

Disability Issues

Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.

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Spring 2016

Fulfilling the Promise of the ADA

By Carol Steinberg

At last year's benefit for the Disability Law Center, I cried as a video of President George H. W. Bush signing the Americans with Disabilities Act (ADA) in 1990 was shown in honor of the law's 25th anniversary.

On July 26, 2015, we celebrated. The ADA insured that people with disabilities would have fuller lives than they did before. It prohibited discrimination against us in employment, transportation, public accommodation, communications, and governmental activities. Places of employment, housing, and other facilities must now make accommodations to allow our participation.

But like many laws, which leave work to be done, there are gaps in the inclusion of people with disabilities. More than 25 years after the ADA was signed into law, we still need to expand employment and housing opportunities for people with disabilities. A bill presently before the Massachusetts Legislature would, if enacted, help fill those holes regarding access to housing and employment. It must finally become law to help fulfill the promise of the ADA. The bill is Senate Bill 1323, An Act Relative to the Architectural Access Board, which

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The Healing Power of Art: from Suicide to Serendipity

By Atara Schimmel

I am a creative and expressive arts therapist and a survivor of Pudendal Neuralgia, a brutal and devastating pelvic/genital nerve pain condition. I injured my pudendal nerve by participating in aerobic and aerobic kick-boxing classes. Prolonged sitting on a hard chair while working on the potter's wheel might have taken a toll on my pudendal nerve as well. For two years my symptoms were minor albeit disturbing. I felt a pinching sensation deep inside of my vagina as though my cervix was being pulled with a tweezer. After two long plane rides from Israel to the U.S. and back my pudendal nerve was further damaged. Within six months my own body became my torture chamber.

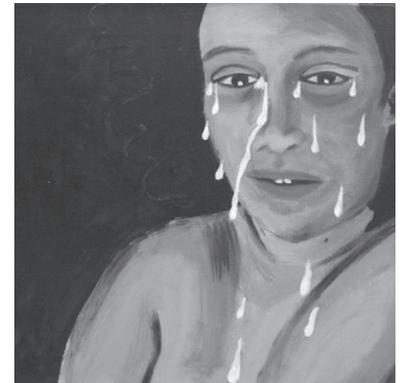


room, for their sake. I was jealous of those who were dying from an illness. At the time, death looked like a luxury.

After a year and a half of relentless suffering I tried to grant myself mercy through suicide. I survived my own suicide attempt and I am here to tell my story and to offer hope to others who are suffering. Art has, and continues to, save my life daily. I cannot imagine being alive today without it. My dedication and commitment to my art, my expression, and my creativity have much to do with my healing.

After my suicide attempt and during my psychiatric hospitalization, Cymbalta was added to the Lyrica that I was already taking. I continued to suffer from 24/7 nerve

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pain as well as from severe insomnia but my pain levels were controlled enough to allow me to concentrate and focus on other things. In the hospital I created paper mache puppets and I water-colored. The repetitive motion of gluing small pieces of paper onto each other helped me gain control of the nauseating anxiety levels that left me feeling that I was made of marbles, spilling all over the place, scattering in all directions. The focus and concentration that making art demanded of me brought me relief from the debilitating anxiety on a minute-to-minute basis.

When I returned home from the psychiatric hospitalization, I started creating mosaics. Working with the broken pieces and putting them together to create something beautiful was a metaphor for my life. Every newly created pot was a victory over my sense of uselessness and devastation. I was proving to myself that I could still create beauty and meaning. I was fighting for my life through my art.

I spent months on the floor of my room creating jewelry from gemstones. Focusing on the gemstones took my mind away from focusing on the pain. Concentrating on twisting the wire took my thoughts away from the fear, the trauma, and the grief. If I could create beauty, then for a moment, I could believe that I was still of value to this world. Deep within me I knew that my value was intrinsic, but I had to work hard to access this sense of connection to my higher self. My art helped me reconstruct a sense of coherence and a sense of identity.

