Tough Stance Against Bullying in Massachusetts

By Daniel T.S. Heffernan, Esquire

Perhaps nothing evokes greater anxiety for parents of school-aged children with disabilities than the fear of their children becoming the victims of bullying. With the explosion of social networks, taunts, parodies, and even violent acts are not only disseminated widely and instantaneously, but in some instances, encouraged. As a lawyer, I have seen how pervasive bullying has become and the enormous pain and damage it causes children and their families. Children are ostracized and humiliated. Some are physically injured and, in some instances, traumatized so seriously that they require psychiatric hospitalization. Some even suffer lingering effects such as post-traumatic stress disorder. At times, the victim gets blamed and labeled as a behavior problem when he/she strikes back at the bullies or acts out in reaction to the unabated bullying. Sometimes the school environment becomes so “toxic” that students can no longer be safe or properly educated there and require specialized placements.

Often more disheartening and damaging than the bullying itself is the failure of school personnel to prevent, monitor, or extinguish such bullying. In fairness, bullying often flies under the radar and school personnel are unaware of it or ill equipped to address it. However, some educators have seemed ignorant of the damage such bullying can cause and have abdicated their roles as educators and taken a “kids will be kids” attitude about bullying.

As a result of publicity around a case of bullying that was believed to cause a high school student to commit suicide, and led to criminal charges against the alleged bullies, Massachusetts recently enacted an anti-bullying statute. Because of the public outcry and media attention, the law was passed swiftly. There is criticism for and against the law. Some say it went too far; others say it did not go far enough. The education community and families are closely watching the effectiveness and impact of this law.

Continues on page 8
Welcome New Federation Staff

The Massachusetts Parent Information and Resource Center (PIRC) welcomes new staff member Gavin Pond. As the Services Coordinator, Gavin is responsible for coordinating PIRC staff for workshops, presentations and resource fairs as well as providing resources to families, communities, organizations and schools. He also maintains the database and supports the development of PIRC publications and materials through research and editorial support. Gavin is a recent graduate of Wesleyan University who wrote his senior essay on the history of education reform movements in Connecticut. Call Gavin at 617-399-8342 or e-mail gpond@fcsn.org.

Family TIES of Massachusetts is pleased to welcome their newest staff member Cheri McLane. Cheri is the Metrowest Regional Coordinator. She lives in Walpole with her husband, Kevin, and three children - Dylan, age 8, Julia, age 7 and Carissa, age 4. Julia was born with a rare genetic disorder and was subsequently diagnosed with hip dysplasia. During those early years, one of Cheri’s biggest challenges was feeling like she had to “do it all on her own.” However, due her research background, she knew how to ask questions, and began directing those questions to professionals and other parents. Early on, she was fortunate to connect with others who generously provided support and guidance. Cheri is pleased to now be in a position to offer the same types of information and support to others.

Cheri works 20 hours a week and is based out of the Department of Public Health office in Canton. Please call and welcome Cheri to the Family TIES family, and let her know if you need information, referrals or support. Call Cheri at 781-774-6602 or e-mail cmclane@fcsn.org.

The Federation is pleased to welcome back Maureen Jerz! Ten years ago, Maureen was a staff member for the Parent/Professional Advocacy League (PAL), which at that time was a project at the Federation. Maureen now rejoins our staff as the Director of Development after working in the development field for four years at Horizons for Homeless Children as their Director of Foundation and Corporate Relations. Maureen is thrilled to be back at the Federation, is enjoying getting to know all of the staff, reconnecting with many former colleagues, and is looking forward to contributing positively to the Federation’s development efforts. Maureen and her husband Joe are also the parents of two young adults, one of whom has learning disabilities. Both are in the process of building careers in the arts.

The Parent Training and Information center welcomes Kate Brewer as the Information Specialist. Kate will be providing information and referral services to families of children with special needs, communities and the organizations which serve them across Massachusetts. Kate is a recent graduate of Bentley University and was trained as an advocate by the Federation in 2003. Kate lives in Duxbury where she has been a member of her PAC for ten years and is the mother of three lovely and amazing daughters. When Kate’s daughters were in need of services, the Federation played a key role in training Kate and aiding her family. Kate is elated to be helping the Federation support families.

Bonnie Thompson recently joined the Federation as an Informational Specialist for the Family-to-Family Health Information Center (F2F HIC). Bonnie and her husband David have one amazing daughter, Olivia, age 11. As the mother of a child who had a stroke at birth, Bonnie has navigated many systems of care through the years. Like many parents, when health insurance concerns arose Bonnie turned to the F2F HIC for guidance. Bonnie began her work with the F2F HIC doing evaluations about the quality of the technical assistance families receive from the Center. She looks forward to her new role providing direct assistance to families and others who call the F2F. She can be reached at 800-331-0688 ext 301 or e-mail her at bthompson@fcsn.org.
“Friend Us”
We need new Friends to help us continue our important work!

Support the Federation’s 2011 “Friend Us” Appeal.

