

Disability Issues

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Passing of a Disability Rights Champion

By Bill Henning

Sybil Feldman died Thanksgiving Eve, November 21, of major respiratory complications that developed after a struggle with pneumonia. A number of close friends were with her at her bedside at Boston Medical Center when she passed. She was 72 years old.

Sybil fought for disability justice; a woman with cerebral palsy who as a child was sent to the Fernald School, an institution for people with disabilities known for human rights abuses and not providing positive education. Sybil fought to get out and could always recite down to the day how long she was there, which was just over 21 years. She said unflinchingly she hated every second of it. Ultimately

Continued on page 8

Accessibility: The Beauty and the Beast

By Sandy Alissa Novack

"The directions are clear enough", I told the man in the wheelchair. **"Enter through the door in front of you and keep traveling until you find the ramp. When you reach the top, go through the door and there will be another ramp which will lead you to the other side of the exhibit."** He nodded in agreement, and manually pushed himself in his wheelchair to the entrance door and then, as the phrase goes, **"all hell broke loose."**



It was November 2012 and we were at the Boston Convention and Exhibition Center for the Architecture Boston Expo (ABX), sponsored by the Boston Society of Architects (BSA). ABX is one of the largest events for the design and construction industry in the country. The BSA had its own interactive exhibit in the exhibition hall, revealing some of the details involved in making spaces truly accessible. The exhibit was designed to provide people with an interactive, direct experience of what a person with various disabilities experiences when a building is "almost accessible" and "fully accessible".

Expo attendees were encouraged to navigate through the interactive exhibit with a wide range of mobility and vision impairment simulation devices. There were multiple types of wheelchairs, walkers, crutches, and canes. Architects and people like myself with a disability assisted visitors through the exhibit. Our role was to ensure that our charges were safe while explaining design distinctions that are, and are not, accessibility friendly.

So why did all hell break loose - not just once, but over and over again? Because we were billed as the Universal Access Exhibit and people were expecting everything to be, well, accessible. After all, we had ramps didn't we? Oh, you say you can't propel yourself up the ramp because it is too steep? And why in the world do we have a plush carpet as well as aesthetically



Continued on page 2

Inside This Issue

Passing of a Disability Rights Champion.....	1	A Disability History of the United States.....	5
Accessibility: The Beauty and the Beast	1	Information Briefs.....	6
From the Editor	3	Workplace Corner: Believing is Seeing.....	7
Mentoring for LGBT Youth with Disabilities.....	4		

pebbled material on the floors that people using wheelchairs and walkers struggle to balance and move forward on? You can't grasp onto the excessively wide handrail, and why did our handrail just abruptly end when you still needed it to help you move a few yards further? Why?...Oh...Ah!



One by one I could almost see light bulbs go off in the heads of visitors, as they realized through the experience of only a few minutes what people who live day in and day out with disabilities or limited mobility due to aging already know - when it comes to accessibility, details matter. A building can, on paper, claim it has accessible features, but does it really?

There were round doorknobs that a person with bundles or someone with an arthritic hand couldn't turn. There were the two sets of doors that people kept getting trapped between because there was no room to navigate a baby stroller, laundry cart, or wheelchair when one set of doors had closed, leaving you with no ability to open the second set of doors. There were straight edge door thresholds that served as stumbling blocks or blockades for people using mobility devices.

My visitor – the man in the wheelchair – finally finished with what I call the *Accessibility Beast* part of the exhibit. I guided him to the other side, which I fondly refer to as the *Accessibility Beauty* part of the exhibit where there are beveled entry thresholds to get over and easy glide flooring. Where the handrails are at an accessible height and extended to more practical end points. The ramp incline is appropriate and the doors have levers. My visitor in the wheelchair breathed an audible sigh of relief and exclaimed, "This is an eye-opening experience!" But we weren't done yet. We still had examples of almost-accessible and fully accessible bathrooms and kitchens as well. My visitor gave me a look that said, "You've got to be kidding. There are more situations I have to struggle through?"



We navigated through the Men's Room with signs much too high to read or feel the tactile image. The bathroom had one railing, but was much too small to get in with a wheelchair

and close the door. A person would have to either forego their privacy, or not use the bathroom. A trash receptacle blocked the so-called, accessible sink, and wheelchair and non-wheelchair users would smack their heads on the protruding paper towel dispenser. If you used a wheelchair, you couldn't see your face in the mirror over the sink because the mirror was hung too high.



What a relief it was for visitors, no pun intended, to visit the Ladies' Room, where there was a height appropriate sign, ample room to enter with a baby stroller, or turn in a wheelchair and close the door for privacy. The paper towel dispenser was

recessed into the wall along with the trash receptacle, so no one with vision impairment or in a wheelchair would travel into it. A wheelchair user could roll up to and under the sink, and see themselves in the mirror.

