***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.*

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**From the Editor:**

Dear Readers,

After a grueling winter with record breaking snow and Swiss Alp style snowdrifts, I am eagerly anticipating basking in warm sunshine and seeing the cheerful faces of spring flowers. It never ceases to amaze me that no matter how harsh the winter is, spring really does arrive. Enjoy the delights of a long awaited for and gratefully received spring!

As you read this newsletter, you will see that communication is the focus of a few articles. Communication is at the heart of every relationship and interaction and yet, we have very little training on how to improve our communication skills. In our public schools, we learn math, reading, history etc., but a class on how to communicate effectively is sorely lacking. Combine this lack of training with our society’s general discomfort to talk openly and directly about disability; it’s no wonder so many of our conversations are messy and frustrating.

In this issue, we offer articles on communicating more effectively with your PCA, medical professionals, and members of your local community. To improve our communication skills we must be bold and as the Nike slogan says, “Just Do It.” It requires taking a risk that what you want to say won’t come out exactly right or what you say may be misunderstood by the other person. It’s up to each individual to choose whether the effort and risk is worth the potential benefit. When it comes to building a strong relationship with your PCA, medical team, and your local community, it may be worth some extra effort.

Marianne DiBlasi, Editor

**Disability Etiquette: Interacting with People with Disabilities in the Healthcare Environment**

**By Sandy Alissa Novack**

Etiquette concerns are especially serious in a medical setting. We are often at our most vulnerable when we are stressed, ill, and baring our bodies as well as our souls to medical staff. Ray Glazier, principal of disAbility Research Associates ([www.disabilityresearch.org](http://www.disabilityresearch.org)) and *Disability Issues* editorial board member, reports “There are about 726,000 adults in Massachusetts with disabilities, or more than 11% of the general population. This means that every ninth person with whom you have contact with is likely to have some form of disability.” The percentage of people presenting with some form of disability will continue to rise higher in many healthcare settings; creating a greater need for medical providers to be trained in disabilities and issues of disability etiquette.

For a solid foundation of general disability etiquette, the United Spinal Association publishes a guide that covers more than spinal disabilities. It includes etiquette for interacting with people who have speech disabilities, learning disabilities, multiple chemical sensitivities, and more. To download a free PDF or purchase printed guides, visit [www.UnitedSpinal.org](http://www.UnitedSpinal.org).

Leana Wen published an article with NPR, *Doctors’ Ignorance Stands in the Way of Care for the Disabled* (May 17, 2014). The article points out, “less than 20% of medical schools teach their students how to talk with patients with disabilities about their needs” and “More than half of medical school deans report that their students are not competent to treat people with disabilities”. Alyce Lanoue, a local retired nurse who is visually impaired, says her daughter is enrolled in a nursing program where addressing disabilities in a medical evaluation is not discussed. Her daughter makes it a point to frequently bring up disability related issues during class discussions. Too often the patient with a disability needs to take on the role of trainer. The good news is that medical providers are often eager to learn and do better.

At Beth Israel Deaconess Medical Center-Boston (BIDMC), more assistance for hospital staff is on the horizon. Health professionals are developing an all-staff training module on disability awareness as well as suggested scripting for handling a range of issues. Sample tips will include:

* ”Human First”: See the person, not just the disability. When speaking or writing, mention the person first. ‘Patient who is using a wheelchair’, not ‘wheelchair patient’.
* Ask, do not assume, if and what a patient may need.
* If a patient tells you what they need, believe it, use it, and act on it.

Additional etiquette that is specific to the healthcare environment include:

* Adjust your pace so that someone with a disability is not left behind when you run on ahead to the exam room. Walk beside the person with a disability, or slightly ahead of him or her, if you are leading the way to a room.
* Physicians need to be aware that radiological tests involving x-rays machines, MRI, mammograms, etc. are one of the least accessible areas of health care today. Doctors should pause and think, as well as seek consultation, about the person with a disability they want to refer to radiology before making a referral.