We all need friends! The Federation, like many organizations, has recently entered the world of social networking. We are delighted to have friends who “like” us on Facebook and are “followers” on Twitter. Our YouTube channel has received over 11,000 “views.” The popularity of Facebook and other forms of social networking reminds our communities of something parents of children with special needs have known for a very long time. We all need networks of support! Friends help friends get things done.

The Federation for Children with Special Needs was founded on the principle of “parents helping other parents.” Thirty-six years ago, around a kitchen table, four friends came up with a great idea to prevent isolation and loneliness while raising their children with special needs. They networked together and supported one another. Then they met some more friends and told them what they were doing and the new friends soon joined in. Through sharing ideas, solutions, hopes and dreams this network grew to become the Federation. Indeed, at the Federation, we know that families helping families is the oldest form of social networking. We have been “friending” families for decades with amazing results!

Today, we are asking for your continued friendship, and your help in reaching new friends.

The Federation is a resource for more than 40,000 Massachusetts families each year. By attending our many workshops, our annual conference, or by calling our Support Center, all families can obtain the ideas and strategies they need to ensure quality education, medical care and other needed services for their children. But, to remain true to our founding vision of being a thriving Parent Center - run by families for families - and to ensure that all children can reach their potential, we need your help.

Can we count on your support today?

Friend us on Facebook. Follow us on Twitter. Check out our videos on YouTube. Write a check.

Use the enclosed envelope to send your donation today. And then, ask a friend to donate as well!

Your generous, tax deductible donation of $50, $100, $250 or more will support the high-quality programs and services that we know families rely on. Thank you for your friendship and support.

Sincerely,

Rich Robison
Executive Director

James F. Whalen
President, Board of Directors

PS. Donate securely online at https://fcsn.org/donations/donate.html or send your check in the self-addressed envelope provided. If your employer has a matching gift program, your donation may qualify thereby doubling your contribution!
This year’s MCAS Parent/Guardian Report (MCAS Report) includes something new. For the first time, the Massachusetts Department of Elementary and Secondary Education is sending home information about “Student Growth Percentiles” (SGPs). SGPs help parents understand how much academic growth their child makes in a subject area from year to year, as compared to their academic peers. SGPs also show how districts, schools, or other groups are progressing. This article gives an overview of SGPs and what they mean for both individual students and groups of students.

**What is the Student Growth Percentile?**

SGPs provide a new answer to the question, *How is my child doing in school?* Previous MCAS Reports show how each student performed on the previous spring’s MCAS tests compared to the grade-level standards. Now the MCAS Report will also show how much a student has progressed since the previous year compared to his/her academic peers. Academic peers are students across the state in the same grade, taking the same test, with the same or similar history of MCAS scores.

In any given year, a student’s growth percentile can range from 1 to 99. For example, a student with a math SGP of 75 means that he or she grew more than 75% of his/her academic peers and less than 25% of his/her academic peers.

**Who will get an SGP?**

Students in grades 4 through 8 and grade 10 who have at least two years in a row of MCAS results will receive SGPs. Students in grade 10 who have attended Massachusetts public schools in grades 8, 9, and 10 will also receive SGPs.

Since two years of MCAS test scores are needed to chart growth, no growth percentiles can be shown for grade 3, as that is the first grade for MCAS testing. Growth percentiles are also not available for science because science is only tested in grades 5, 8 and high school. Students who took the MCAS-Alt for the two most recent MCAS tests will not receive SGPs, nor will MCAS retest results be used in calculating student growth percentiles.

**What are growth percentiles for groups of students?**

Growth percentiles can also show how districts, schools, or other groups of students are growing in comparison to each other. When percentiles for every student in a group are ordered from lowest to highest, the middle point, or median, is the growth percentile for the group. Growth percentiles for schools, districts, and other groups can then be compared to each other and to the state median. The state median is always 50, so a typical growth percentile is between 40 and 60. Student growth percentiles outside this range are considered to be lower or higher growth.

**Why are growth percentiles important?**

For individual students, SGPs give parents another way to understand their children’s academic progress. A student with a lower SGP may have experienced unusual difficulties at home or at school. Parents may want to discuss the reason for low growth with the teacher and explore remedies such as extra academic or other support. Parents of a student who received a very high SGP may find that a new accommodation or teaching strategy paid off and should be continued.

Growth percentiles for districts, schools, and groups provide valuable information about how well a child’s school is educating its students. The MCAS Report gives growth percentiles for the student, the school, and the district, showing how all three compare to the state median. Parents of students who get higher growth percentiles than their school may want to work with their school to improve curriculum and instruction for all students. Parents of students who are growing at a slower rate might initiate a discussion about resources or strategies that could help their child grow at the same rate as his/her classmates.

Comparing how groups of students grow academically also provides useful insight about a school’s effectiveness at promoting student growth among *all* student groups, such as students with disabilities or English language learners. Looking at student performance in this way can help parents, districts, and schools examine why results differ for certain groups of students. This information is a valuable key to identifying approaches and best practices that have proven effective in helping all students, or specific groups of students, grow.