When I had healed enough to be able to take painting classes...a whole new world of expression opened itself before me. I began to dream. To dream that one day my art would tell

my story. I began to dream that one day my art would tell the story of the millions of people who are suffering from chronic nerve pain and in particular genital pain. I was learning that my paintings could speak to the gut and I knew that one day they would pave the way to a greater healing, to a collective healing.

I believe in my art with all of my heart and soul. It has saved my life. It continues to save me on a daily basis from overwhelming anxiety and trauma. My sense of self has strengthened. My sense of purpose and my mission are crystal clear, and as beautiful to my heart as the gemstones that kept me company when suicide and terror haunted me. I am still haunted, but alongside the trauma there is beauty, hope, and tremendous faith in our ability to heal ourselves and to inspire healing in each other.



Atara Schimmel is a creative and expressive arts therapist, a healer and an artist. She is dedicated to raising awareness about and offering support to those suffering from chronic pelvic/genital pain. Atara is the founder of Project Angel, a grassroots movement that is currently lobbying the American Congress of Obstetrician and Gynecologists to create curricula for all pelvic pain conditions. To see more of her art and advocacy visit her website at www.ataraschimmel.com

InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs InfoBriefs



Reporting Disability Placard Abuse

Some of the most common forms of placard abuse are:

- Parking in a handicap spot without a placard or handicap plate.
- Using someone else's disability placard or handicap plate.
- Using an expired placard.
- Using a placard or plate that was issued based on incorrect or outdated information.
- Making a counterfeit placard or altering an existing one.

If you see someone abusing a disability placard you can call your local police department or fill out an online form at the RMV, http://www.massrmv.com/rmv/hp_complaint/

PATH-WAY Providing Access to Happiness

PATH-WAY is a not-for-profit organization created, designed, organized and committed to elevating the lives of individuals with varying degrees of abilities.

PATH-WAY provides inclusive social and networking events in the New England area. They have a variety of events throughout the year that include anything from game nights to volunteering. Every event is physically accessible and open to anyone with or without disabilities.

For more information, visit www.path-way.org or contact them at stephv@path-way.org or 508-733-3240.



A PATH-WAY Skating Event

Disability Issues is a publication of Spaulding Rehabilitation Network, a member of Partners HealthCare. The Spaulding Rehabilitation Network includes Spaulding Rehabilitation Hospital. Its main campus located in Boston, as well as Spaulding Rehabilitation Hospital Cape Cod, two long-term care facilities Spaulding Hospital Cambridge and Spaulding Hospital North Shore and two skilled nursing facilities, as well as twenty-three outpatient sites throughout Eastern Massachusetts. Spaulding is a teaching hospital of Harvard Medical School and the official rehabilitation hospital of the New England Patriots. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by *U.S. News and World Report* in its Best Hospitals survey with a #6 ranking in 2013. For more information, visit www.spauldingnetwork.org.

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From the Editor

Dear Readers,

Even after a calm winter with virtually no snow, I still find myself craving the arrival of spring to soothe my weary bones and lift my spirit. Spring and hope are intertwined in the mind, body, and soul. It's true that hope does not fade away in the summer, or fall away in autumn, or perish in the deep freeze of winter. But none of those seasons can match the resurgence of hope that spring brings to drive away the darkness.

As people with disabilities, we certainly have more than our fair share of dark days. Pain, exhaustion, and despair are frequent visitors in our lives and at times we wonder if the light of a bright new day will ever shine for us. When I was in my 40s, I was in what I called "a dark place" for a few years. At the time, I didn't call it depression, but that's certainly what it was. I remember wondering if I would ever feel happy again. During this time, I read a poem by Emily Dickinson that I hung onto:

Will There Really Be A "Morning"?

By Emily Dickinson

Will there really be a "Morning"?
Is there such a thing as "Day"?
Could I see it from the mountains
if I were as tall as they?

Has it feet like Water lilies?
Has it feathers like a Bird?
Is it brought from famous countries
of which I have never heard?