Sample issues for radiological tests include:

* Weight-bearing x-rays of feet may not be possible if a person with a disability cannot climb stairs to reach the equipment and if the equipment can not be lowered to the person’s feet.
* A full mammogram may not be possible if the person with a disability cannot move their body into the necessary positions.

The following individuals share some disability related experiences and advice:

* Elizabeth Dean Clower, a public health physician who uses a wheelchair, believes doctors should consider scheduling longer length appointments for some patients with disabilities who may have complex needs and require more time for a comprehensive exam. Patients can also plan ahead and ask their doctor to talk with the front desk about scheduling a longer appointment for their next visit. This respects the time and needs of both the patient and physician.
* Katie McGuinness accompanies her 94-year-old father to all his medical appointments. She states some medical providers direct the conversation to her rather than to the patient, her father. She encourages medical professional to always look at and talk to the patient.
* Karen Schneiderman, a Senior Advocate at the Boston Center for Independent Living, states that people with disabilities sometimes are afraid to say they need something disability related for their medical care; or they fear there could be repercussions for speaking up. She also says some people may not want to ask for help out of concern they would be laughed at or ridiculed.

Of course, it works both ways. Did it ever occur to you that some of the staff at your medical office may have fears of their own? One healthcare worker recently asked me a question she had been wondering about, and knows others without disabilities would like an answer to, but are afraid to ask. Her question is, if you enter a restroom with multiple stalls, and all except the accessible one are occupied, is it acceptable to use it if you are not a person with a disability? She has observed ladies who are waiting their turn, lower their eyes in disapproval when someone, seemingly without a disability, enters or leaves the accessible stall. She knows that disabilities are not always visually obvious and these stalls are not exclusively reserved for disabled individuals; sometimes people without a disability may need the extra room or accessories of an accessible stall. Even knowing all this, it’s confusing to know what to do. She is glad I am interested in opening up the topic of disability etiquette because she knows that she and others without disabilities welcome some guidance on all kinds of disability etiquette matters.

Elana Premack Sandler, former Project Leader of Patient and Family Engagement at BIDMC, says, “I think a common stumbling block for providers and other medical office staff is not knowing what may be okay to ask. Most people want to be respectful and think that not directly addressing a disability is the best way to do that.” Elena also shared, “It would be helpful to know from people with disabilities; what is the best way to ask? What are you comfortable sharing?” She acknowledges it’s important to respect that everyone’s comfort zone is a bit different.

Elana also says she has heard from family members who coordinate the care of their loved ones with cognitive disabilities that it’s important for a provider to talk about what they are about to do so the patient is not taken by surprise. For example, “I’m going to stand behind you and adjust this so I can get a better x-ray’’, or “I’m going to raise the bed now.” Elana adds, “I think these ways of communicating are respectful to all patients and honor that a person’s body is his or her own.”

*Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G**is a Social Worker and a consumer advisor on the Beth Israel Deaconess Medical Center’s Universal Access Advisory Council.*

**Tips for Talking with your PCA**

**By Ray Glazier**

First and foremost, your personal care assistant (PCA) is your paid employee through the MassHealth PCA Program. As a side note, these considerations also apply equally to home health aides who provide in-home services through the Dept. of Veterans Affairs Homemaker/Home Health Aide Program. Even if the PCA is actually a family member or a personal friend, it is important to maintain the employer / employee distinction when it comes to your personal care. You are the boss in this situation, because you best know your needs and how you want them met. So you need to be clear from the outset about your expectations. Clear reciprocal communication is key in any employer / employee relationship.

PCA management is especially complex because by its very nature the relationship between you and your PCA is very up close and personal. PCA work usually involves activities that are very personal, even intimate — things like toileting, bathing, and dressing. A long-term or live-in PCA may become a close companion and confidante, a stand-in for a family member or a dear friend. This can make it difficult to be direct about saying what you want done and give directions about how you want it done. So it is important to maintain a distinction between working PCA activities and personal time.

