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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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From the Editor....

Dear Readers,

We are thrilled to launch our newly revised online version of the *Disability Issues* newsletter! With this change, we are now able to publish color photos, which is ideal timing, so you are able to see Ms. Wheelchair-Pennsylvania in all her rainbow-colored vibrancy! We are also able to provide direct links to an increased number of web resources.

In this issue, we bring you a series of articles that address easing loneliness. Ms. Love sets the context with song lyrics and provides ways for a person with a disability to ease loneliness and find the “love cure.” In the articles that follow, we see her wisdom applied by people with disabilities. We hope this issue will inspire some new creative thinking about ways to be more socially engaged.

We encourage you to share the newsletter with friends and family who you think would be interested in the entire newsletter or a specific article. If they are interested in becoming a regular subscriber and receiving *Disability Issues*, all they need to do is, send an email to SubscribetoDI@gmail.com with their First/Last Name and Email Address and they will be added to our subscriber database.

If the online version is not accessible and you need to receive *Disability Issues* in print format, we can add you to our list of subscribers who receive a Large Print text only version of the newsletter. Please contact Colleen Moran at cmmoran@partners.org or 617-952-6927 to give her your First/Last Name and Mailing Address and ask to be added to the Large Print mailing list.

Enjoy this online version of *Disability Issues*!

Marianne DiBlasi, Editor

Love and Intimacy Corner



Will You Be Lonesome Tonight?

By Ms. Love

I like reading my email from you, my readers. I like knowing what is on your mind and the questions you ask are always ones that others have too. Over the years, the question I receive most often is about loneliness. Readers have written me about yearning for a relationship with someone special, about yearning for the opportunity to meet others in social ways, about yearning to be part of the life that others have and we want too—choices of people to date, marriage to someone wonderful – the lifelong built-in spouse and partner, the great sex life, the kids and grandkids.

But what if life is not like those clips where the woman runs in slow motion towards the man in the field and the music plays dramatically as the couple embraces and it all ends happily? What if it is hard to be social because of a communication disability, a mental health issue, or a physical limitation? What if you are mostly home-bound with your disability? What if you live in a rural area and your community does not provide para-transit to meet someone for bowling or for a date?

According to Spinditty.com (<https://spinditty.com/playlists//Pop-Rock-Country-Songs-About-Loneliness>) many of us feel a temporary loneliness, such as when a significant relationship ends in divorce or death, but one out of five Americans feel chronically lonely. And, the site states for adults over the age of 45, one in three adults are lonely. On the other hand, BBC News (<https://www.bbc.com/news/stories-45561334>) found higher levels of loneliness in younger people than in elders. Regardless of the statistics about who is lonelier than who,

the bottom line is that plenty of people find themselves lonely. The BBC article includes information about a woman named Megan who talks about loneliness and being blind.

Many artists sing about the human condition of loneliness, such as Luther Vandross singing "Any Love" https://www.youtube.com/watch?v=_hQwuZPnqm4

*What a world for the lonely guy
Sometimes I feel I'm going to lose my mind
Can anybody tell me just where to find
Any love, any love?*

*Everyone needs a love no doubt
Any love, any love
Everybody feels alone without
Any love, any love*

*And I know there's a love waiting
To enter my life, enter my life
Every day as I live
I try to think positive
I pray for someone good to come
Any love*

*Love is sweet and so divine
And I can't wait for my love life to shine
Can anybody tell me where I can find
Any love, any love?*

Another example of a song on being lonely is a song by Bobby Vinton at https://www.youtube.com/watch?v=djU4Lq_5EaM

*Lonely, I'm Mr. Lonely
I have nobody for my own
I am lonely, I'm Mr. Lonely
Wish I had someone to call on the phone*

If you can't remember hearing songs about loneliness, the Spinditty site has created a list of songs at <https://spinditty.com/playlists/Pop-Rock-Country-Songs-About-Loneliness>. A classic is Eric Carmen's "All By Myself", available at <https://www.youtube.com/watch?v=iN9CjAfo5n0>

*All by myself
Don't want to be, all by myself any more
All by myself*

Don't want to live all by myself anymore

Hard to be sure

Sometimes I feel so insecure

And love so distant and obscure

Remains the cure

If love “remains the cure,” how do we as people with disabilities find the love cure?