Oh some Scholar! Oh some Sailor!
Oh some Wise Men from the skies!
Please to tell a little Pilgrim
Where the place called "Morning" lies!

Like Emily Dickinson, when we feel despair I think we all wonder if the dark night will ever end and we call out for reassurance from someone, anyone, who can tell us where the place called "Morning" lies. If we can hang on and persevere, morning will eventually come. It always does. Sometimes it comes by creating art or kissing the nose of a horse; sometimes by advocating for a bill to be passed; and sometimes by putting on lipstick and heading out the door in your prettiest dress.

May the sweetness of warm sunshine and budding flowers bring renewed hope that no matter how dark or long the night is, "Morning" will always come.

— Marianne DiBlasi, Editor

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Strongwater Farms Therapeutic Equestrian Center in Tewksbury

by Mary Jane Fietze

Strongwater Farms is a Therapeutic Equestrian Center in Tewksbury, MA that was established in 1997. Patti Lessard, Director of Operations & Programming, was the first full-time person hired at the Farm, just 3 years ago. She sums up the Farm as “a place of healing.” Anyone who is cognitively challenged, physical challenged, or has emotional concerns benefits from time spent with the horses. Patti says, “The horses are deep souls. They have an instinctive sixth sense and can size you up in a minute.” She asks her **At Risk Youth Class**, to tell her which horse they are drawn to. Ultimately, the horse and rider choose each other. It is the bonding between the horses and people that heals, regardless of what type of adversity the person might be facing. Many people never actually ride the horses. They learn unmounted activities, such as grooming. It turns out; this is just as meaningful for the students.

I visited Strongwater Farms on a frigid day, but the interactions between the horses and humans would melt even the Grinch’s heart. In a class I observed the Instructor, Ellie, ask the intellectually challenged boy if he would like to tell Liam, about his day. (Liam is a cross between a Quarter Horse and an Arabian). With his mother’s encouragement, he slowly and briefly opened up and shared that he had gone to visit his brother who lives in a special home. Liam nodded and loudly snorted. The boy was startled at first, but soon laughed with glee! “You have been blessed,” Ellie said interpreting Liam’s nonverbal expression of love. Liam is one of the twelve working horses that serve over 150 people a week.

Andrea started as a therapeutic rider, and then learned to be a side walker for those with balance problems. Next she learned to be a volunteer groomer. Andrea shared with me, “Spending time at Strongwater Farm is very healing for me; physically & mentally. It’s difficult to put into words the healing power of the horses. It’s better than any other traditional medicine I’ve ever had.” She introduced me to all the horses and the first one I met shook his head “No” when she asked him if he wanted to say hello. We moved on to the next stall and Liam also declined. I think he was tired from his earlier class. I was all set to leave, when I asked Andrea to open the window of Karlton’s stall. He let me stroke his nose and I kissed him. It was calming, yet euphoric, just as a first kiss should be!

Patti explained to me that a horse’s walk simulates the gait of a person and the simple movement of the horse affects the body, mind, and spirit. When a rider is astride the horse, the spine-to-spine neuron’s interaction stimulates the central nervous system. The movement triggers neurons in one’s brain, which heightens the awareness of your body and how it reacts to the movement of the horse’s body. This, in turn, enables core strengthening; which facilitates fine and gross motor skills.

The Veterans, which Patti works with, suffer from post-traumatic stress disorder (PTSD) and most are veterans from the Gulf War. Patti said, “They have a hard time letting go of their past. Their positive bonding experiences with the horses carry over to other parts of their life, like their workplace and family.”

The Farm is accessible, both figuratively and literally, to a wide range of disabilities and demographics. There is no charge for Veterans and their families. Some of the riders use a mechanical lift to mount the horse, which actually lifts and places the rider on the horse. Other riders use a walk-up ramp, which puts the rider closer to the height of the saddle and makes mounting the horse easier.

