

Disability Issues

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Youth Leadership Emerging in Massachusetts

By Joe Bellil

Where are tomorrow's leaders? Who are the young men and women with disabilities who will one day lead the way in education, business and government and serve as advocates for disability rights?

They're all around us. These teens and young adults with disabilities have grown up with the ADA, are technologically savvy and skilled in using social media. They want to go to college and go to work – and to see a better world.

Easter Seals is one of a growing number of organizations nationwide that are working to identify potential young leaders with disabilities and train them for their future roles.

Largely mainstreamed in school, these future leaders need the opportunity to connect with other youths with

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Horseback Riding for Body and Spirit

By Linda Long-Bellil

A terrific outdoor activity that can be enjoyed in the summer and year round is horseback riding. There are several riding stables in Massachusetts that offer horseback riding for children and adults with disabilities or special



Photo: Courtesy of www.narha.org

abilities. Lovelane provides weekly riding lessons to about 110 young people age 16 and younger. Owner Debbie Sabin started the program about 20 years ago with a borrowed stable and borrowed horses and now has several horses of her own with instructors who are licensed as both therapeutic and Massachusetts riding instructors. Ms. Sabin notes that horseback riding has many benefits such as normalizing tone and helping to maintain attention in a way that is "much more motivating than sitting in a therapy room doing exercises." Children find the experience empowering and instructors find the work

needs. This type of horseback riding is often described as "therapeutic horseback riding." The lessons are considered therapeutic because they are offered as part of an occupational, physical or speech therapy program. Therapeutic riding combines these activities with the fun of riding a horse.

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One such stable is Lovelane Special Needs Riding Program in Lincoln, MA. Lovelane offers therapeutic riding lessons to children with a wide variety of physical, cognitive and intellectual dis-



Photo: Courtesy of Lovelane

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Youth Leadership Emerging in Massachusetts

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disabilities and to work with peer leaders who are succeeding in school and on the job.

They also need information about the resources available to them as they make the transition from high school to higher education and work.

In Massachusetts, a group of young men and women with disabilities known as **Act Today Influence Tomorrow** (ATIT) was organized in 2008 by Easter Seals and the Boston Center for Independent Living. Their first project was to create a video detailing barriers they had encountered when trying to use the MBTA bus and subway service in the Boston area.

They presented the video to senior MBTA officials, who agreed to address the problems. Several of the youths became MBTA monitors to help ensure that the work was carried out.

In 2009 ATIT began a move to include disability history and awareness in school curricula throughout Massachusetts. First, they learned how a bill becomes a law and researched similar programs in other states.

Next, they worked with then-State Sen. Steven A. Tolman and his staff to draft the measure. The bill, designating October as *Disability History Month*, urged cities, towns, public schools and colleges to establish programs to increase the awareness and understanding of the contributions made by people with disabilities.

The youth leaders enlisted the support of other disability organizations, lobbied for the bill and testified at a public hearing. Thanks to their hard work, the measure was passed by both houses and signed by Governor Deval Patrick on August 26, 2009.

The following year marked the launch of another youth leadership initiative – the *Massachusetts Youth Leadership Forum*.

This annual event helps students in their final two years of high school make the transition to higher education or work and provides them with resources that will be useful to them as adults.

“When I was wearing my YLF t-shirt with everyone else, it made me feel like a leader for people with disabilities – fighting for change.”

- Derek Joyce

To be accepted as delegates or peer leaders for the multi-day forum, held at Bridgewater State University, students must submit detailed applications and undergo a rigorous interview process.

The delegates and peer leaders attend workshops and discussions on a wide range of subjects, including assistive technology, independent living, employment, college and higher education, advocacy, the disability rights movement and community leadership. The peer leaders, who are either working or in college, help in the planning

process, act as mentors and assist the delegates.

The experience has been life-changing for many participants. “When I was wearing my YLF t-shirt with everyone else, it made me feel like a leader for people with disabilities – fighting for change,” delegate Derek Joyce said. “I could see myself and others 20 years in the future – a strong and powerful team. We would be taking the place of the disability leaders we met at YLF.”