- **Be a joiner:** Sometimes readers write me that they go to support groups for people with their kind of disability. I advise them to make the most of it by participating in discussions, going early and staying late to start conversations with others in the group. Maybe offer to help find speakers for future support groups. In short, be a doer and a person who joins in with others. That is one way to make connections and make friends.
- **Be inclusive:** Often readers write me about their negative experiences, such as people at support groups who have similar disabilities but are often older or younger than they are and therefore, not someone they are likely to date. Instead of looking to only date, look to make friends. At the end of the day, everyone needs friends to call and talk to, to spend time with, and to bond with over shared interests, hobbies, and activities. Don't be quick to weed out potential friends; instead seek to include people different than you. You don't need a clone of yourself, you need someone who brings out the best in you. That could mean you need friends both older and younger than yourself, friends of different cultural backgrounds, friends with and without disabilities.
- **Strut your stuff:** No matter what your disabilities may be, you are special and don't forget this. What your Ms. Love means by this is, you have probably learned a thing or two over the years about perseverance and speaking up for yourself in a variety of situations, so don't dismiss your strengths when you are making friends. Other strengths might include your sense of humor, your love of animals, etc. If you don't become best friends with someone, so be it, but there are others out there who would appreciate a friend like you. Continue to add people to your friendship circle.
- **Volunteer in the community or at school or the workplace:** Volunteering often puts you in touch with a different group of people than you see day to day. Since you are all volunteering for the same cause or activity, you already have shared

interests and friendship often grow out of shared interests. If you live in the Boston area, consider attending Boston Center for Independent Living (BCIL) events and activities. Consider joining one of their advocacy efforts, going to a class or a social event. It is nice to feel needed and independent living centers near you need people who are passionate about affordable and accessible housing, transportation, health care, and more. You won't be lonely at the end of the day when you have spent the day lobbying for others with disabilities or trying out great activities together, such as, a recent Adaptive Yoga class at BCIL. At work, volunteer to be on the staff holiday party or other kind of committee to spend time with new-to-you co-workers.

- **Plan ahead:** Hoping for the day when friendship turns into a love interest? Concerned about how your disability may impact how you express your love? If you have read some of my past columns, you may already know about the book *The Ultimate Guide to Sex and Disability* by Kaufman, Silverberg and Odette. This might be a good time to re-read some of those chapters. The same goes for *The Sex and Pleasure Book: The Good Vibrations Guide to Great Sex for Everyone* by Queen and Rednour. Consider signing up for free emails from The Mighty at <https://themighty.com/why-join-the-mighty/>. The Mighty writes about different disabilities and illnesses, with different viewpoints by different writers, including articles about issues such as loneliness and socializing.

You know, even though my pen name is Ms. Love, even I have my moments when I feel lonely. With Valentine's Day soon upon us, remember the words of the rock band, YES, singing "Owner of a Lonely Heart" <https://www.youtube.com/watch?v=SVOuYquXuuc>

*Move yourself
You always live your life
Never thinking of the future
Prove yourself
You are the move you make
Take your chances win or loser.*