The not quite accessible and more accessible kitchens had provided visitors with additional awareness of how architectural design can increase safety and ease of use. On display also were notification systems, available to alert people to the daily sounds of door knocking, phone ringing, and more. Static height and adjustable tables were displayed side by side for comparison.



Who came? People with and without disabilities stopped by and enthusiastically tried out all the ins and outs of the exhibit to increase their understanding of how when it comes to universal design, the details matter. A couple of professors were seen guiding their architecture and design classes through the exhibit, which holds promise that universal design will be on these students' radar screens as they enter their profession.

Sandy Alissa Novack is on the Editorial Board of "Disability Issues," a Geriatric Social Worker, and a consumer advisor on the Beth Israel Deaconess Medical Center's Universal Access Advisory Council.

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From the Editor

Dear Readers,

It's with great sadness that, we once again share a tribute for a dear friend and passionate disability rights advocate who passed away in November. **Sybil Feldman** advocated for her own right to equal access for independent living, education and employment. And then, devoted her enormous energy and commitment to obtaining those rights and freedoms for all in the disability community. Sybil, you leave a great legacy of activism, friendship and vitality for life. You will be sorely missed.

In the spirit of Sybil's passionate fight for "Access Is a Right, Not a Privilege", we bring you multiple articles and information briefs that address accessibility from various perspectives – architectural design, access to art, and "quiet day" at a local museum.

Beyond physical accessibility, we have two articles that address attitudinal prejudice for two populations within the disability community. The first is an article that discusses stigma as a barrier to hiring people with psychiatric issues. The second is a powerful article sharing the infrequently written about experience of being an LGBT youth with a disability.

Our final perspective on attitudes and accessibility is through two books. We provide you with a review of a book that goes back hundreds of years to look at the history of disability. And, a newly published book, written by a member of our *Disability Issues* editorial board, Mary Grimley-Mason, about women with disabilities who have overcome social, environmental and physical barriers to be a mother and raise their children.

May this issue do Sybil's legacy proud.

Marianne DiBlasi, Editor

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Mentoring for LGBT Youth with Disabilities

By Danya Holtzman and Alex Freeman

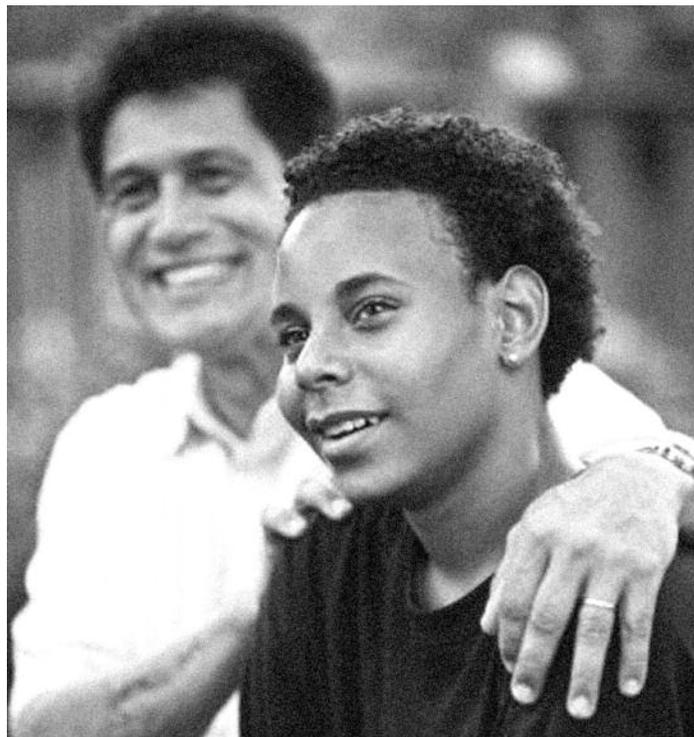
As a dual minority, LGBT youth with disabilities are confronted with a frustrating conundrum: they do not feel fully included in either the LGBT or disability communities, yet they are at an even greater risk for bullying, prejudice, and depression than their single-minority peers.

In fact, these youth can experience prejudice from within their own identity groups. According to one source, "Often... disabled people, including adolescents, are perceived as having no sexual feelings or needs" (Lesbian, Gay, Bisexual and Questioning Youth—Special Populations). Because of the belief that those with disabilities are asexual, many in the heterosexual and LGBT communities discount the sexual identities of youth with disabilities. This results in further alienation of LGBT youth with disabilities, this time from a group they should be able to look to for support.