The Farm could not exist without both the 350 volunteers and their annual Gala, which includes dinner, dancing, and a silent auction. It is their major fund raiser; however, they also have a golf tournament in the summertime and other fund raisers throughout the year.

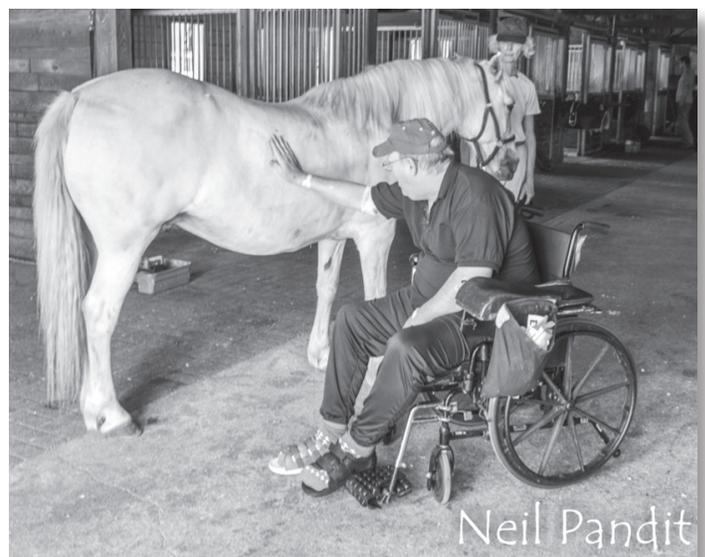
My brief visit to this Therapeutic Equestrian Center was both breathtaking and beautiful. There are 6 seven-week sessions a year and many insurance companies cover equine therapy. Each session begins with an assessment of the potential rider. The sessions fill up fast so sign up now and let the healing begin.

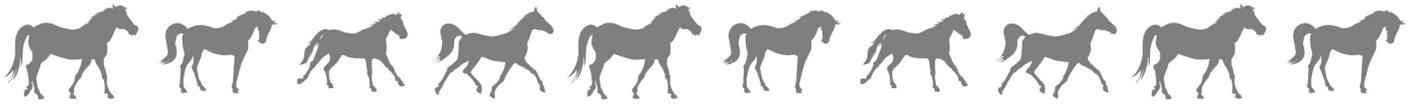
For more information, call 978-851-5540 or visit www.strongwaterfarm.org.

Mary Jane Fietze has been living with Multiple Sclerosis for 24 years. She writes for The Burlington Union about disability topics and has been on the Burlington Disability Access Commission, BDAC, for 13 years. Mary Jane has won several awards in hand cycling and enjoys demonstrating her ability to kids as part of BDAC’s “differently-abled talks” to schools.

“Always be on the lookout for the presence of wonder!”

—E.B.White





Easter Seals Therapeutic Equestrian Program in Canton

By Susan Murray

The Massachusetts Hospital School (MHS) in Canton, MA is a residential facility for individuals ages eight to twenty-two who have disabilities, as well as significant medical needs. Easter Seals and MHS have had a longstanding relationship predicated on their shared mission of programing aimed at helping people with disabilities “to get the most out of life”. The therapeutic equestrian program is one of many of their collaborative programs.

Eleven horses, 2 pigs, 3 bunnies, cats, and a miniature donkey named Floyd live in the barn and grounds at MHS. Students interact with all or as many of the animals as they wish. Some students are most comfortable just spending their time at the barn caring for the horses and other animals and never ride. This interaction in itself has a calming and therapeutic effect. For students who want to ride, there are fully accessible lifts and ramps designed to safely help them mount the horses.

The MHS program has two unique components that are geared toward individuals who are tenuous about actually being on a horse but want some experience. One is a riding

simulator that is built low to the ground for easy mounting; it has a saddle and can mimic the rhythm of riding. The simulator, complete with a head and tail, gradually introduces a student to the movement of a horse and also helps to calm fears of height and large animals. Another mechanism for giving a student the experience of controlling a horse is a program called “therapeutic driving”. The student controls the horse from a cart pulled by a horse.