Mass PIRC has two Bulletins about SGPs. Read “Student Growth Percentiles: What does it mean for individual students,” and “Student Growth Percentiles: What they tell us about schools, districts, and groups of students” at www.masspirc.org.
The Mass Family Voices Listserv & MassHealth Update

By Beth Dworetzky

Since 2002, the Mass Family Voices project has hosted a listserv. A listserv is a way to use a single internet e-mail address to send e-mail to and receive e-mail from many other people who share a common interest. The common interest shared by the members of the Mass Family Voices listserv community is children and youth with special health care needs.

We use the list to share information and resources, ask questions and learn from each other’s experiences and expertise. Membership is free. There is a policy that governs confidentiality and no one can use the list to advance their own business interests. Using Traducelo Ahora, an on-line translation program, members can send and receive e-mails in Spanish.

The list began with 25 members and today is a virtual community of more than 500 caring, sharing individuals. Recently, a Family TIES of Massachusetts staff person sent a message in search of a car seat to help a family. In addition to receiving several donated car seats, she received additional generous offers of gently used clothing, fuel assistance and other supports and services for the family.

So, if you are looking for a connection to other families raising children and youth with special health needs who understand the daily struggles of keeping our children’s lives as normal as possible so they can be as extraordinary as possible, please consider joining your voice with the Mass Family Voices network of families. Learn more about the list at www.massfamilyvoices.org/Listserv_Info.html. To receive an electronic invitation to ‘en’list, send an e-mail request to massfv@fcsn.org.

MassHealth Update

If your working or non-working income has changed, up or down, you’ve changed jobs or taken on additional work, you must report it to MassHealth within 10 business days, even if you just completed an annual Eligibility Review Verification (ERV) form. To report changes, send two recent pay stubs from all employers and a note with your name, address, and your or your child’s MassHealth number to the MassHealth Enrollment Center (MEC)* that serves your city or town. Make a copy of the information before you mail it. Mail it registered, return receipt.

*If you don’t know the MEC that serves your city or town, the Massachusetts Family-to-Family Health Information Center can find out for you. Call 1-800-331-0688, ext. 210 or e-mail massfv@fcsn.org.

In Memorium

Polly Arango
Judith Ann Hoyt
Cassie Johnston

As parents, family leaders, and advocates, we truly “stand on the shoulders of giants.” Our work today is easier due to the efforts of those who came before us and paved the way for our children with special needs to be educated alongside their peers, and to have access to quality supports and healthcare. We pay tribute to three such giants.

The Family Voices network of family leaders and friends suffered a tremendous loss on June 26, 2010, with the sudden, unexpected passing of its founding Executive Director, Polly Arango. Polly was a passionate, visionary, persistent, powerful, humble, and tireless mother, advocate, mentor and friend whose belief in the power of community was exemplified in her lifetime of work for families and children. The power of Polly’s words will remain with us always, “Let us remember as each of us makes decisions that will affect children—whether we are parents, educators, health professionals, or government officials—it is our duty to consider if that decision either affirms or denies a child’s most basic human rights.”

Judith Ann Hoyt died on September 5, 2010. Judy was a Master of Education and a pioneer in changing the field of education. Her efforts on behalf of her eldest son Rick, allowed countless individuals with disabilities to be educated in public schools alongside their non-disabled siblings, friends and peers. Judy founded ASHS, Association for the Support of Human Services, a human service agency that created Kamp for Kids, the first ever summer camp for children with and without disabilities.

On September 21, 2010, Family Voices and the Early Intervention community lost another voice when Cassie Johnston died. Cassie was a long time member of Family Voices, working in Washington State. She was a gifted leader, and had a lovely way of helping and supporting others, while at the same time having them realize their own strengths and leadership ability. She spent many years working in the early intervention system and never lost sight of how critical early supports and services are to the well-being of young children with special health care needs and/or disabilities and their families.
If you are the parent of a child who receives special education services, you’re probably familiar with your role in the Individualized Education Program (IEP) process. At least once a year you meet with other members of your child’s IEP Team to evaluate your child’s progress, set new goals, and decide on appropriate services. You are an important and equal member of your child’s Team, and work together with school professionals. You communicate with your child’s teachers and receive regular progress reports. But, have you thought about taking the next step? Have you thought about becoming a parent leader in your school community? When you become a parent leader, you have the chance to make positive change happen not only for your child but for other children in your district as well.

Sometimes parents of children with disabilities feel isolated. School newsletters are full of announcements, but the information does not always pertain to your child and family. Conversations on the playground or at Parent Teacher Association/Organization (PTA or PTO) meetings may be about issues that are hard to relate to. It’s important to realize two things:

1. Other parents of children with disabilities probably feel the same way you do.
2. The school community is not excluding you intentionally. People who have chosen to be actively involved have the biggest say in the school community agenda. If you take steps to become active in your school community, you too can help shape the agenda.

Don’t know how to become a parent leader? Below are some ideas for taking those next steps.

• Attend a local special education parent advisory council (PAC) meeting. By state law, every district must have a PAC that advises school officials about district wide special education issues. Most PACs have regular public meetings, with invited speakers. Your director of special education can...
Family TIES of Massachusetts is a statewide information and support network for families of children with special needs. It is a project at the Federation for Children with Special Needs, funded by the Massachusetts Department of Public Health, Division for Perinatal Health, Early Childhood and Special Health Needs. It is not uncommon for parents and guardians of children and youth with special needs to feel overwhelmed. In addition to their “normal” family and work responsibilities, they feel compelled to become “experts” about their children’s medical, educational, social and other special needs.