The forums were organized by **Easter Seals** in collaboration with the **Boston Center for Independent Living**, **Partners for Youth with Disabilities** and the **Center for Human Development**. Funding was provided by the Massachusetts Rehabilitation Commission.

The next phase of youth leadership development is the year-round *Youth Leadership Network*, which will offer transition-age youths with disabilities additional opportunities to gain a greater sense of empowerment and connections.

They will learn about leadership by participating in projects to advance the disability rights movement and learn to lead by example.

Through this and the other youth leadership programs, we are developing the next generation of educators, advocates, civic leaders and catalysts for change. We are giving them the opportunity to develop the skills they need – to match their determination to change the world.

Joe Bellil is the VP of Public Affairs at Easter Seals Massachusetts. Photos courtesy of Joe Bellil



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From the Editor

Transition is in the air at *Disability Issues*. As our readers know, Work Without Limits, through the MI-CEO grant, has been a key sponsor of *Disability Issues* over the past several years. Due to the ending of the federal funding for the MI-CEO grant, Work Without Limits has had to end their sponsorship for *Disability Issues*. Although the funding for the MI-CEO grant is ending, Work Without Limits is not! They continue to be an informative and essential resource in the disability community. Please continue to visit them at www.workwithoutlimits.org.

On behalf of myself, and our readers, we bid a fond farewell to Work Without Limits as a sponsor and extend a hearty "Thank you!" for your dedicated leadership. In response to this transition, I am delighted to share that our second co-sponsor, Spaulding Rehabilitation Hospital, has generously expanded their support of *Disability Issues*. With their commitment, this long-standing newsletter continues to be published.

In this summer issue, we have an article about the benefits of participating in an adaptive horseback riding program. My mom signed me up for horseback riding lessons when I was a young teen and I loved it! A highlight of my teen years was the time I spent at the barn with the horses and becoming friends with the other riders.

You'll hear what Easter Seals is doing to develop youth with disabilities to become our next generation of leaders and advocates. These youth are standing on the shoulders of the many disability advocates who fought, and are still speaking out, to secure equal opportunities and access for people with disabilities. Great strides for accessibility are being made in a surprising place – at Science Fiction Conventions! These conventions model what's possible when organizations have a commitment to inclusivity for all.

Finally, you'll hear personal reflections from two individuals with disabilities who speak about social interactions and attitudes that people with disabilities often encounter in daily life. Their stories remind me of a button I picked up at an event last year, "Attitudes are the Real Disability."

Marianne DiBlasi, Editor



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To view *Disability Issues* on-line go to
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Disability Access at Boston's Science Fiction Conventions

By A. Joseph Ross

Long before there were Star Trek conventions, there were science fiction conventions, which date back to the 1930s. There are two held regularly in Boston every winter. I attended **Arisia**, New England's largest and most diverse Science Fiction and Fantasy Convention, over the Martin Luther King Day weekend in January 2012 at Boston's Weston Waterfront Hotel. Arisia 2013 will be held at the same hotel January 18-21, 2013.

Since I have been disabled in recent years due to back pain, I have paid some attention to the accommodations for disabled people at these conventions. At Arisia this year, I noticed signs in the hallway asking people not to pet or otherwise distract working animals unless invited to do so by their owners. There have always been some people in wheelchairs, and occasionally at conventions in recent years, I've seen attendees in scooters. I had always assumed they were available only to hotel guests, which large numbers of convention attendees are not. But I see from the Arisia website that they are available to all attendees and the cost was generally \$50 a day.

