***Disability Issues***

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*Providing individuals with disabilities, their families, friends, and advocates with relevant information to enhance their quality of life, health, and employability options.*

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 in Charlestown, which is a national model for environmental and inclusive design as well as Spaulding Rehabilitation Hospital Cape Cod, Spaulding Hospital Cambridge and two skilled nursing facilities, as well as twenty-five outpatient sites throughout Eastern Massachusetts. Spaulding strives to continually update and improve its programs to offer patients the latest, high-quality care through its leading, expert providers. Spaulding has been awarded a Model Systems designation in three specialty areas- Brain Injury, Burn Injury Rehabilitation, and Spinal Cord Injury - by the National Institute on Disability, Independent Living, and Rehabilitation Research. Spaulding is a teaching hospital of Harvard Medical School as well as the official rehabilitation hospital of the New England Revolution. 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 #5 ranking in 2016-2017. For more information, please visit [www.spauldingrehab.org](http://www.spauldingrehab.org/).

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**From the Editor:**

Dear Readers,

Since the last issue of *Disability Issues*, we have elected a new President. As I hear who President Elect Trump is appointing as cabinet members and we learn more about their values, many of us are feeling afraid about what may unfold over the next four years. In response to these feelings, I’ve noticed a heightened sense of urgency to “do something”, to take action, to get involved. With Trump’s values leading our nation, many of us are alert and awake. We are keenly paying attention to what is happening, maybe in a deeper way than ever before. When we imagine what might happen during the next four years, many of us are afraid. Will critical disability services be ravaged? What will happen to people who are already marginalized?

I’ve pondered over what to do with my overwhelming sense of fear and I’m actually afraid of feeling afraid – a downward spiral, for sure! Buddhist nun, Pema Chodron talks about this downward spiral, “Whatever form fear hardens into, it continues to escalate and results in actions that can do great damage. It escalates into wars and riots. It escalates into violence and cruelty. It creates an ugly world, which breeds more fear.” Creating more fear isn’t the answer, but what do we do with all these feelings? If you believe like I do that, Love really does trump Hate, perhaps it’s time to take action, to “do something” that creates more love and peace in the world.

In our society, there are many who are suffering and we are needed -- you and me and every one of us. We need people who have the strength to act with courage and kindness in the face of fear. As people with disabilities, we have been readying ourselves for years to act with courage and hope in the face of fear. We know how to speak truth to power. We know how to rally together and work for justice and equality for all. We know how to succeed and flourish against all odds. We can use all that we’ve been learning to reach out to a hurting world and “do something”, take action, get involved.

What if each of us plunged into just one activity of service or social activism in our local community to help others in need? What if each of us engaged in intentional acts of kindness and generosity toward a family member, neighbor, medical professional, co-worker, or PCA? If each of us did this, many hearts would turn from pain to peace, and there truly is nothing this world needs more than peace.

Marianne DiBlasi, Editor

**Medical Errors Happen, But Recent Conversations About Them Are Changing Policies, Procedures, and Offering Healing**

**by Sandy Alissa Novack**

Medical errors happen. Not long ago, I read online that the third leading cause of death is medical error. I am partly attracted to such facts because I have had the opportunity to participate in some trainings and conferences on the matter. What follows is a summary of what I have learned, as well as some resources that may be useful to you and your friends and family.

Years ago, I participated in Patient-Teachers in Patient Safety (Patient TIPS), a program of Beth Israel Deaconess Medical Center-Boston, the Institute for Professionalism and Ethical Practice (IPEP), and Boston Children's Hospital. Patient TIPS was co-facilitated by Dr. Sigall Bell, Director of Patient Safety and Quality Initiatives at IPEP and David Browning, MSW and Senior Scholar at IPEP. Patient TIPS aims to improve communication with patients and family when things go wrong and improve communication and collaboration between medical providers to improve patient safety. These trainings used patients (including me) and family educators in medical error disclosure and prevention workshops. Myself and other patient volunteers engaged with various medical providers while we jointly role-played various scenarios of medical error.