Do you ever wish someone could help you learn about your child’s diagnosis, support networks, early intervention and other community-based programs, services, and resources that will help support your child and family? Do you need ideas to fund assistive technology or adaptive equipment, financial support to attend a conference, or help paying for health-related services? If the answer is “yes” call Family TIES.

Last year, more than 1,700 parents called us looking for information and support. Our Regional Coordinators, who are parents of children with a variety of special needs, are available to assist with research, provide up-to-date information about resources, and free up your time so you can do something other than make phone calls.

Family TIES offers support in many languages. We have staff and friends at the Federation who together can offer bilingual, bicultural support for those who speak Spanish, Portuguese, Cantonese, Vietnamese, Amharic, Swahili, and Tigrina. In addition, with help from the Massachusetts Department of Public Health, we have access to a telephonic interpreter service. This allows us to request a phone-based interpreter to facilitate a three-way call. Many of our written materials are available in several languages, as are the Let’s Get Organized and Listening & Learning trainings. Truly, we are able to offer support and expand access to services for many families. Please call to help us bring our resources to your community.

The Regional Parent Coordinators look forward to hearing from you! Contact your coordinator at 1-800-905-TIES (8437) or through our Web site at www.massfamilyties.org.
Bullying is defined broadly as the repeated use by one or more students of a written, verbal, or electronic expression, or a physical act or gesture, or any combination thereof, directed at a victim that:

(i) causes physical or emotional harm to the victim or damage to victim’s property;

(ii) places the victim in reasonable fear of harm to himself or of damage to his property;

(iii) creates a hostile environment at school for the victim;

(iv) infringes on the rights of the victim at school; or

(v) materially and substantially disrupts the education process or the orderly operation of a school.

Bullying also includes cyber-bullying.

The statute prohibits bullying not only at school and school-sponsored activities and functions, but also beyond if the bullying creates a hostile environment at school for the victim or infringes on his/her rights at school or is otherwise disruptive of the school. In addition, the statute imposes obligations on schools, including non-public and charter schools, to:

1) provide instruction on bullying prevention in each grade;

2) develop and adhere to a plan to address bullying prevention and intervention;

3) provide professional development in these areas;

4) annually provide written materials regarding bullying policies to students and parents;

5) have personnel report incidents of bullying to the principal or designated person; and,

6) inform the parents of both the victim and the perpetrator of any instances of bullying.

Concerning a child with special needs who has a disability affecting social skills development or making that child vulnerable to bullying, the Team is required to include in the IEP skills and proficiencies needed to avoid and respond to bullying.

There are several practical things that parents and advocates can do to reap the benefits of this new legislation and focus on bullying:

• **Ask for your school’s policies and procedures about bullying** – if they do not have these yet, insist that they do so and ask to join in the process of publicizing those policies and procedures to bring special attention to children with disabilities. Make sure the school is providing the information and training they are now required to.

• **An ounce of prevention** – be proactive about any instances or brewing issues around bullying by meeting with the teacher or school staff to develop an effective response. Nipping things in the bud early and preventing them from escalating can avoid major problems or damage.

• **Insist on being well informed** – schools sometimes fail to communicate with families about bullying because they minimize it or because they want to “handle it themselves.” Make it clear that you want to be told immediately about any issues regarding bullying that arise.

• **Consider modifications to an IEP or 504 plan** – students may require certain services, such as counseling, or additional monitoring or aide support, to respond to or prevent bullying or harassment. Know that if the bullying has resulted in such significant damages or issues, placement in a private school or other program may be warranted.

Although it is uncertain what impact this legislation and the recent attention will have on bullying of students with special needs, I am hopeful that it will significantly decrease bullying in our community and lessen its impact.

Daniel T.S. Heffernan is a member of the Federation’s Board of Directors and a partner at Kotin, Crabtree & Strong where he concentrates on special education and civil rights law. Contact him at dheffernan@kcslegal.com.
The Federation for Children with Special Needs will host its annual *Visions of Community* Conference on Saturday, March 12, 2011, at the World Trade Center in Boston. Highlights for the 2011 conference include a keynote address by Marianne Leone, actor, screenwriter, and author. Marianne has written *Knowing Jesse: A Mother’s Story of Grief, Grace, and Everyday Bliss*. It is an unforgettable memoir chronicling the joy, grief, and triumphs of her son Jesse, who lived a remarkable life with cerebral palsy. (See book review on page 14.)

Conference attendees will be able to attend workshop sessions (many presented and/or translated into Spanish, Portuguese, and Cantonese) about Early Childhood, Special Education, No Child Left Behind (NCLB), the Individuals with Disabilities Education Act (IDEA), Health Care for Children with Special Needs, Transition, Social/Recreation Opportunities and more. This is also a great time to network with other families and pick up free resources from our many exhibitors.


