMR. Aunque es difícil de cuantificar, se cree que este límite ha excluido a un número importante de individuos de los servicios del DDS y que le ha causado dificultades tremendas y caprichosas al gran número de personas y familias que necesitan desesperadamente servicios de la única agencia capaz de ofrecérselos. Por apenas un punto de diferencia en el cociente intelectual, a muchas personas con deficiencias intelectuales que hasta ahora recibían un apoyo amplio de sus distritos escolares se les ha cerrado en la cara la única puerta a los pocos servicios restantes.

El 23 de julio de 2012, el Tribunal de Apelaciones de Massachusetts, en el caso Tartarini v. Department of Mental Retardation, 2012 WL 2047771 (Mass. App. Ct.) revocó este límite. A Tartarini se le había medido un cociente intelectual de 71 a los 18 años de edad, de 69 a los 40 años y de 71 a los 42 años. Se determinó que el cociente intelectual vigente era el de los 18 años y que, por lo tanto, ella no era elegible para los servicios del DDS/DMR. Esta determinación fue confirmada por un funcionario de audiencias y por el Tribunal Superior de Massachusetts. Sin embargo, el Tribunal de Apelaciones revocó la decisión e invalidó el límite del DDS argumentando que la regla de un cociente intelectual de 70 o inferior era incompatible con la legislación que la autorizaba, ya que la legislatura de Massachusetts “no le había dado al Departamento [DDS/DMR] discrecionalidad absoluta para definir en qué consiste el retraso mental. La ley exige que la reglamentación del Departamento se fundamente en la opinión de las “autoridades clínicas”.

Esta revocación es una buena noticia para las familias que necesitan servicios del DDS para adultos. La esperanza es que las personas a quienes se les denegó la elegibilidad en base al límite de un cociente intelectual de 70 puedan presentar o reabrir sus solicitudes de servicios del DDS. Además, un gran número de personas con deficiencias intelectuales pero con cocientes intelectuales superiores a 70 ahora pueden ser elegibles para recibir estos servicios fundamentales como adultos.

Daniel T. S. Heffernan es miembro de la Junta Directiva de la Federación para Niños con Necesidades Especiales y socio en el bufete de Kotin, Crabtree y Strong, donde se especializa en educación especial, lesiones personales y elegibilidad para servicios a adultos. Puede escribirle por correo electrónico a dheffernan@kcslegal.com.
Children with Special Needs Need Families

By Annessa Lewis, VISTA Volunteer - Massachusetts Adoption Resource Exchange (MARE)

You may not know the Massachusetts Adoption Resource Exchange (MARE) by name, but you may have seen MARE’s work — Wednesday’s Child on WBZ TV with news anchor Jack Williams, and Sunday’s Child in the Boston Globe. MARE educates the public about adoption from foster care and recruits potential parents for some of the harder-to-place youth in state care including older children and teens, siblings, youth of color, and youth with special needs.

These children need a loving, supportive family just like yours; you could make a difference in the life of a child. MARE is currently working to find adoptive families for 491 children; 168 of these children have an identified physical disability. While over 90% of the children MARE serves have one or more emotional, physical, or intellectual disabilities, these 168 children, through no fault of their own, are among the most difficult to recruit adoptive families for. They are medically-involved and live in either temporary foster homes that are equipped to handle their special needs or in pediatric nursing homes. They will face better futures if they can be moved from temporary care into permanent, loving, capable families who can advocate for their medical needs.

In 2010, one of MARE’s Child Services Coordinators recognized a trend: a high number of children with developmental and physical disabilities were not getting inquiries from prospective parents, and were not being matched with families. With that realization, MARE began an initiative to expand matching opportunities for this underserved population. MARE began with an Adoption Party that August at a therapeutic riding center for fourteen children with disabilities, and twelve invited families.

Each year, however, hundreds of Massachusetts teens “age out” of foster care at eighteen to “independent living.” Already burdened by their experiences of abuse, neglect, and instability, these teens leave state care without the ongoing guidance to become productive and connected citizens. Young adults with physical disabilities age-out at twenty-two and, while they are likely eligible for additional services through various programs of the Commonwealth’s Office of Health & Human Services, they lack a life-long family to consistently advocate for their needs.

All children deserve a family’s guidance, stability, and love. In partnership with the Massachusetts Department of Children & Families (DCF), and private agencies throughout the state, MARE has helped find adoptive homes for over 5,750 children since 1957. With 600 children waiting to be adopted in foster care right now, more children need MARE’s help, and yours, every day.