We learned the number one thing patients and families wanted after an “adverse event” is an apology. We also learned how medical providers can burn out if they do not receive support on how to respond after medical error. We discussed with the medical providers such issues as difficulties providers may have staying patient-centered after an adverse event, resulting in withdrawing from the patient/family needs. This is sometimes what happens when providers are afraid of being sued or afraid of a patient's anger. By having patients in the room participating in such trainings, medical providers claim they are able to think about and improve ways of enhancing their handling of medical errors back in their hospital practice. Patient volunteers spoke about feeling more a part of the medical team rather than separate from it.

It also reinforced our awareness of how patients are an important contributor to their own safety and have an equal right to speak up. For example, if we notice that a medical provider has touched something unclean in the room and has not washed their hands before touching the patient.

I recently attended an annual dinner of Medically Induced Trauma Support Services. This non-profit defines medically induced trauma as “the emotional toll that results when something goes wrong during medical or surgical care. It may or may not be an error, but is an undesirable outcome due to some aspect of diagnosis or treatment. These events can significantly affect the emotional well-being of the patient, family member, or medical provider.” The keynote speaker was attorney Richard C. Boothman, who designed an approach to medical errors at the University of Michigan Health System that is now referred to as the Michigan Model. He spoke of how requiring a patient to make a legal claim is actually harmful to the patient. “We can't rationalize that a patient we hurt is litigious for standing up for themselves.”

According to Attorney Boothman, not a single hospital that has embraced a program of apology and communication after error has ever gone back to not apologizing and not communicating.

Boothman shared what has been learned from hospitals who do practice communication and apology. “Hospitals and medical providers are not as good as we hoped we were...When you act ethically, you bring up everyone around you...we have learned what accountability is...We have learned that the relationship is key between patient/family and medical providers and we should not abandon it when things go wrong...We have learned that we are far from patient-centered, for example, when informed consent is just about getting a paper signed…We learned that we are all in this together and it is not an issue of just the provider and patient. For instance, lawyers should not prosecute cases just to prosecute...Nothing bad can ever happen if you show compassion...Let's find the courage to expect more from our government, more from our health care, more from ourselves.”

I attended a *Communication, Apology and Resolution Forum* sponsored by the Massachusetts Alliance for Communication and Resolution following Medical Injury and the Massachusetts Medical Society. What is wrong with the current system - the deny and defend approach? Presenters pointed out that patients find this approach unfair, slow, inequitable, inefficient, isolating, and providing no apology. Physicians find it expensive, stressful, and the deny and defend model does not move the health care system forward. But a CARe approach is transformational. Presenters pointed out that “the reactive stance becomes proactive; the adversarial becomes advocacy; a culture of secrecy becomes full disclosure and transparency; denial is transformed into apology, which is healing; individual blame turns into system improvement; and patient/provider isolation becomes supportive assistance.”

Part of the CARe approach is to get to healing. In a legal case, deposition after deposition delays healing and moving on. CARe wants to resolve the issue quickly to start healing.

Lastly, I attended *Setting a Research Agenda for Studying the Emotional Impact of Harmful Events and Medical Errors on Patients and Families*, partly funded by a grant from the Agency for Healthcare Research and Quality. Research on short and long term emotional aspects of adverse events has been limited, but conferences such as this one show that finally a light is being shown on the issue, which is a first step for addressing the problem. To be explored is the psychological (such as anger, loss of trust in healthcare) and behavioral (such as activism and altered healthcare seeking behaviors).

*Sandy Alissa Novack, MBA, MSW, LICSW, ACSW, CSW-G, is a social worker who is on the editorial board of “Disability Issues” and is on the Beth Israel Deaconess Medical Center Universal Access Advisory Council.*

**SIDE BAR:**

**Patient Safety and Medical Error Resources**

Medically Induced Trauma Support Services ([www.mitss.org)](http://www.mitss.org))

Betsy Lehman Center for Patient Safety and Medical Error Reduction ([www.betsylehmancenterma.gov)](http://www.betsylehmancenterma.gov)) Click on Resources & Tools for a listing of multiple resources, including, *Be an Informed Patient* and *When Something Goes Wrong*.