**Nominations Needed:**

**2011 Community Partnership Awards**

Do you know a parent, student, health provider, teacher, administrator, coach, neighbor or other individual who has worked to create and support the inclusion of individuals with disabilities in your community? Each year, the Federation awards Community Partnership Awards to individuals in Massachusetts who have demonstrated outstanding efforts at creating a ‘vision of community’ where everyone, regardless of ability, feels welcome, and has opportunities to participate. Award categories include Community Outreach, Inclusive Recreation, Educators (Inclusive and Special Education classrooms), Parent Advocacy, and Self-Advocacy.

Think about the people you know who have made a difference in the lives of individuals with disabilities, and nominate that person for a Community Partnership Award. The Federation will present the 2011 Community Partnership Awards at the *Visions of Community* Conference on March 12, 2011.

Submit your nominations on-line, through e-mail, or snail mail. Find everything you need to nominate that extraordinary individual at http://fcsn.org/conferences/voc2011/cpa.php. The nomination deadline is January 21, 2011.
connect you with your PAC, or you can ask other parents of children with disabilities. For more fun and less anxiety, attend the meeting with a friend. Introduce yourself to the PAC leaders and other parents. Ask them to help you understand what the PAC does. Volunteer to do something small, such as bringing a snack to the next meeting. Gradually you will become familiar with the PAC’s activities, you’ll understand what PAC leaders do, and you’ll be able to see how you can use your talents and interests to make a contribution. You and your PAC leaders can also get support, information, and training from the Massachusetts Association of Special Education Parent Advisory Councils (MassPAC) at the Federation for Children with Special Needs, www.masspac.org, as well as the Federation’s A.P.P.L.E. Institute, http://fcsn.org/apple.php.

Even though your child receives special education services, there’s no need to limit yourself to groups which focus on special education. For example, every school – according to state law – must have a school council composed of parents, teachers, outside community members, and students (in grade 9 – 12 schools). School councils help principals by adopting educational goals for the school, identifying the needs of students, and reviewing the annual school building budget. All school councils must follow Open Meeting Law. Attend a meeting as an observer to learn what your school council does. Talk with individual school council members about what they do, and how your perspective as the parent of a child with disabilities could be valuable. Parent members of the council are elected by other parents. Speak with your principal to find out how you can get on the ballot. Learn more about school councils at http://pplace.org/publications/bulletins/English/ppbulletinv9n1.pdf.

Getting involved with your local PTA or PTO is also a great way to help make special education issues more central in the life of the school. PTAs/Os are not just about fundraising. They often host speakers, provide volunteers for school activities, and offer school professionals (such as principals and superintendents) important feedback from families. Becoming active in your school’s PTA/O can ensure that your voice is heard. Call the school, check the Web, or read the school newsletter to see the PTA/O meeting schedule. As mentioned above, it can be uncomfortable to go alone; invite a friend so you can listen and learn together. Introduce yourself to the other attendees and to the PTA/O leaders. You don’t have to tell your family story, just get to know people, and offer to help. Over time, you will see how your experience and talents can make a difference.

Another way to become a parent leader in your district is by being elected to School Committee. School Committees have broad responsibilities. These include making district policy, hiring the superintendent, and negotiating district employee contracts. School Committee members who are knowledgeable about special education can make a very real, far-reaching, and positive difference for all families. Since School Committees follow Open Meeting Law, you can learn what they do by attending a meeting, or by watching one on your local cable channel. Get to know your School Committee members and talk to them about issues that are important to you. Get contact information on the district Web site or call the Superintendent’s office. Over time, you may decide to run for school committee. For more information on School Committees, visit the Massachusetts Association of School Committees at www.masc.org.

Finally, the National PTA has written National Standards for Family-School Partnerships, which are available at www.pta.org/topic_getting_involved.asp. These standards provide additional ideas for becoming a parent leader in your district and partner with your school. Children with disabilities need you. Please consider taking steps to become a leader in your school community.

The Federation is currently involved in adapting the National Standards for Family-School Partnerships for Massachusetts. For more information, see www.masspirec.org. For more information about MassPAC, visit www.masspac.org.
It was an ordinary Tuesday evening when I turned on my TV and sat down to watch my new favorite show, Glee, about a fictional high school glee club. The episode took place a few weeks before a competition where the glee club would perform song and dance routines against other high schools. The glee club director, Will Schuester, told Principal Figgins that he needed a wheelchair accessible bus for the competition, as one of the students, Artie, is in a wheelchair. The principal replied that they didn’t have the money in their budget for the bus.

“You can’t do that!” I yelled at the TV. “That’s a violation of the Americans with Disabilities Act (ADA)!”

The glee club paid for the bus by holding a bake sale, along with a donation from cheerleading coach Sue Sylvester. Sue’s charitable nature towards students with disabilities is the one exception to her selfish, narcissistic behavior that has earned her the reputation of TV’s meanest villain. Later in the episode, it is revealed that Sue has a sister with special needs. Even though Artie got the accommodations he needed, I was still upset that the ADA was never mentioned in the episode.

Even though the show is fictional, I realized that Artie’s situation often happens in real life. Many school administrators are unfamiliar with the details of ADA. When students, teachers, and parents see students being denied their rights on a popular TV show, they may believe that such discrimination is normal. They may even be less likely to advocate for the services their children need.