Your MassHealth PCA evaluation by your provider agency is based on how many minutes per week the nurse feels are required to address each of your specific service needs. However, as the consumer-employer, you decide how to allocate your allotted PCA hours. You might decide on a particular day, for example, that you prefer your PCA spend some time accompanying you to a ballgame or doing your nails and skip your daily shower. Your PCA can provide any form of assistance you need with any activity that is mutually agreeable and is not illegal, destructive, or sexual. But your PCA is not your personal slave.

So the very first rule in communicating with your PCA is mutual respect. Some examples are:

* Instead of, “Give me my cell phone.” [Sounds demanding] You can say, “Please hand me my cell phone.”
* Instead of, “I need my cane.” [Avoid dependency terms like “need.”] “Please hand me my cane.”
* Instead of, ”I dropped my book.” [Sounds like “poor me.”] “Please pick up my book.” [More direct and less emphasis on your disability.]
* Instead of, “Could you / would you wash the dishes before you leave?” [Never make a request as an indirect question.] “Please wash the dishes before you leave.
* Instead of, “I’d like you to fix my lunch now.” [Too wishy-washy and not explicit.] “Please warm up the casserole leftovers for my lunch.”

Secondly, it is unwise to assume that your PCA knows your mind about a task, even if he or she has done it before.

* Instead of, “Put away my gloves.” You can say, “Please put my gloves in the top dresser drawer.” [Polite and specific.]

Another PCA consumer-employer misstep of which I have too often been guilty of is bundling requests, just to get them off my mental to-do list (and onto someone else’s plate). If you say, “Please sweep the floor, wash the dishes, start the laundry, and make my lunch.”, you will be lucky if the first two items are remembered and acted upon. It makes more sense either to state the most important task first and wait till that is finished before making the next request, or to make and present to the PCA a written note with the day’s activities with the tasks in descending priority order. In either case, be sure to note deadlines: “The trash must be put out by pickup by 7:30 this morning.” or “I must be bathed and dressed in time to leave at 1:30 for my 2:00 doctor appointment.”

Another caution: If you have more than one PC, never gossip about or badmouth one to the other. This will almost certainly boomerang to bite you in the backside. Pointing out one PCA’s shortcomings to another sets a negative dynamic. But pointing out one PCA’s positive accomplishments to another can be motivating. At the same time, do not say (or imply) something like: “I wish you were more like Janet.”

Establishing and maintaining good lines of communication is crucial to effective PCA management. If you have other PCA topics you would like read about in future issues or to receive advice anonymously from a consumer veteran about a specific question, feel free to email the author at raymondglazier@gmail.com.

*Raymond E. Glazier, Ph.D., formerly of Abt Associates Inc. in Cambridge, is an SSDI beneficiary who returned to full-time employment in order to support himself and his family; now semi-retired, he is founder and Principal of disAbility Research Associates, LLC of Belmont, MA.*

**Disability Access Commissions** A**re Making a Difference**

**By Mary Jane Fietze**

Local Disability Access Commissions (DAC) were first established to advise their municipalities to achieve inclusiveness by removing barriers both to public buildings and services. Its main objective is advisory, not enforcement, and the Massachusetts Office on Disabilities (MOD) is the technical advisor for local DACs, of which there are 160 in the state. Navigating through bureaucracy is a slow process and yet, it is impossible to share with you all the great success and creative projects that the state’s DACs are achieving.

“Disability Advocacy is like eating soup with a fork," explains Victoria Buckley the Chairman of Lexington’s DAC, “because progress is slow and you only get a little each time.”Several of the local commissions actually have the Selectmen try out a wheelchair or a blindfold and a walking stick to experience first-hand what it is like to be either mobility challenged or visually impaired. Watching beads of sweat appear on the participant’s forehead as he/she attempts to maneuver up a ramp, that is *not* to code, gives them a direct experience which emphasizes the importance of the Americans with Disabilities Act (ADA) building code.