In addition to all these pressures, youth may encounter challenges integrating their various identities. LGBT youth with disabilities might feel the need to choose between a disability and sexual identity, may feel anxious about identifying with yet another socially stigmatized group, or may not feel fully accepted by those same groups (Lesbian, Gay, Bisexual and Questioning Youth—Special Populations).

This is where Mentoring comes in. While mentoring is beneficial to all youth, it can have a dramatic impact on youth pushed to the margins of society. According to the assistant attorney general, Laurie Robinson, "...through mentoring organizations, youth are provided with programs that help keep them in school, out of trouble, and most importantly, put them in direct contact with caring adults who provide crucial support and guidance."

Mentors can do wonders for a youth's self-esteem and self-confidence, by simply being a friend who accepts them for who they are and believes in their ability to achieve their dreams. A mentor can also help prevent many dangerous and unhealthy behaviors, and can be a good person to go to for advice when other trusted adults are not available. More specifically, youth with disabilities and LGBT youth benefit from many of the same interventions. For example, in the mentor training at Partners for Youth with Disabilities, we discuss ways in which a mentor can help their mentee with disclosure of their disability: picking the right situations, creating and practicing a script, and encouragement through the whole process. This same process can easily be applied to the "coming out" stage in the life of a young LGBT person. Likewise, bullying is a very pressing issue in both communities, so having a trusted adult there for support



and encouragement is even more important for LGBT youth with disabilities.

Each year, society gradually gets more and more accepting of both the LGBT and the disability communities. Hopefully with this growth of acceptance, more attention will be paid to how we can better the lives of these youth that find themselves stuck in the middle.

Danya Holtzman is a recent graduate of the University of North Carolina at Chapel Hill, and she is working at PYD as an AmeriCorps Ambassador of Mentoring.

Alex Freeman is the director of the Young Entrepreneurs Project at PYD, and he is also pursuing a Master's degree in School Psychology at Tufts University.

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A Disability History of the United States

by Kim E. Nielsen

Review by Kate Ryan

Most people in the disability community know about the disability rights movement that began in the late 1960's. Many people today even remember it and were a proud part of it. However, as Kim E. Nielsen points out in her marvelous new book, *A Disability History of the United States*, people with disabilities have lived in this country for much longer than fifty years; they have lived here, in fact, since people first came to this continent.

Nielsen's book is a thoroughly readable, enjoyable history of the United States as seen through the lens of disability. She manages to cover hundreds of years of history and go across lines of class, race, gender and disability to find the common threads linking the members of the disability community together, and acknowledging how disability has evolved and changed over the centuries.

One thing that surprised me greatly was that disability did not always have stigma attached to it. "Physical disability was relatively routine and unremarked upon among colonists unless it resulted in an inability to labor in gender- class-, and racially appropriate ways." (p. 19) Nielsen notes. Indeed, prior to the arrival of Europeans, "disability does not have a history among North American indigenous communities...[they] had no word or concept for what in American English was today call 'disability'." (p.2) Nielsen instead says that many indigenous populations saw people as having many gifts, and being disabled in one area of life did not mean that you did not have gifts in another.

Disability itself cannot be looked at in isolation, for your class, gender, race, and type of disability all have profound implications on how you experience the world. It is very refreshing to read a history that does not assume that all people were white, upper-middle class men, and to have a historian acknowledge that race, class and gender privileges not only affected, but also permeated, the world of disability. For example, non-whites were much more likely to be committed to state mental asylums, and Gallaudet did not have any African-American alumni until 1954. Although she does not have a disability herself, Nielsen does an adept job of giving credit where credit is due, and to acknowledge that the

vast majority of gains Americans with disabilities have made over the years is due directly to their own hard work and persistence. She lauds the ADA while at the same time criticizing it and explaining how it was built on decades of prior legislation.

People with disabilities are a very diverse group, but this book shows how the common struggle for civil rights unites us all, and continues to do so, regardless of our background. We can be proud of our community's past accomplishments, while looking back to see how far we've come, and looking forward to what we have yet to accomplish. *A Disability History of the United States* will help us all to recognize this.

Kate Ryan has a master's degree in interdisciplinary studies with a focus on disability studies. She currently works as a personal care aide while searching for work in the disability field.

A Disability History of the United States, by Kim E. Nielsen; published by Beacon Press, 2012, Boston, MA.