Glee producer Ryan Murphy has said the show is about “inclusion.” Not only is there a character in a wheelchair, but Glee’s cast is also racially and ethnically diverse.

Yet for all the inclusion on Glee, it is clear that they still have a lot to learn about special education. Another aspect of Glee that has caused controversy in the disability community is that the actor who plays Artie does not have a disability; he is former boy band member, and dancer Kevin McHale.

Like many forms of entertainment, Glee is a reflection of the culture in which it takes place.

Just as on television, real life has many administrators like Principal Higgins, who refuse to give students the accommodations they need because of budget constraints. Real life also has unlikely advocates like Sue Sylvester, who support special education because they have a relative with a disability, and teachers like Will Schuester, who go to great lengths to help their students succeed.

Whether your child’s teacher is a Principal Figgins, a Will Schuester, or a Sue Sylvester, one thing is for sure. It is necessary for all to be educated about special education, so that we can help all students reach their potential.

Even the producers of Glee seem to have become more educated. Zack Weinstein, an actor who is in a wheelchair, was a guest star on one episode. Sue’s sister Jean and cheerleader Becky Jackson are played by actors with disabilities.

When I reflect on how far society has come, both to accept and educate children with special needs, I realize that it’s possible to open people’s minds. Now that’s something to sing about!

Learn more about the ADA at the U.S. Department of Justice Web site at www.ada.gov.

The Boston College Campus School is a private, publicly funded, special education day school, for students ages 3-21 with severe multiple disabilities, including complex healthcare needs. Founded in 1970, the school is located on the Boston College Campus in Campion Hall and is an integral part of the Lynch School of Education. While the program employs appropriately credentialed and licensed staff, it benefits from involvement of University student interns.

- Staff/Pupil ratio 1.2
- 11 month, 198 day school year
- Current enrollment 45
- Transdisciplinary team approach for service delivery

The Boston College Campus School is licensed by the Massachusetts Department of Education and is a member of the Massachusetts Association of Chapter 766 Approved Private Schools.

For further information, please contact us:
Phone: 617-552-3460
Email: odonnee@bc.edu
140 Commonwealth Avenue, Campion 197, Chestnut Hill, MA 02467
www.bc.edu/campuschool
“Stay Put” Applies From the Date of Parents’ Rejection, Whether or Not Parents File an Appeal

By Robert Crabtree, Esquire

In a September 2010 decision, the Bureau of Special Education Appeals (BSEA) confirmed that under our state’s regulations, when parents reject a school district’s proposed IEP or finding of no special education needs, a student is immediately entitled to “remain in his or her then current education program and placement” pending the resolution of the dispute, “unless the parents and the school district agree otherwise.” In Re: Uxbridge School District, BSEA #11-1115 (September 1, 2010, Crane), interpreting the regulation found at 603 C.M.R. 28.08(7). This right applies, said the hearing officer, regardless whether or when a parent files a request for hearing at the BSEA. In this respect Massachusetts students enjoy a higher level of protection than is generally applied under IDEA, where stay put rights are typically interpreted as applying only if parents eventually initiate a due process appeal.

Uxbridge is consistent with earlier BSEA decisions, including most recently, Charles S. & Triton Public Schools, BSEA#07-0082 (October 13, 2006, Sherwood), where the hearing officer also held that stay put applies as soon as there is a dispute without regard to whether an appeal is filed. Interpreting the Massachusetts right as more expansive than the stay put right under IDEA alone, both hearing officers applied the rule that a state standard that is more protective of students with disabilities than IDEA by itself will supplant the lower federal standard and be enforced as if part of the federal law. David D. v Dartmouth School Committee, 775 F.2d 411 (1st Cir. 1985).

Each of these decisions dealt with parents’ rejections of their districts’ determinations that the students in question were no longer eligible for special education. This is especially important since the Department of Elementary and Secondary Education (DESE) posted an advisory memorandum in 2001 asserting that in the case of a rejected finding of ineligibility for special services parents would have to initiate a BSEA proceeding in order to have stay put rights apply. (See, http://www.doe.mass.edu/sped/advisories/01_4.html.)

As noted in Uxbridge, “The DESE advisory does not provide any analysis or explanation” of its position, “nor does the advisory reference or discuss state or federal stay put regulations or statute.”

“Accordingly,” the hearing officer said, “it is not possible to consider these statements contained within the advisory as having any persuasive authority.” Parents whose districts refer to the DESE’s 2001 advisory memorandum on findings of ineligibility should keep the Uxbridge and Triton decisions in mind in defense of their stay put rights.

These cases remind us that parents and advocates need to stay alert to defend against efforts that are occasionally made to reduce students’ rights under Massachusetts law. Not too long ago, for example, DESE proposed regulatory changes that would have limited the stay put right by requiring parents to initiate BSEA proceedings within a fixed number of days, without which a district would be free to implement whatever proposed plan or finding had been rejected. Those draft regulation changes, proposed in 2001, were withdrawn following a well organized protest by parents and advocates.