The therapeutic equestrian program is open to all members of the community and approximately 50% of participants are from the community. All instructors are licensed and certified by the Professional Association of Therapeutic Horseman Association (PATH). For more information about the Easters Seals MHS program contact Erin Fitzgerald, Equestrian Program Manager at 781-830-8753 or erin.m.fitzgerald@massmail.state.ma.us

Susan M. Murray is a retired health care consultant and an editorial board member of “Disability Issues”.

Love and Intimacy Corner



Life Requires a Forward Thinking Perspective

by Ms. Love

Some may think Ms. Love has a cushy job; what is not to like about writing about love and intimacy, the joy of a young crush, romance, and more? Well I admit on many days your Ms. Love can think of oodles of topics to write for you regarding upbeat and loving matters.

Not so at the moment. At the moment, throbbing head pain and many other health issues consume your Ms. Love. Why have my migraines and other conditions flared so? My landlord is turning over the apartment above me, and for two solid weeks there has been banging, drilling, thudding overhead as old windows are replaced, new floors put in, and more. In addition to the noise, the smell of floor adhesives and other irritants has left me with irritated eyes, trouble breathing, and added gasoline to fuel the fire of my migraines.

So, do I feel sensual as I lie in bed with ice packs on my head as I try to quiet raging head pain? Heck no. Do I feel I look sexy when I am vomiting with the migraine? You know the answer -- NO. I have made no inroad with the landlord about being sensitive to my health issues, nor do I have no reason to believe the noise and smells will be stopping any time soon above me. What can Ms. Love do? Indeed, what do you, dear readers, do when you are being stressed by work, health issues, school, home – fill in your own source of stress – and love and intimacy seem to fall not just way down on your list of

priorities, but actually does not even make the list?

When throbbing head pain eases a tad and I can feel myself more able to think, I regain my usual sense of perspective that I have developed over years of having disabilities. I may have some tough days because of my disabilities, but I have made it through them before and know I will rise to challenges in the future. It is with this perspective of inner strength and going forward that I stand up a smidgen taller – though leaning heavily on a cane. I hold up my head a bit straighter, puff out my chest, take the first stab with my cane outside the apartment door after a migraine attack, thereby announcing not so much to the world but to myself “I AM HERE, WORLD.” Sometimes I will wear a favorite sweater or shirt that makes me feel confident or pretty. A woman once told me her philosophy of stepping out in the world after stresses. She dresses up as if for a special date and puts on her lipstick, even if she is only going to the grocery store for a loaf of bread. And, because life is always stressful in some way, long ago she made it her practice to dress to the nines and wear lipstick whenever she leaves her house.

The fact is, however you sashay yourself out of bed in the morning – after the flu, after discharge from the hospital after surgery, after being let go from your job, after flunking a crucial academic course –you did get yourself up out of bed.

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Fulfilling the Promise - Continued from page 1

would greatly improve accessible employment and housing opportunities in this state. Advocates have been trying to get this bill passed for nine legislative cycles. Right now it is poised for success as it has passed through the Senate and is before the House Ways and Means Committee.

Twenty-two years before the ADA, Massachusetts law required that buildings open to the public be accessible. Since 1968 we have had the Architectural Access Board (AAB) which was “designed to provide full and free use of buildings and facilities so that persons with disabilities may have the education, employment, living and recreational opportunities necessary to be as self-sufficient as possible and to assume full responsibilities as citizens.”

The AAB’s regulations are much more effectively implemented than the ADA. While the ADA requires a time-consuming civil rights lawsuit brought after an inaccessible building is already built or renovated when the barriers are difficult and expensive to undo, the AAB regulations are part of the Massachusetts building code, and are enforced by local building inspectors when the building is first constructed or remodeled.