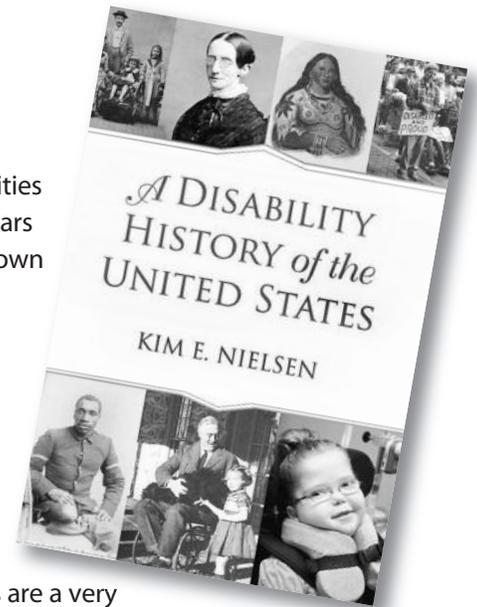


Photo: Yoshiko Dart, Office of Disability Employment Policy Website

Access to Art at the MFA



The Museum of Fine Arts (MFA) in Boston offers multiple programs tailored for people with a wide range of disabilities to enjoy the arts. Access to Art tours are visitor centered, interactive tours designed for groups with disabilities, which may include physical disabilities, cognitive disabilities, people with dementia, or those undergoing medical treatment, among others.

Feeling for Form is a program that provides tours for visitors of all ages who are blind or have low vision. A Feeling for Form is an opportunity for tours of the collections through tactile exploration of selected sculpture and furniture, and through verbal description, tactile graphics, materials and objects for artworks that cannot be touched. Trained Museum volunteers and Access staff lead these tours.

A Hand's Reach to Art provides access to MFA programs and events for visitors who are Deaf or hard of hearing. Throughout the year, a selection of gallery tours, performances, and demonstrations are presented in American Sign Language (ASL) or are sign-language interpreted.

Children and teens with disabilities are served through **Artful Adventures**, an inclusive program at the MFA. For children with autism, **Beyond the Spectrum** offers a specialized experience once a month.

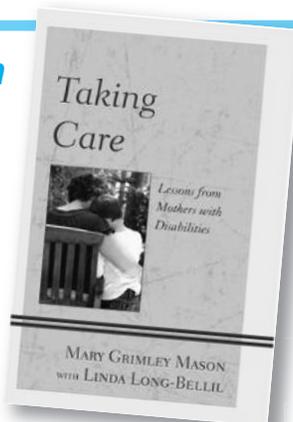
For more information on these programs, visit www.mfa.org/visit/accessibility or contact Hannah Goodwin at 617-369-3189, Valarie Burrows at 617-369-3302, or e-mail access@mfa.org.

Taking Care: Lessons from Mothers with Disabilities

"This is the hardest thing you will ever do," says Melanie, a young disabled mother with cerebral palsy, about raising a child, but she goes on to say that it is fulfilling, joyous and "an amazing gift."

Melanie's voice echoes many mothers with disabilities, who share many issues about parenting with all mothers but who have additional social, environmental and physical barriers to overcome in caring for their children. Despite the special challenges disabled parents face, approximately 8 million adults with disabilities in the United States are parents. The higher percentage are disabled women.

Taking Care: Lessons from Mothers with Disabilities gathers together some of the lessons learned from the experiences of mothers with disabilities. The successes of these women as mothers challenge stereotypes about good mothering. The barriers they encounter show the need for better accommodations from the society in which they live. The book, based on twenty-six interviews and other autobiographical narratives, covers the mothering cycle from



pregnancy and birth to raising a child through young adulthood. These women's stories reveal major themes which have shaped their experience of motherhood and which can offer a significant model for all parents.

Taking Care: Lessons from Mothers with Disabilities by Mary Grimley-Mason with Linda Long-Bellil is available at Amazon.com and BarnesandNoble.com.

Quiet Day at the Charles River Museum of Industry & Innovation

The Charles River Museum of Industry & Innovation, 154 Moody Street, Waltham, MA, hosts **Quiet Day** for children with Sensory Processing Disorder (SPD), which affects a variety of disabilities, on the last Sunday of the month from 10am to 5pm. During **Quiet Day**, the museum will disable any exhibit that produces uncomfortable noise levels, equipment such as sound block headphones, weighted blankets will be offered, and a separate space for reducing stimuli will be available. Admission is \$7.00 per adult and \$5.00 per child, student or senior. Free to children under 6, active and retired US Military, and Museum members. For more information, email: info@crmi.org or call 781-893-5410 or 617-823-5081.