Awareness to Action: Celebrating 10 Years of Inclusive Schools

This year marks the 10th anniversary of Inclusive Schools Week, an annual event hosted by the Inclusive Schools Network at the Education Development Center, Inc. This year’s event will be celebrated from December 6-10, 2010.

This week is not only a time to mark progress made in providing quality education to the diverse student population, it is also a time for teachers, students and their parents to think about ways to continually work towards improving education for all students.

Read more about the history of Inclusive Schools Week, get ideas for marking the occasion in your community, and download free celebration and awareness materials at http://www.inclusiveschools.org/week2010.

Once again, the Federation is proud to be a partner organization in these efforts and is the official on-line store for purchasing celebration kits and other merchandise. Visit https://fcsn.org/inclusiveschools/orderform.html.
Our children who use assistive technology (AT) and durable medical equipment (DME) grow too quickly! The time and energy we spent getting their needed AT and medical equipment is too dear to let outgrown equipment sit idle in a closet. Whether it’s paid by the school, private insurance, MassHealth or out-of-pocket, there are ways to donate, exchange or sell gently used AT so that other children locally, or across the world, may benefit.

You need to determine who and how the equipment was purchased. If it was purchased by your public school system, they own it and it should be returned to them for use by another child. To help schools maximize their investment in equipment, the Massachusetts Rehabilitation Commission (MRC) is rolling out their AT School Swap Program to help school districts inventory and exchange their unused AT.

If the equipment was purchased by private health insurance, call your provider to see if they have regulations around returning or recycling.

If the equipment is yours to pass on, here are some options and organizations around New England that recycle, receive or sell used AT and DME. See the list below for contact information.

Donate it: There are several non-profit organizations that take and refurbish your used medical equipment such as walkers, wheelchairs, bath chairs, positioning seating etc. Some groups will refurbish equipment to be delivered to children in impoverished communities where access to equipment is difficult. Organizations such as New England Assistive Technology Marketplace (NEAT) and Pass It On have warehouses of refurbished equipment that they sell for reasonable prices. Be sure to get a receipt as donating equipment is a tax deduction on your federal tax return! You can of course always donate your items privately to a family or school.

TIP: Be sure to ask if there is a delivery or transportation charge for pick up at your home.

Sell it: There are several local and national resources for listing medical equipment for sale. Interested buyers can contact you by email and hopefully come to check it out. MRC’s GetATStuff.com is a free online classified service where you can sell or buy used equipment to help with vision, hearing, daily living, mobility, communication, recreation and more. Both NEAT and GetATStuff.com offer online inventories of available items by category. Some resources, like GetATStuff.com allow users to receive email alerts when equipment they need becomes available. Items such as adapted strollers go fast!

TIP: Like any online auction or classified system, decide in advance what forms of payment you will accept. Set up a PayPal account or specify cash only if selling locally.

Whether you donate or sell your no-longer needed equipment, you will feel good that you have helped another child here in Massachusetts or across the ocean. Plus you’ll have a newly vacant spot in your attic or basement!

Places to donate and purchase used medical equipment:
- Assistive Technology Exchange in New England: www.getATstuff.com
- AT School Swap Program: www.massmatch.org/school_swap/login.php
- Home Sweet Home Program: www.stavros.org/home_sweet_home.html
- Pass It On Inc.: 508-477-6966
- Southeast Center for Independent Living: www.secil.org/docs/uredp.html
- Wheelchair Recycler: www.wheelchairrecycler.org

Services for finding/selling used equipment:
- Abledata Classifieds: www.abledata.com/abledata.cfm?pageid=91185&ksectionid=19328
- Alpha One Classifieds: www.alpha-one.org/classified_ads.htm
- Assistive Technology Exchange in New England: www.getATstuff.com
- Disabled Dealer (national): www.disableddealer.com
- Ebay (national): www.ebay.com category: Medical, Mobility, Disability
- Equipment Exchange Yahoo Group: SpecialChildExchange@yahoogroups.com
- Freecycle (find a local group): www.freecycle.org
- Pass It On Center (national): www.passitoncenter.org

Donate internationally:
- Chariots of Hope: www.chariotsofhope.org
- International Medical Equipment Collaborative: www.imecamerica.org

Randi is the parent of a child with cerebral palsy who relies on assistive technology for mobility, communication and daily living. Randi is also a member of the MassMATCH AT Advisory Committee, and the Federation’s Board of Directors. Learn more about MassMATCH at www.massmatch.org.
Knowing Jesse: A Mother’s Story of Grief, Grace, and Everyday Bliss
By Marianne Leone. Simon & Schuster. 2010

When Marianne Leone was pregnant, she went for pre-natal care, was careful about her diet, and took care of herself. However, even though she attended to her own health and the health of her unborn child, Jesse was born 10 weeks premature. Complications after his birth caused cerebral palsy. Jesse could not use his arms or legs, was non-verbal, and experienced daily, uncontrollable seizures.

Despite his physical challenges, Jesse was a personable child who loved to travel, swim, wind surf, and make friends. He was also a straight A student and a poet. When he was 17 years old, he died in his sleep. Knowing Jesse is the story of his mother’s quest to find the right doctors, the right school, and the right services and supports so her son could accomplish his dream of going to school with his peers and having the opportunity to learn the same things they were learning.