Massachusetts Coalition for the Prevention of Medical Errors ([www.macoalition.org](http://www.macoalition.org/))

Massachusetts Alliance for Communication and Resolution following Medical Injury ([www.macrmi.info)](http://www.macrmi.info))

Agency for Health Research and Quality (www.ahrq.gov/patients-consumers)

Brigham and Women’s Hospital Quality and Safety ([www.brighamandwomens.org/about\_bwh/quality)](http://www.brighamandwomens.org/about_bwh/quality))

## **Partnering with Families to Build Dignified, Meaningful Lives**

## **By Ken McDonnell**

As the saying goes, home is where the heart is. For adults with developmental disabilities and elders in need, this adage takes on special importance. Growing evidence shows that people with disabilities and elders in need do best when they reside in a home setting, where they can develop strong and enduring relationships with their caregivers and their families. This approach is accelerating broad interest in two new models of residential supports for people in need: Shared Living (SL) and Adult Family Care (AFC).

These programs support individuals who are unable to live alone independently in the community and wish to live in a private-home setting. The home can be that of a caregiver who is not a family member, or that of a family member, normally a parent, sibling, or other relative. In Massachusetts and Rhode Island, Seven Hills Foundation is breaking new ground in overseeing these innovative, highly beneficial modes of residential care.

Seven Hills’ Shared Living program closely matches the adult or elder in need with a compassionate family, couple, or individual who welcomes the person to live in their home and becomes his or her caregiver. Adult Family Care participants live with a member of their family, who serves as caregiver. In both programs, caregivers provide assistance with bathing, eating, dressing, and other activities of daily living.

“These arrangements provide a variety of benefits to both the adults we support and their caregivers,” said Leslie Courtney, vice president of Seven Hills Family Services. “By residing in a family setting, the individual can develop a greater sense of belonging, companionship, independence, dignity, and community integration – in short, the most normal life possible, depending on his or her disability. The family setting is the key to improved quality of life.”

Both arrangements offer the caregiver a concrete way to help a loved one or other adult in need while receiving comprehensive supports. Seven Hills provides care coordination, nursing support as needed, ongoing training, respite care, a monthly stipend, and other assistance to ease the responsibilities of care.

Before they learned about Adult Family Care, Rosemarie and Steve Geary struggled to balance their work schedules with the needs of their daughter, Samantha, a young woman with Down syndrome. Today, AFC has eased the challenges of caring for Samantha. “Monthly visits by our AFC nurse help us help Sam more fully,” said Steve. “She gives Sam a mini physical exam and offers tips and training to us all on home safety, healthy eating, exercise, and many other topics.” “Respite care gives Steve and me a break from time to time, and the stipend is a big plus,” said Rosemarie. “AFC has transformed our lives in so many wonderful ways!”

For four years, Kwaku Achamfour has been a Shared Living caregiver for Jonathan. “I’ve always dreamed of helping others,” said Kwaku. “Sharing my life with Jonathan is more than simply supporting him. He is my friend, my brother. The joy is helping him make positive changes in his life and helping him achieve his goals.” Along with the advantages of residing in a family setting, Shared Living has helped Jonathan become more confident and relaxed when he and Kwaku are out in the community.

Matt is a 24-year-old man with a disability who has always lived with his mom, Pam. The supports they receive as an AFC household have made a world of difference in Matt’s quality of care, and Pam welcomes the practical assistance and financial help. “Seven Hills has been there for us every step of the way,” said Pam. “From our case manager to our visiting nurse to ongoing training, the supports I receive gives me added confidence as Matt’s caregiver. And the supports he receives give him greater independence and self-esteem.”

For more information about Seven Hills’ Shared Living and Adult Family Care programs, please visit <http://www.sevenhills.org/affiliates/seven-hills-family-services> or call 508-755-2340 (TTY: 508-890-5584).