Believing Is Seeing

By Sandy Alissa Novack

Dr. Daniel B. Fisher, M.D., Ph.D. was one of the provocative panelists at the recent National Disability Employment Awareness Month program at Cambridge Public Library, Successful Solutions: New Approaches to Integrating People with Disabilities into the Workplace. Dr. Fisher is described in the Cambridge Commission for Persons with Disabilities and Cambridge Department of Human Service Programs' literature as "A person who has recovered from schizophrenia. He was hospitalized several times prior to becoming a psychiatrist. Dr. Fisher is one of the few psychiatrists in the country who publicly discusses his recovery from mental illness. He is a role model for others who are struggling to recover, and his life dispels the myth that people do not recover from mental illness." It was an evening of telling stories about how to get employment. Dr. Fisher revealed that he himself was diagnosed with schizophrenia in his 20's.

Citing stigma as a barrier to hiring people with psychiatric issues, Dr. Fisher went on to say that "Work can be crucial to restoring a sense of usefulness and dreams, or it can destroy... Disclosure is a tremendous challenge when you are dealing with a mental health issue. Most people with such an issue try to treat first and THEN disclose, so as not to risk stigma... Find your passion, and find a work setting that will allow you to pursue it... It is easy to build physical ramps, but it is hard to build attitudinal ramps. It is important to have flexible scheduling to help with being successful in employment, and flexible scheduling helps those without disabilities, too!"

Members of the audience seemed to very much appreciate Dr. Fisher sharing his experiences, and asked questions of him regarding being out of work due to a psychiatric disability. "Sometimes you have to be creative on your resume as to why you are not working, such as you are volunteering or taking a course... You need someone to speak up for you, preferably not your therapist, so be careful who you pick for references. You don't want your reference to say 'He did well, especially considering his mental illness'... Put your positives forward first, what you are able to do. Then you can say you need time off to go to therapy. You need to get to know your supervisor (and vice versa) so they see how

going to therapy could be helpful."

On how to handle an audience question about a more prolonged gap in work history, Dr. Fisher stated, "List what you learned, and what you did. You have to rely more on people speaking up for you in a reference. Lots of people have ups and downs, but show willingness and that you really care about a job, and how you are in line with their mission. Everyone is flattered if you know something about their business, so do your research before you talk to people. People have egos, and you need to play them... How to change peoples' attitudes toward disabilities? Show business that people with a variety of disabilities can work. Maybe we need in-service on this."

...when it comes to offering people with disabilities an opportunity in the workplace, maybe it is an attitude of first believing...

We often hear the phrase "seeing is believing", but it seems that when it comes to offering people with disabilities an opportunity in the workplace, maybe it is an attitude of first believing that leads to then seeing a way to make a job work for employees with disabilities and employers.

Sandy Alissa Novack is on the Editorial Board of "Disability Issues", a Geriatric Social Worker, and a consumer advisor on the Beth Israel Deaconess Medical Center's Universal Access Advisory Council.



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she lived in her own apartment with the support of personal care attendants, developing many friendships and carving out a strong niche as an advocate for independent living, Olmstead compliance, and the dignity and rights of people with disabilities.

A fixture at disability events in Boston for decades, during the 1990s Sybil became an activist with ADAPT, protesting national policies that steered funding to institutional care instead of community-based services. Tagged "Sybil Disobedience" by the late disability author and advocate Laura Hershey, she engaged in direct-action protests in locations such as the U.S. Capitol, San Francisco, Atlanta, Nashville, Chicago, Baltimore, and Orlando. She was arrested an estimated six times in actions that helped lay the groundwork nationally for programs and services that enhance the freedom of people with disabilities. Sybil also carried the disability message to members of Congress and to the Massachusetts state legislature, governor, and attorney general in more conventional ways, testifying in hearings and telling her story during public meetings.

Though Sybil is not survived by any biological family, she had many devoted friends who, in essence, became her family. Over the years she received critical services from, among others, the Bristol County Arc, the Boston Community Medical Group, and the Boston Center for Independent Living and took to the frontlines of countless disability rights activities as a member of the Cape Organization for Rights of the Disabled, the Massachusetts Statewide Independent Living Council, ADAPT, and Boston Center for Independent Living (BCIL). Her life after Fernald was a dramatic shout in the face of those who would isolate, demean, and deny people with disabilities. She even camped out overnight in 1992 in protest against Fernald's very existence, this after having spent the day on a 14-mile freedom march there from Old North Church in Boston with 20 other like-minded activists.

Memorial donations may be sent to BCIL (60 Temple Place, Boston, MA 02111) for the **Sybil Feldman ADAPT Trip Fund**, which will support activists to link with ADAPT to advance the cause of disability rights.

A funeral mass for Sybil was held on December 15 and a celebration of her life was hosted by BCIL on January 4.

Bill Henning is Executive Director of the Boston Center for Independent Living (BCIL).