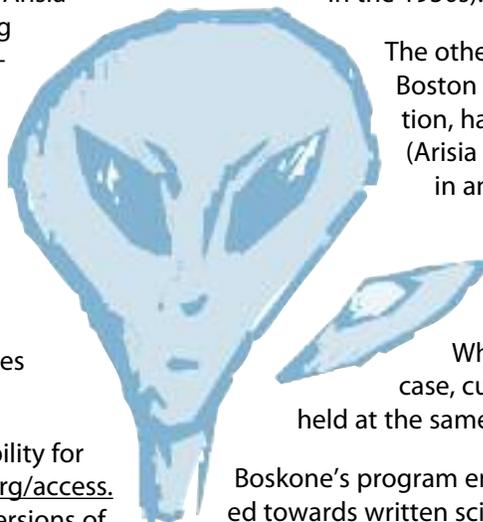
Arisia has a lot of information about accessibility for the disabled on their website w.2013.arisia.org/access. The services include braille and large print versions of the program schedule, hearing assistance transmitter/receiver sets, and tactile tours. The convention allows people with disabilities to bring a physical assistant with them, without charging extra, provided the assistant never leaves the side of the disabled person. Assistants who want, at times, to explore the convention on their own must purchase a paid membership.

In addition, there was a panel this year on "Disabilities in Science Fiction." on which I was a panelist. I think most of the audience had disabilities of one kind or another, and the first half of the panel's allotted 75 minutes was spent with people introducing themselves and talking about their disabilities. After that, the panel turned to how disabilities are depicted in science fiction stories. At one point the discussion veered off onto how disabled characters are treated on television. No conclusions, but some interesting discussion.

While Arisia is a science fiction convention, panel topics vary far and wide, from discussions about particular science fiction authors, comic books, movies, or topics to some

very eclectic subjects, including legal issues (I moderated a panel on Forensic Evidence in the Courts this year), alternative lifestyles, and just interesting topics. A couple of years ago I moderated a really fun panel on *Mad Magazine*, bringing together people of various ages who had their love for this wonderful magazine in common.

There is also a costume competition, gaming, and "filking." Filkers are devoted to the folk songs of the science fiction community and get together to sing them (the word "filk" originated from a typo in a convention program book in the 1950s).



The other major science fiction convention in Boston is **Boskone**. This is an older convention, having been around since the 1960s (Arisia started in the 1990s). It is also older in another sense: While there are people of all ages at both conventions, the average age of Boskone's attendees is older. Boskone is held over President's Day weekend. While this has not always been the case, currently both conventions are held at the same hotel.

Boskone's program emphasis is different. It is more oriented towards written science fiction, science panels, author readings, and the history and customs of the science fiction fan community. There is no costume competition, but there is filking, as well as special events, sometimes including a play.

Both conventions take their names from the "Lensman" novels of E.E. Smith, written in the 1930s and 40s and are run entirely by volunteers.

Boskone has no specific information on their website about disability access, though I have seen wheelchairs, scooters, and service dogs. As a member of Boskone's parent organization, I intend to advocate for better disability information and services in the future.

**Boskone's website is www.boskone.org
Arisia's website is www.2013.arisia.org**

Joe Ross is an attorney practicing in Boston. He has been attending science fiction conventions since the 1960s and is a longtime member of the New England Science Fiction Association (NESFA), which puts on Boskone, and is past president of Arisia's parent organization, Arisia, Inc.

Cumulative Effect

by Barbara Ceconi

Dressed for work, I am rapidly walking down the street with my guide dog, on my way to facilitate a training session. I worry, as always, that the mass transit will be late. While walking, I am deep in thought on the subject matter of the day's session.

Suddenly a man stops me. "Do you know where you are?" he asks.

I jerk myself from my thoughts, momentarily confused by the sudden interruption. Of course I know where I am and where I am going. What sort of question is that? Stunned, I look at my dog and respond, "Toto, we're not in Kansas anymore?" I walk away shaking my head, annoyed by the interruption.

I run into a convenience store to buy some mints. The clerk rings up a few orders and I hear no one else in line. "Could you get me some wintergreen Tic Tacks please?" I query. "On the left," he responds, apparently not looking up. The boxes are recognizable by shape, but not the flavors. I ask him again, explaining that I am blind. With a surprised, "Oh," he leans over the counter and grabs a pack for me.