*Ken McDonnell is an Advancement Associate at Seven Hills Foundation.*

**THE PCA CORNER**

**The Good PCA and Your Health**

**By Ray Glazier**

Only a seasoned PCA consumer knows how vitally important a good PCA is to the consumer’s health and vitality. Among the crucial care tasks that come to mind are safe transfers (safe for both parties), skin care and skin integrity checks, accurate meds maintenance and administration, thorough and consistent regular bathing. And then there are items not so survival critical, like careful dressing and grooming (not only for the lady consumer), maintenance of a clean and orderly home environment, and honest and accurate record keeping. How to find the Good PCA?

In previous columns we have touched on PCA recruiting, for which each MassHealth PCA Program consumer receives training from the Personal Care Management (PCM) agency through which services are provided. Crucially important in a PCA candidate is some familiarity with the Independent Living concept. For this reason, I have usually steered clear of individuals with a health care background or health care experience. For the most part, they just don’t get it; they are more accustomed to working on people, not with them. Secondly, the PCA candidate’s health status is a legitimately paramount consideration. A PCA who is incapacitated by a chronic or episodic physical or mental illness cannot be relied upon. Many PCA positions also require a measure of physical strength, depending upon the consumer’s care plan and specific needs.

The qualities to look for in a good PCA candidate include those one would want in any employee — integrity, honesty, reliability, responsibility. But these desired characteristics take on a new dimension when this is the person who will be getting you out of bed, toileted, showered, and dressed each morning, as well as preparing your meals, cleaning, shopping, and running errands, etc. The ideal PCA also has the qualities of a trusted friend — caring, concerned, patient, forgiving, loyal.

A consumer new to depending on PCAs may, as I once did, look for the one perfect PCA who can be all things and do it all. It just doesn’t work that way: Even the perfect sole PCA will inevitably need a sick day or a personal day to accommodate, for example, a heavy date, a doctor appointment, a time-critical personal errand, an important exam. For this reason and because any one person has a limited skill set, I advise having multiple part-timers sharing the duties and the schedule, if ones approved hours permit.

No PCA is perfect, but good ones, while somewhat hard to find, are definitely keepers. So it behooves the enlightened consumer to look out for PCAs’ health. MassHealth does not offer health insurance to PCAs, although that might contribute substantially to stabilizing the PCA workforce. A somewhat dated state survey study found that the majority of PCAs do have health insurance, either through another family member or coverage on another job. Two unrelated, independent PCAs with complementary skills and different schedules are preferable, in my opinion and in my decades of experience.

Some mutually beneficial good preventive health practices for you and your PCA include thorough annual physicals, regular checkups, annual flu shots, healthy eating, a sound sleep regimen, and daily exercise. For the consumer, daily exercise includes stretching and repetitive range of motion for all immobilized joints, while transfers, other daily *living tasks* for the consumer, and doing passive exercises all contribute to your PCA’s exercise regime. I often jokingly tell my PCAs that I should be charging them gym membership fees.

*Raymond E. Glazier, Ph.D. has decades of professional experience studying PCA issues, as well as decades of personal experience as a consumer in the MassHealth PCA Program. He is a principal of disAbility Research Associates LLC and welcomes comments or questions at* [*ray\_glazier@post.harvard.edu*](mailto:ray_glazier@post.harvard.edu)*.*

**2016 Spaulding Hackathon Hacking Rehabilitation**

**By Tim Sullivan**

For the 2nd year in row Spaulding Rehab conducted a Rehabilitation Medicine Hackathon. Based off of the success of last year’s, the first ever held nationwide, Spaulding expanded its efforts to encourage innovation to benefit the community with disabilities. This year’s event had over 100 participants and over a dozen teams. The Spaulding Hackathon served as a catalyst to jump start many new ideas and approaches to rehab medicine.

“The first year really lit the spark that has energized so many in our region and well beyond,” said Dr. Binder. “With the level of talent and diversity from divergent fields participating, we are just beginning to scratch the surface of the impact we can have on the communities we serve.” One of the teams from last year’s event developed an app which identifies disability accessible parking spaces throughout the city of Boston. Winner of the Best Design Award at the Spaulding Hackathon and as part of the Spaulding Accelerator Program, the team was able to further develop their idea and ultimately received a $60,000 grant from the Office of Massachusetts Attorney General.