But the AAB’s jurisdiction has flaws. It is not aligned with the ADA in important respects. This incongruence, which would be fixed by Senate Bill 1323, is unfair and confusing not only to people with disabilities, but also to architects, developers, building owners, and businesses.

First, although there has been much renovation of beautiful old mill buildings into housing, this boom does little to meet the vast housing needs of people with disabilities. Buildings occupied before September 1, 1991, which are converted into multiple dwellings, unlike newly constructed housing, need not have units that can be modified and made accessible as needed. Senate Bill 1323 would correct this and the supply of accessible housing would grow.

Secondly, the AAB does not govern places where people work unless those places are open to the public. This means the Board has to allow offices and factories to be places that physically disabled persons cannot work.

For example, the Board had to allow a large building on the Boston waterfront undergoing a huge renovation to retain stairs through its offices that were for employees only. And the Board couldn’t require a major university spending 7 million dollars renovating a historic building to put in an elevator leading to employee offices on the fourth floor—including the office of the Diversity Officer—because the areas were only for university employees. As a result, people with disabilities are barred from employment in those offices in the waterfront building and in the University forever.

Senate Bill 1323 will require all employee spaces to be accessible. It will directly impact thousands of people with disabilities who cannot work now because those spaces are not accessible. For example, I know an unemployed scientist who has multiple sclerosis and has been unable to take jobs, or

even go for interviews, because labs are on the second floor in buildings without elevators and she has trouble with stairs.

Over 25 years after the signing of the ADA, we must make sure that a law that improves housing and employment for people with disabilities is enacted in Massachusetts. Please reach out to your State Representatives and tell them about Senate Bill 1323. Ask them to support the legislation and contact House Ways and Means Chairman, Representative Brian Dempsey, to ask for prompt consideration of the bill.

Carol R. Steinberg is an attorney, a wheelchair user, a member of the Massachusetts Architectural Access Board, past president of the Board of the Disability Law Center, and a member of the Government Relations Committee of the Massachusetts Multiple Sclerosis Society.

Senate Bill 1323 Advocacy Resources:

Legislation information:

<https://malegislature.gov/Bills/189/Senate/S1323>

Massachusetts House of Representatives contact information: <https://malegislature.gov/People/House>

InfoBriefs InfoBriefs InfoBriefs

REquipment DME Reuse Program

REquipment is an innovative durable medical equipment (DME) reuse program that gives

a second life to valuable, no longer needed medical equipment. REquipment accepts and picks up donations of gently used manual wheelchairs, power wheelchairs, scooters, lifts, standers, shower equipment and more. Cleaned and repaired items are provided to children, adults and seniors here in MA at no charge and without the hassle of paperwork and delays. Items can be used for short or long term and delivery is available in Greater Boston and Central MA.



To find and request DME online, visit:
www.dmeREquipment.org

To donate your good condition DME,
call our Support Line at 1-866-544-9540.

For more information, contact REquipment at
info@dmerequipment.org.

The REquipment Program is managed by the Massachusetts Rehabilitation Commission and The Boston Home with support from Spaulding Rehabilitation Network.

New PCA Benefits

By Raymond Glazier

Most PCA consumers and practicing PCAs are aware of these program improvements, but potential PCAs, potential consumers, and provider staff may not be mindful of them. Since before unionization, PCAs have received time and a half pay for day hours worked on four holidays: New Year's Day, Independence Day (July 4th), Thanksgiving Day, and Christmas Day. Local 1199SEIU (Service Employees International Union) United Healthcare Workers East became the MA PCA union with the state legislature's passage of the Quality Homecare Bill in 2006. Since then there have been several PCA benefit improvements, in addition to escalations in the uniform hourly wage:

Paid Time Off: Starting in 2009, all eligible PCAs receive a paid time-off bonus to compensate PCAs for time taken off without pay during the year. Eligibility requirements include having worked at least a yearly total of 1500 hours in the PCA program and averaging at least twenty-five work hours per week. These payments, automatically calculated by the Fiscal Intermediary processing time sheets, do not affect the consumer's number of approved service hours.