The Federation appreciates the work MARE does to ensure all children have a permanent home. For more information about MARE, the many services available, the children in need of adoption, and how you can make a difference, please call MARE at 617-54-ADOPT (617-542-3678), or visit www.MAREinc.org.

Update on Health Care Reform: Is health insurance a right, a responsibility or a privilege? (continued from page 3)

By January 1, 2013, new federal funding will be in place to state Medicaid programs that choose to cover preventive services to patients at little or no cost.

So Is health insurance a right, a responsibility or a privilege? Like many of other families who rely on access to quality health care, I knew early on that my son would live or die, would live better and enjoy life if he had quality care. What I could afford was another story. Is health insurance a privilege? Somewhat. Not too long ago only people who were employed, or could afford the premiums had coverage. While this has improved with MassHealth options and Premium Assistance, some find the process difficult and confusing. And others who have Medicaid say they have difficulty finding providers who accept their plan. (For help contact the Family-to-Family Health Information Center, massfv@fcsn.org.)

As a result of the legislative changes that ACA provides, having health care is both a right - and – a responsibility. Of course it should be. How will our nation be productive if its population is not healthy and productive? How will caregivers be able to work the jobs they were trained to do, if access to quality care is not affordable? Scheduling routine preventive care exams saves lives and reduces health care costs. This is our responsibility too. The law is not perfect, but it is a whole lot better than we had just a decade ago.

RESOURCES TO CHECK OUT

The Affordable Care Act: Immediate Benefits for Massachusetts http://www.healthcare.gov/reports/statehealthreform/massachusetts.html

Healthcare.gov http://www.healthcare.gov/

The Supreme Court Decision http://www.supremecourt.gov/opinions/11pdf/11-393c3a2.pdf
About Katie Lynch and the Purple Shoes Challenge

Katie Lynch was born with a unique form of dwarfism, used a powerchair for mobility and needed personal assistance all her life. In her 27 years, along with her health challenges, Katie faced societal barriers head on. When once asked by a television reporter why she worked so tirelessly on behalf of Children’s Hospital Boston, Katie Lynch looked into the camera and said, “Because every human being is worth it.”

Katie did not qualify for the Special Olympics because she did not have an intellectual disability, but she longed to compete. Unable to participate on school teams, Katie, with support from her adaptive PE coach, developed a rigorous workout routine, and engaged in any adapted activity that she could think up. This is how she found herself at the start of the Boston Marathon in 2001.

For Katie, the reward of crossing the finish line was about more than testing her physical limits. For Katie, the ultimate reward was the opportunity to share her deeply held conviction that we all need to acknowledge the worth of every individual and remove the barriers that prevent people from participating in the community.

When Katie passed away in 2002, those who knew of her love for opening doors and her interest in athletic competition for ALL knew that her spirit and her work had to continue, and so began the Purple Shoes Challenge, as well an accompanying half marathon and 5k.

Purple Shoes Challenge athletes have a wide range of physical disabilities, and the program’s Director, Dr. John Passarini, works with all the athletes to establish appropriate goals. Dr. Passarini is an inspiring coach, and has received rave reviews from participants. This year will be the fourth annual Purple Shoes Challenge, and organizers are actively looking for more athletes who would like to join us. Help spread the word!

Advocates Celebrate 40 Years of Special Education (continued from page 1)

language was other than English, and students with disabilities were frequently expelled, or prevented from attending school. This report provided the basis for the legislative efforts resulting in Chapter 766.

Finally, Federation founder and longtime Executive Director, Martha Ziegler spoke of the role of parents on the Coalition for Chapter 766 and their efforts to work with stake holders across education and government to create the ground-swell needed to enact such a revolutionary law. Forty years later, we can measure the progress and results in dramatic ways. We also recognize there is a long way still to go.

Forty years doesn’t seem so long ago until you realize how far we have come.

Self-Advocate Mike Mayes, a young man with Autism spoke of how his Mom and school changed his life and helped him to become the man he is today.

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Visit fcsn.org for more details about these and other events...

**Parent Consultant Training Institute Fall 2012**
SCAN360 • Springfield, MA
Tuesdays & Thursdays September 18 - October 16, 2012. Apply Now!
Federation Main Office • Boston, MA
Fridays, October 5 - November 30, 2012

**Visions of Community 2013**
Seaport World Trade Center • Boston, MA
Saturday, March 9, 2013

**Gala 2013**
Seaport Hotel • Boston, MA
Friday, May 3, 2013

INFORMING, EDUCATING, EMPOWERING FAMILIES