In this moving tribute to her son, Marianne relates her struggles and successes in securing the services Jesse needed to participate in daily life as much like other kids his age as possible. Additionally, she underscores the importance of the parent-to-parent connection, and having a mentor — someone who really understands your life, who offers advice and guidance when you feel lost, and who helps you develop the advocacy skills to get the services your child needs to be successful.

Seeing is Believing: Video self-modeling for people with autism and other developmental disabilities

Video self-modeling or VSM is an instruction method for children with autism spectrum disorders and other developmental disabilities. The VSM method is based on years of research by the author and others to show the effectiveness of having a child be his or her own model for positive behaviors. The child is filmed while engaging in the desired behavior or performing a specific task. These videos are played back for the child when he or she is acting inappropriately. The video not only shows the acceptable behavior, but also shows the child that he or she can do it!

Dr. Buggey’s research also showed VSM was a way to help overcome situations when children would successfully complete tasks or use language for a therapist, but would not ‘perform’ for anyone else in any other setting. The use of VSM was a way to prompt and reinforce desired behaviors in other settings, such as at home, in school and other places in the community. VSM can also be used to help children learn academic skills, like math and reading.

The goal of this book is to provide a how-to manual for parents, teachers, therapists and others who want to try VSM. There is guidance about use of video cameras and editing. Case studies highlight the use of VSM for teaching a variety of skills and behaviors in different settings.

The Autism Transition Guide: Planning the journey from school to adult life

Using an individualized, child-driven approach that focuses on an individual’s interests, abilities, and needs, this book provides a framework to help families with 14 – 20 year old children with autism spectrum disorders transition to adult life. The authors, both with extensive experience working with children with autism and their families, explain the laws that protect their children’s rights, and that provide the backdrop for the choices they and their children will make about guardianship, post-secondary education opportunities, living situations, work and more. There are vignettes that illustrate each step in the process. The appendices include transition planning tools, and resources.
STOP That Seemingly Senseless Behavior! FBA-based interventions for people with autism
By Beth A. Glasberg, Ph.D., BCBA. Woodbine House 2008. 154 pp

Individuals with autism may exhibit behaviors that don’t make sense to others. Some make funny faces in response to questions, hand flap, or talk endlessly about a single topic of interest. Other behaviors, like head banging, biting and hitting are dangerous not only to the individual but also to others. This book provides an overview of functional behavior assessments and how to use the information to create behavioral health plans to stop senseless behaviors, while reinforcing more acceptable ones.

Included in the book are charts readers can use to help figure out the activities and situations that elicit different behaviors and what they mean. For example, some behaviors are to get attention; or to avoid tasks the individual is asked to do, like homework. Other behaviors are to get access to preferred materials, like a favorite food or book. Successive chapters provide guidance, for parents and professionals, to help them figure out what each behavior means, and ideas for introducing a new behavior or skill to replace a less desirable or dangerous behavior. In addition, there are examples of ways to reinforce the new behaviors and skills. Of particular use is the chapter about strategies for preventing challenging behaviors, ideas any parent or teacher might use to diffuse a difficult situation and redirect a child’s attention.

The appendices include sample checklists that may be used to enhance communication between home and school, as well as sample behavior plans.

Activity Schedules for Children with Autism. Teaching independent behavior

Whether we use a date book, PDA (Personal Digital Assistant), write out daily ‘to-do’ lists or use other organizational tools, we all need occasional prompts to make sure we get to appointments on time, remember to order and pick up prescription refills, and do the laundry.

Some individuals with autism need even more prompting to remember to accomplish daily tasks like brushing teeth, making the bed, doing homework, or to break down the steps to bake a cake independently.

The use of activity schedules to teach individuals with autism to complete tasks independently is based on research conducted at the Princeton Child Development Institute. The authors provide step-by-step guidance and examples for creating and teaching activity schedules for children, adolescents, and adults with autism.

Gravity Pulls You In: Perspectives on Parenting Children on the Autism Spectrum

John Elder Robison wrote the foreword for this powerfully intimate collection of poems and essays written by parents of children with autism spectrum disorders. Mr. Robison was not diagnosed with Asperger’s syndrome until mid-life. As a kid, he shared how frustrated, and at times angry, he would get by the things he couldn’t do. However, unlike parents who are aware of the implications of their children’s diagnoses, he never experienced a “sense of loss,” as he was unaware of his “limitations.”

In this book, mothers and fathers express their own frustrations, grief, and fears, as well as appreciation of their children’s gifts, and share glimpses of the lives they’ve created with and for their children.
SAVE-THE-DATE

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

**Visions of Community 2011**
Seaport World Trade Center • Boston, MA
Saturday, March 12, 2011
Informing, Educating, & Empowering Families and the Professionals Who Serve Them.
7:30 am - 5:00 pm

**Gala 2011**
Seaport World Trade Center • Boston, MA
Friday, May 13, 2011
Annual Celebration
6:00 pm - 10:00 pm