I am nearly at the subway station. Without a word, someone grabs my arm and drags me across the street. I struggle to pull my arm away from this stranger. "What are you doing?" I sputter. "I was just trying to help. Sorry." The person walks away. Since the experience was disorienting on several levels, I now have no idea what corner I have been deposited on. I ask a passerby where I am. "On the corner of Harvard and Beacon," answers someone. It's a four-way intersection, so that doesn't situate me. I wait for someone else to pass. "Excuse me, what store am I in front of?" No response. Wait for the next person. "Can you tell me where the bank is?" hoping for information so that I can puzzle out my position. I feel frustrated and angry that others think they know what I need better than me.

After I receive the direction, I walk, reoriented, towards the subway stop. Once aboard, a pleasant woman offers me her seat. I respond with a curt, "No."

My response was sharp and out of line. After the string of incidents, I am in no mood to be gracious. This well-intentioned woman, must have been shocked by the hostile intonation of my voice, and justifiably so. Others near her could have been as well. Interactions like these can cause people to jump to the conclusion that people who are disabled are angry. Normally, I would have thanked the woman and smiled. I snapped at her because of the accumulated frustration I experienced during my brief walk. And those emotions landed on her. This is known as cumulative effect.

Cumulative effect occurs frequently with people who are discounted over and over again. Unfortunately, the individual who experiences such recurring incidents draws a conclusion: it is due to my difference, in my case, my blindness.

Cumulative effect occurs frequently with people who are discounted over and over again. Unfortunately, the individual who experiences such recurring incidents draws a conclusion: it is due to my difference, in my case, my blindness.

Barbara Ceconi is currently the principal of Ceconi Consulting Group and a founding partner of Access Umbrella, Inc., an accessibility and diversity, consulting firm. She has worked extensively with for-profit and non-profit organizations, as well as the medical professions. She assists organizations in exploring issues of disability and diversity among employees and customers.



Barbara Ceconi

Information Briefs

Learn to Fly: Wheels to Wings

Wheels to Wings is a flight training program for people with physical disabilities.



Why Learn to fly? "Flying takes you to a different world with new perspectives. You start

thinking of your world from above and your senses are in tune to the world of flight. You are no longer limited by your cares, concerns and duties on the ground. Flying will allow you to conquer new exciting challenges. It changes how you perceive yourself and what you know you can accomplish. Become a pilot and become transformed!" - The Experimental Aviation Association Sport Pilot License

Northampton Airport's Light Sport aircraft has a large cabin. Its extra wide cabin doors and 2-way adjustable seats make for easy entrance and comfortable experience. The ergonomic arrangement of the controls and instruments, plus the aircraft has terrific visibility! *Design Technik* is currently making custom parts for hands-only control, making the aircraft adaptable for people who don't have use of their legs.

For more information, call 413-584-7980

or visit www.Fly7B2.com.

You'll find Wheels to Wings under Programs.

Robots and Beyond: Exploring Artificial Intelligence at MIT

Robots and Beyond shares the results of decades of Artificial Intelligence innovation at MIT. You're invited to explore the ideas that shaped the way Artificial Intelligence and the birth of robotics are synonymous with research at MIT.



Robots and Beyond give you a behind-the-scenes look at the inventive concepts and processes that lead MIT's Artificial Intelligence labs to great contributions in many areas including medicine, underwater exploration, and entertainment.

You'll learn about tele-operated surgical robots, robotic legs, and socially intelligent humanoid robots that interact with their environments in human-like ways. You'll see prototypes and other media that trace the evolution of some of MIT's resident robots, including Kismet, Cog, and RoboTuna.

This permanent exhibit is on display at MIT's Museum-Building N51, 265 Massachusetts Ave, Cambridge MA.

Open daily 10am-5pm.