Many local DAC’s have the luxury of a healthy Handicapped Parking (HP) Fund; which are funds accumulated through violators fees for people who park illegally in HP spots. The common response from a DAC regarding HP parking violators is mixed. On one hand, illegal use of HP parking means that a disabled person cannot go shopping, get to an appointment, or dine in a restaurant. On the other hand, violation fees also means money in their HP Fund is increasing; and more money means more creative projects can be developed.

The obvious utilization of HP funds include curb cuts, ramps, elevators, and automatic doors; however some communities have gone beyond the ordinary. Jeff Dougan from MOD suggested that Burlington’s DAC utilize the funds to pay for a special police detail to monitor HP spots in a specific area and ticket the violators. After receiving project approval from the Selectmen and coordinating with the Burlington Police Department (BPD) for implementation, the special detail, which was coined “Operation Access” by the BPD, was created. For 10 days during early-mid December, police monitored HP spots at the Burlington Mall. What happened? 154 people received $200 tickets for illegally parking and 15 people were issued a $500 fine for misuse of the placard; meaning that the person using the placard did not match the person in picture on the placard. In addition to the $500 fine, the placard was immediately seized, forcing the actual owner to reapply at the Registry of Motor Vehicles for a replacement.

Burlington was not the first town to implement this type of Handicapped Parking surveillance program; Waltham was the first in the country! Fall River, Scituate, Leominster, Framingham, and Bellingham have also found success from this special detail.

Each Commission is unique and many have a town employee/ADA Coordinator assigned to answer municipal accessibility issues and to guide the DAC volunteer members. Over the years, new technologies require new responses in providing accessibility. For example: The Watertown Commission has been funding closed captions for their cable televised Town Council Meetings since 2011. Captions provide accessibility to the deaf through on-screen verbal descriptions. Courtesy of the Arlington DAC, the Mass. Rehabilitation Commission sponsors a Job Fair for the disabled each year at the Arlington Town Hall.

The Burlington DAC’s commitment to education is reflected in the *Differently-Abled talks* presented annually at the elementary schools in town. Members of the DAC talk to the children about their personal experiences of living with a disability. “We are *differently abled* because we are still able to do things like you, but we do them in a different way,” explains Maura Mazzocca, who is blind. The children look on fascinated, as she instructs her guide dog “Jolley” to find the door, and they squeal in glee as he brings her to the janitorial closet, not the exit door. Most local DACs have between 5-9 hardworking, members; however, Jolley is not an official member, just an enthusiastic supporter.

*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.*

**ADA 25 Boston Celebration Set for July 22nd on Boston Common**

**By Tim Sullivan**

The Americans with Disabilities Act (ADA) is one of the most transformative laws in US history. Its mandate created access and opportunities for persons with disabilities. To commemorate the historic 25th anniversary of its signing, the ADA New England Center with cooperation of state, city and area organizations is proud to announce that the official **“ADA 25 Boston” recognition will occur on Wednesday, July 22nd from 11am-3pm on the Boston Common.**

This free family-friendly event is open to the public and will include dignitaries, celebrities, music, demonstrations, education booths, music, games and much more.  The theme of the event will honor the tremendous achievements accomplished in the past 25 years to advance the quality of life for persons with disabilities, while also rallying the public to forge ahead and take on new challenges. The event will start with a festive march around Boston Common kicked off by City of Boston Mayor Martin J. Walsh.

“Please join us in commemorating the landmark passage of the nation’s premier civil rights laws, the Americans with Disabilities Act (ADA).  Much remains to be done to achieve full inclusion for all Americans with disabilities, but it is a different and better world today thanks to the first 25 years of the ADA. Meet many of the advocates who helped pass the ADA, as well as our young people advocating on behalf of the next 25 years of the ADA, “ said Oce Harrison, Director of the New England Americans with Disabilities Act Center in Boston.

The ADA 25 Boston committee is made up of a dozens of groups and organizations from business, government, community and non-profit sectors. They represent constituencies from the broad range of the disabilities spectrum including physical disabilities to mental health and cognitive. The committee’s goal is to ensure that all are welcome in this celebration.