Overtime Pay: In September 2013 the U.S. Department of Labor determined that the nation's 2 million direct care workers, including all PCAs were subject to minimum wage provisions and overtime protection, effective January 2015. Workers in the MassHealth PCA Program already were being paid above the minimum wage, but now they receive time and a half pay for day hours worked over 40 hours in a given week. These payments, also automatically calculated by the Fiscal Intermediary processing time sheets, do not have an impact on the consumer's number of approved service hours.

Earned Sick Time: Beginning in July of 2015, PCAs earn one hour of sick time for every 30 hours worked, up to 40 hours in a calendar year; this can be tracked by the number of hours year-to-date appearing on the consumer's biweekly Payroll Record. Up to 40 hours of unused sick time can be carried over to the next year. Sick time may be used to care for the PCA's physical or mental illness or medical appointment, including routine medical appointments, or for the care or medical appointment accompaniment for a PCA's child, spouse, parent, or spouse's parent, as well as to address the psychological, physical or legal effects of domestic violence. Sick time must be reported separately on a special Sick Time Activity Form that can be obtained from the consumer's Fiscal Intermediary or downloaded from their website. Hours of Sick Time are separate from, and are not subtracted from the consumer's number of approved service hours. Consumers are cautioned to be alert to

patterns of Sick Time usage that may indicate possible fraud or abuse by the PCA.

Other Standard Benefits: By law, PCAs also have Workers Compensation insurance coverage for on-the-job injuries and Unemployment Insurance.

Future Benefit Goals: Consumer advocates, including this writer, have long argued that offering a health insurance plan (perhaps MassHealth) to PCAs, including a family option would substantially contribute to a larger, more stable PCA labor pool. This strategy has worked very well for United Parcel Service in attracting a large, loyal cadre of part-time workers.

Over a decade ago, the Commonwealth commissioned a direct mail survey of a random sample of active PCAs in an effort to understand the health insurance needs of PCAs. The findings from the survey report, embargoed and never published, showed that the majority of respondents already had health insurance through another job or through a spouse. However, a major methodological shortcoming of this project was that it only surveyed persons already working as PCAs and not potential PCAs for whom the benefit might be enticing.

Raymond E. Glazier, Ph.D. is a longtime consumer in the MassHealth PCA Program who has for over two decades researched PCA issues for state and federal government agencies in connection with his former employment by Abt Associates Inc. and currently with disAbility Research Associates of Belmont, MA.



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Life Requires a Forward... - Continued from page 5

Rather than dwell on what has not been stellar, focus on your eagerness and craving for better times. The hunger for living life, the intense energy focused on better times, THIS is sexy. Yup, sexy. It shows up with a twinkle in your eye, a little more bounce in your step, perhaps a lilt to your voice. It is because you have known hard times that you can better relish good times, and that's darn sexy.

So put on your equivalent of lipstick and get thee out and about! Remind yourself that a fine life, one including love and intimacy, might be just around the bend in the road that was so stressing.



The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at DI.LoveandIntimacy@gmail.com. Questions chosen to be featured in the, Ms. Love column will appear under a pseudonym to protect privacy and may be edited.

*Life begins
at the end
of your
comfort zone*

InfoBriefs InfoBriefs InfoBriefs

Cambridge Women's Center

The Cambridge Women's Center is open to all who identify as women. It offers a variety of groups such as yoga, sewing, feminist book group, support group for survivors of child sexual abuse, trauma survivors' writing group, teen group, narcotics anonymous, mah jongg, and others. A kitchen and computers with Internet access are available. Everything is free. A wheelchair lift is available, and every effort will be made to make a group accessible upon request.

The Center is located at
46 Pleasant Street, Cambridge MA.

For up-to-date schedule listings or other information
call the Women's Center Support Helpline at 617-354-8807
or the business line at 617-354-6394 or
visit www.cambridgewomenscenter.org



The Women's Center