For more information, call 617-253-5927 or visit www.web.mit.edu/museum/exhibitions/robots.html

Adaptive Sports and Recreation Programs from Cape Ann to Cape Cod



Photo courtesy of www.spauldingnetwork.org

Spaulding's Adaptive Sports program offers adaptive sports and recreation activities in Boston, Cape Cod and the North Shore. Whether it is wheelchair tennis, hand cycling, adaptive rowing, waterskiing or windsurfing, those living with disabilities after illness or injury can try a new sport or get back to one you have always loved.

The Spaulding Rehabilitation Network is dedicated to enabling individuals of all abilities to lead active, healthy lifestyles. Participation in sports and recreational pursuits helps to make this possible.

For more information, contact Katelynne Steinke at 877-976-7272, Ksteinke@partners.org or visit www.spauldingnetwork.org Adaptive Sports is under Programs & Services/Inpatient Services

Information Briefs

The Life is Good Festival 2012

The Life is Good Festival is a one-of-a-kind fundraiser held at Prowse Farm in Canton, MA on September 23 & 24. 100% of the profits from the event will go towards the Life is good Playmakers, helping kids overcome poverty, violence and illness.

This two-day celebration of music and optimism features three stages of nationally known musical talent, hands-on games, interactive arts activities, and the "Good Kids" zone — home to the top acts in kids entertainment. Whether you want to compete in the seed spitting contest, have a picnic, watch the BMX bike stunt show, contribute to a mural, climb a rock wall, or hang out at the kids stage on a comfy bean bag chair, there is something for everyone!

In past years, the festival has provided excellent accessibility for folks with disabilities including; raised access platforms for people who want to enjoy the music, a roped off section in front of each stage, ASL interpreters, and even a section of the lawn marked off for guide dogs to use the restroom!



For more information about the Festival, visit www.lifeisgood.com/festival

The Advocacy Corner

Disability Is

by Kate Ryan

Disability is.

It just is.

It is neither a blessing nor a curse.

It is not fiction; it is not imaginary, it exists in ways we can see and we cannot see.

Disability is not a curse from God or punishment for your sins or your past life. You do not have a disability because you or some deity chose you to learn a lesson through it.

Disability is doing what you can, with what you have. It is accepting your limits and pushing your boundaries.

Disability is not a tragedy. It does not need prayers or candles or sorrowful glances.

Disability does not need pity. Disability needs action.

Disability is not because you did not work hard enough or try enough, or because you unconsciously sabotaged yourself from achieving your goal.

Disability is not because you did not try this or that treatment, cure, or ritual.

Disability is in spite of thousands of years of people trying to rid the world of it and of people with disabilities.

Disability is you, and it is not you. It is of you and about you. It is inherent within you and totally without you.

Disability is happiness and sorrow, and taking joy in things ordinary and extraordinary.

Disability is a warm, caring community with a slightly warped sense of humor.

Disability is finding bodily fluids to be very, very funny.

Disability is, and it isn't, and nobody can define it but you.

Kate Ryan has worked in various capacities in the disability field for years.

She has a Master's degree from Lesley University in Interdisciplinary Studies/Disability Advocacy.

Her specialty is recreation for children with special needs.



Horseback Riding for Body and Spirit - Continued from page 1



rewarding because “the joy and motivation of the children is contagious.” Ms. Sabin is always working to recruit physical, occupational and speech therapists to this exciting work.

Therapeutic riding can be a rewarding experience for all involved. To find a therapeutic horseback riding association in your area, just visit the website of the North American Riding for the Handicapped Association (NARHA) at www.narha.org.

Linda Long-Bellil is a Project Director in the Center for Health and Policy Research at the University of Massachusetts Medical School.

Another local stable that provides therapeutic riding both to children and adults is Equine Partners in Hopkinton, Massachusetts. Started in 2008, Equine Partners offers a variety of programs including equine assisted psychotherapy with a licensed therapist and/or certified equine specialist certified by North American Riding for the Handicapped Association (NAHRA).

According to co-owner Elizabeth Timlege, horses can be helpful in facilitating psychotherapy in a variety of ways, including their ability to reflect what is going on with the person.



Photos this page courtesy of www.narha.org