To learn more about activities, sponsorship opportunities and information visit [www.ADA25Boston.org](http://www.ada25boston.org/).

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

**Ways2Go Travel Training Increases One’s Transportation Options**

**By Linda Shepard Salzer, Ways2Go Travel Trainer**

Travel training can increase one’s ability to get and keep a job, socialize, and become or remain independent. Ways2Go, a program of Door2Door by SCM in collaboration with Mass Rehab Commission, Cambridge Commission for Persons with Disabilities, and the MBTA provides travel training for seniors and persons with disabilities throughout the MBTA bus and subway service area. Ways2Go launched in July 2013.

Travel Instruction includes orientation, familiarization, and travel training. Ways2Go partners with the MBTA to provide System Orientation Training, a half-day introduction to the T. These include classroom and hand-on portions covering safety, trip planning, reduced fare, accessibility, how to use the fare vending machines and read schedules and maps.

System Orientation generally takes place at the MBTA Emergency Training Center adjacent to Broadway Station on the Red Line and concludes with a short bus and subway ride. We limit these to 12 participants for an optimal learning environment.

We offer a general System Orientation or one specifically designed for individuals who are blind, in which we focus on the auditory and tactile features, including a tactile map, and allow the individuals more time to explore out of service vehicles.

Some people will gain all the information and experience they need by attending System Orientation but many will want additional one-to-one, personalized assistance. Ways2Go Travel Trainers then practice with the individual; going to the destinations he or she chooses working toward safe, independent travel for at least some trips. Ways2Go Travel Trainers recognize that individuals learn at different paces and in different styles and adapt accordingly.

Ways2Go actively participates in the Massachusetts Travel Instruction Network (MATIN) and the Association of Travel Instruction (ATI). ATI will hold its August 2015 conference in Boston, August 12 – 14 at the Courtyard Boston Downtown, 275 Tremont St. For more information, visit [www.travelinstruction.org/annual-conference](http://www.travelinstruction.org/annual-conference).

Ways2Go operates under a federally funded grant, so there is no charge to participants. For more information, to sign up for System Orientation or Travel Training, or to schedule an outreach presentation, please call 857-756-5893, e-mail us at traveltraining@scmtransportation.org or find us on Facebook by searching on “Ways2Go Mobility Management”

*Linda Shepard Salzer is a Ways2Go Travel Trainer at Door2Door Transportation by SCM in Somerville MA.*

**Love and Intimacy Corner**

**State Resource Guide on Relationships and Sexuality Gathers Together Much Information**

**By Ms. Love**

The Massachusetts Department of Public Health and the Department of Developmental Services have a winner in their *Healthy Relationships, Sexuality and Disability Resource Guide*, 2014 edition. It is available for free download from a computer at <http://www.mass.gov/eohhs/>, enter **“Healthy Sexuality and Disability and Resource Guide”** in the Search box. If you do not have access to a computer, you can call the Executive Office of Health and Human Services at 617-573-1600.

Many people seek sex education, socialization, intimacy, and other sexual health material but do not always know where to turn; this guide can give readers some options. The guide offers a wide range of resources that are intended for youth, parents, adults with disabilities, or educators and other professionals. Some cover multiple disabilities and others focus primarily on one or two kinds. And, as is often true in such matters, you should not necessarily skip over a listing because you are not seeking information about the particular disability covered in the listing. Some gold nuggets of information can be found by reading widely about other than your own disabilities as well as on socialization and intimacy in general.

Below are a few listings that I found interesting, but I suggest you look through the whole guide to find resources that are most useful for your needs. Costs vary for the resources listed but some excellent ones are free.

*Asperger’s and Girls* by Tony Attwood. Published by Future Horizons (2006). A book focused on girls and women with Asperger’s.

[www.GirlsWithNerve.com](http://www.GirlsWithNerve.com) connects teens with epilepsy with information on everything from epilepsy to menstruation and dating.