Participants came from a wide variety of fields including medicine, engineering professionals, entrepreneurs, advocates, software programmers and students. The diverse cross section of students allowed teams with varied skills sets to collaborate together on product ideas. The team after the day and half of hacking, presented their product pitches to a team of seven panel experts. The prizes chosen ranged from the Best Design award with $10,000 design services prize from MadPow and first and second prizes with cash, legal and iOS support. The winning group chosen was “un-Caney” which offered a fresh approach to canes to encourage use and decrease falls.

The Spaulding Hackathon was once again hosted in collaboration with MIT Hacking Medicine and focused on the development of creative and innovative solutions specifically for rehabilitation medicine challenges. Based on the interest generated by the now annual event, Dr. Binder announced the creation of the Spaulding Accelerator program for start-ups to facilitate early stage development of new products and services for entry to the market. All of the teams selected for awards at the Hackathon were eligible to participate in the Spaulding Hackathon.

This year’s event was held in Microsoft’s New England Research and Development Center (N.E.R.D) in Kendall Square, Cambridge, Massachusetts. Among the many exciting aspects this year were two key note speakers, Dr. Hugh Herr, Director of the Biomechatronics Group at The MIT Media Lab and Andrea Ippolito, VA Innovators Network Lead, Department of Veteran Affairs and Co-Founder MIT Hacking Medicine.

The ultimate goal of the event is to advance the mission of Spaulding Rehabilitation Hospital and rehabilitative medicine by improving the quality of life for patients and families. “This is such an exciting time as the power for innovative ideas to revolutionize our approaches is greater than ever. It was such a thrill to be at this year’s event and see it grow even more as we foster these teams to make profound change to our field,” said Dr. Binder.

To learn more about the Spaulding Hackathon visit [www.spauldingrehab.org/hackathon](http://www.spauldingrehab.org/hackathon)

*Tim Sullivan is Director of Communications, The Spaulding Rehabilitation Network & Partners Continuing Care.*

**LOVE AND INTIMACY CORNER**

**Resources for When You Do, and Especially When You Don't, Know How to Ask a Question**

**by Ms. Love**

My dear readers, recently your Ms. Love and Disability Issues' editor, Marianne DiBlasi, attended a party celebrating the 10th anniversary of sex-positive retail store Good Vibrations in Brookline, MA. There we learned the breaking news of an additional Good Vibrations store opening just that day at 52 John F. Kennedy Street in Cambridge, MA 02138. We congratulate Good Vibrations for opening an additional store in Massachusetts so women and men have a place to ask the sales associates/sex educators their questions and buy appropriate products for their needs and interests. If you have a question about the mild, the wild, or your health and disability needs and sexuality, this is a safe and non-judgmental place to seek answers. Don't even know how to word your question? That’s okay too. The trained staff can ask questions to help clarify your needs.

If you go to either store location in Massachusetts, or peruse their website ([www.goodvibes.com](http://www.goodvibes.com/)), you might be interested in the equivalent of the Encyclopedia Britannica for love and sexuality for your night table, *The Sex & Pleasure Book: Good Vibrations' Guide to Great Sex for Everyone* by Dr. Carol Queen with Shar Rednour. Published in 2015, this 473-page large paperback book will cost you $24.95 but you will be referring to it for years and years to come. Whereas there is a ten-page section formally titled “Disability & Sex”, there are many other areas of the book where disabilities and health issues are discussed too. These include a section on when sex hurts (find information on vulvodynia here), and also a section on sex and trauma.

If this book whets your appetite for more reading, the recommended reading list at the back of the book suggests a number of options on health and disability related issues, including: *The Illustrated Guide to Better Sex for People with Chronic Pain* by Rothrock, D'Amore and Belt, and also *Sexy After Cancer* by Barbara Muser. The illustrations in Dr. Carol Queens’, *The Sex & Pleasure Book,* help a reader's understanding on a topic, such as pictures of sex toys or sexual positions. There is also advice across the lifespan, including a section on at what age you use what words as a parent talking to a child, and sexuality issues as an elder. Here is an idea: Consider buying a copy of this book this Valentine's Day—for a friend or family member, or even as a gift for yourself.