[www.MariaTalks.com](http://www.MariaTalks.com) (AIDS Action) provides information about everything from sexual health and family planning to HIV and STI, domestic violence, and sexual assault.

*Gay, Lesbian, Bisexual and Transgender People with Developmental Disabilities and Mental Retardation: Stories of the Rainbow Support Group* by John D. Allen. Published by Harrington Park Press (2003).

*Impact* online newsletter offers a “Feature Issue on Sexuality and People with Intellectual, Developmental, and Other Disabilities”. Published by the Institute on Community Integration, and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota. Volume 23, number 2 (Spring/Summer 2010). Articles include: *New Ways to Think About Parents with Intellectual Disabilities, Teens and Sex Today*, and some positively super resource lists, including one called *Sexuality and Adults with Disabilities: Resources Supporting Dating, Marriage, and Parenting*. The issue can be found at <https://ici.umn.edu/products/impact/232/>.

Ms. Love hopes you find these resources helpful. Healthy, safe sex and being comfortable talking open and honestly about your unique body and what you find pleasurable is your right and an essential part of life.

*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.*

**INFORMATION BRIEFS**

**Find Your Summer**

Boston offers exciting summer options for residents and visitors of all ages. Many activities are free. See a movie in your local park, attend festivals, listen to a concert on City Hall Plaza, or learn to paint on the waterfront. Explore your city this summer!

For a one-stop website that lists great events all season, visit [www.cityofboston.gov/SUMMER](http://www.cityofboston.gov/SUMMER)

For accessible information and activities, visit *Wheelchair Accessible Boston* at

[www.massvacation.com/navigate/accessible-travel/](http://www.massvacation.com/navigate/accessible-travel/) or call Massachusetts Office of Travel & Tourism at 617-973-8500.

**Playscape for all Ages and Abilities**

The **Playscape at Ripley** is a new, nature-based park and playspace for all ages and abilities in Concord, Massachusetts. Its universally-accessible design purposefully engages people of all abilities with nature on multiple levels – physical, social, and sensory. The Playscape’s universally-accessible reinforced stonedust path, accessible sandbox, and hills for rolling engage visitors on a physical level, while the Playscape’s many natural beauties stimulate the senses. And when visitors are ready to relax, the accessible picnic tables provide all with a spot to rest.

The Friends of the **Playscape at Ripley** are holding three outreach events at the Playscape in the spring/early summer to introduce people to this unique public space. All events are free of charge and open to the public:

* Sunday, June 14, 2-4 pm: event for the special needs community,
* Sunday, May 3, 2-4 pm: event for young families, including families of young children with special needs;
* Monday, June 8, 10am-12pm: event for seniors.

Visitors at each event will be able to explore the Playscape, participate in a nature-based art activity, and enjoy some treats!

The Playscape is located at the Ripley School Administration building, 120 Meriam Road, Concord. For more information about these events, contact Friends of the Playscape at Ripley committee member Jennifer Saxe on (978) 369-6790 or at ccc-development@verizon.net. To learn more about the Playscape, visit [www.ripleyplayscape.org](http://www.ripleyplayscape.org).

*Outreach events made possible thanks to Northwest Suburban Health Alliance/CHNA 15 DoN Funds from Lahey Hospital and Medical Center and Winchester Hospital.*

**The Zola Center’s Free Food Distribution Program**

The *Irving K. Zola Center for Persons with Disabilities* is located at 20 Hartford Street, Newton Highlands, MA 02461. The Zola Center operates a Free Food Distribution Program that is open to all residents of Newton and surrounding towns. There is no registration to receive food items. Items vary each week but can include fresh fruit, vegetables, prepared foods, fresh bread and rolls from local bakeries and pastry from Starbucks.

Beginning Saturday, January 17, 2015 this program will operate every other Saturday from 12:00-1:00 P.M. Doors to the building will open at 11:00 A.M. Please bring your own grocery bags to transport food. The Zola Center also offers free “Meditation Class” and “Reiki Treatments” once each month. For more information call; 617-277-5131 or e-mail zolacenter@juno.com

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