Speaking of Valentine's Day, your Ms. Love recently went to a free workshop at Good Vibrations called “Flirting with Finesse: Courting and Safely Seducing.” I took notes so I could share some of the great suggestions with you:

* **Don't flirt with someone unless you are prepared for rejection**: Check in with yourself about your current level of self-esteem, and how you would handle future interactions with the subject of your flirtation if they are not interested in you.
* **Develop your ability to read body language**: For example, if a person is laughing, they are welcoming your flirtation, but if they have their arms crossed they may be giving a message that they are not interested at the moment.
* **Know your style of flirting versus the style of the person with whom you are flirting**. Polite flirting is shown with proper manners, and non-sexual communication before touch. Playful flirting is light-hearted, not goal-oriented – think Marilyn Monroe. Sincere flirting is looking for a deep emotional attraction. Physical flirting is more overtly sexual and using a lot of body contact, such as dancing at a club. Think of James Bond when you think of traditional flirting – there is a pursuer and aggressor, and the person being pursued.
* **Pick-up lines based on flirting styles:**

Polite: “If you are interested, I would love to buy you a drink.”

Playful: “How much does a polar bear weigh?” (Enough to break the ice!).

Sincere: “How was your day?” or “Have you read anything good recently?”

Traditional: “Can I take you out?”

Physical: Holding out a hand to dance or giving a hug.

* **Flirting is much more fun when you are engaging with someone's interests**. First, be aware of what makes you interesting—such as having watched every episode of the Twilight Zone at least five times or having just won a chili cook-off.

*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*](mailto: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.*

**INFORMATION BRIEFS**

**Seven Hills Adult Family Care and Shared Living**

Seven Hills is one of the largest foundations on the east coast, providing help to over 40,000 seniors and adults with disabilities. A new office recently opened in Fall River, MA and Seven Hills is reaching out to partner organizations that would benefit from their resources. Presentations can be delivered on-site at a convenient time for staff members who are interested in learning more about the full range of programs at Seven Hills Foundation.

There are two programs that adults with disabilities and seniors who are unable to live alone independently may benefit from: **Shared Living** and **Adult Family Care**. These programs provide care recipients an opportunity to live in a home setting within the community for as long as possible. Please refer to the article on Page 1 of this newsletter, ***Partnering with Families to Build Dignified, Meaningful Lives,*** for a full description of these programs.

For more information, please visit [www.sevenhills.org](http://www.sevenhills.org) or contact Carole Graves, Outreach Enrollment Coordinator for Seven Hills Family Services AFC program at [cgraves@sevenhills.org](mailto:cgraves@sevenhills.org) or 774-232-9293.

**“Focus” on Vision Impairment & Blindness Conference**

**Meeting the Needs of Individuals with Intellectual Disability & Vision Loss**

**When: March 8, 2017 • 8:00 am - 3:30 pm**

**Location: Four Points by Sheraton, Norwood, MA Welcome Remarks: Paul Saner, Commissioner** Massachusetts Commission for the Blind

**Keynote Speaker: Susannah Rowe, MD MPH**

Director, Exceptional Vision Service, Vice Chair for Patient Safety and Quality, Assistant Professor Department of Ophthalmology Boston University School of Medicine

**Ten Years and Counting: Lessons from a Decade of Successful Eye Surgery for People with Intellectual Disability**

Registration Forms available December 2016: Registration Brochure and Form, including CEU information, will be down-loadable from “Training and Events” section of DDS website: **www.mass.gov/dds/visionloss** and from the “Perkins Professional Development Calendar” on the Perkins website: **www.perkinselearning.org/events-monthly**.

For additional information, including sponsorship, vendor or advertisement opportunities please contact: Lisa.DiBonaventura@state.ma.us or 508-384-5539.

**Registration needed by February 24, 2017 to attend.**

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