*See yourself
You are the steps you take
You and you, and that's the only way*

*Shake, shake yourself
You're every move you make
So the story goes*

...There's no real reason to be lonely

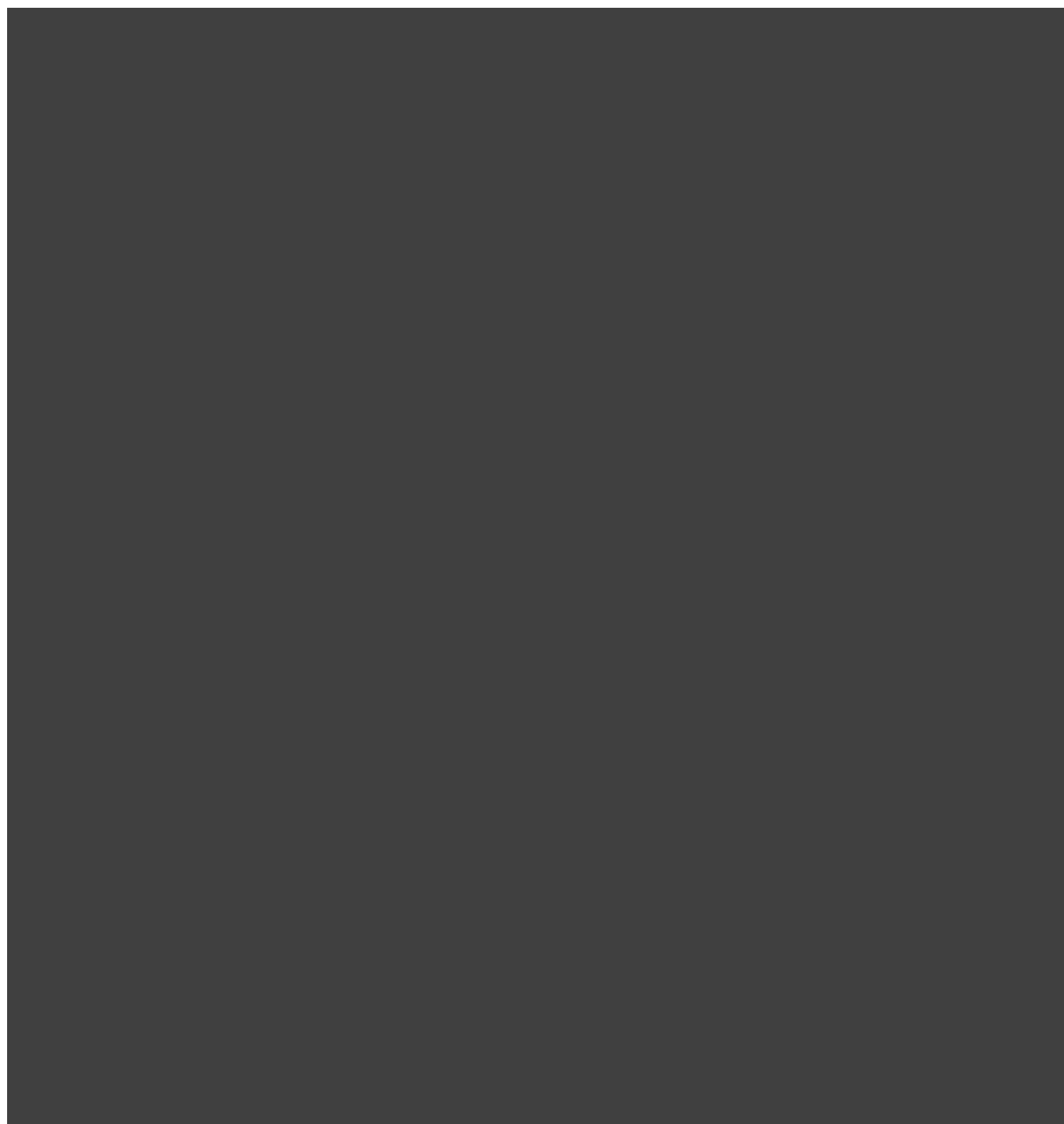
Be yourself

Give your free will a chance

You've got to want to succeed.

To your success in easing loneliness! And remember, Ms. Love is thinking of you this Valentine's Day.

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.





Barb Zabloutney, Ms. Wheelchair Pennsylvania 2018.

Photo Credit: Jason Bafile Photography

Role Models and Disability Advocates:
The Inspiring Tales
of Three Ms. Wheelchairs

~ Part 1 of 3 ~

by Sandy Alissa Novack

At this past Fall's Abilities Expo in Boston, I had the pleasure of meeting Ms. Wheelchair-Pennsylvania, Ms. Wheelchair-Rhode Island, and Ms. Wheelchair-America. Each woman had a story to tell about how they came to be a Ms. Wheelchair and how they are using in the opportunity to empower people with disabilities during their reign. For this issue, I interviewed Barb Zabloutney, Ms. Wheelchair-Pennsylvania. The Spring issue will contain my interview with Tina Guenette Pedersen, and the Summer issue will conclude the series with an interview with Karen Roy, Ms. Wheelchair-America.

Sandy Novack (SN): Please tell our readers about Ms. Wheelchair-Pennsylvania and your roles.

Barb Zabloutney (BZ): Ms. Wheelchair-Pennsylvania is a 501c3 non-profit organization that works to celebrate the achievements of women wheelchair users. The most articulate spokeswoman is chosen to be the titleholder and throughout her reign she works to empower people with disabilities throughout her state. I am the current reigning Ms. Wheelchair Pennsylvania for 2018, until I crown my successor January 2019. Once my reign is over, I will be taking over as Vice President of Ms. Wheelchair-Pennsylvania. I also chose to accept the position of Director of Recruitment for the Ms. Wheelchair America board. My job will be working to recruit and empower more women to compete in their states.

SN: Why did you apply to be Ms. Wheelchair-Pennsylvania?

BZ: I was sick of dealing with a lot of ignorance daily. Complaining on Facebook does not solve the issue, but gaining a platform like this will help solve it if I put the work in, and I have

SN: Can you tell us a little bit about your relationship to disability, and about your Ms. Wheelchair platform?

BZ: My platform is: changing ignorance with education and inclusion. I coined it as the R.A.I.N.B.O.W. platform which is an acronym for **R**allying **A**gainst **I**gnorance **N**ow **B**enefits **O**thers **W**ith disabilities. I chose that because my nickname is Rolling Rainbow. My disability is a T10 Incomplete Anterior Cord Syndrome Spinal Cord Injury, which I sustained in December 2007 when I was 21 years old. I was paralyzed on impact due to not wearing a seat-belt when I hit a patch of black ice and wrecked my car.

SN: I was fortunate to meet you today, but where can people meet you going forward? What are the messages you want to give to people you meet with and without disabilities?

BZ: I plan to attend the Abilities Expo in New York at the beginning of May. I can always be found on my social media pages, mostly my YouTube channel (@RollingRainbowBarb). The message I would like to give people with and without disabilities is that it is okay to

have a bad day. Just remember that after those storm clouds there will always be a beautiful rainbow you can seek out and look forward to the future.

SN: You and your fellow Ms. Wheelchairs are smart, dynamic, active women in the world. You also happen to be quite beautiful, yet I understand outward beauty is not something you competed on to become Ms. Wheelchair. What is the message about beauty that Ms. Wheelchair is communicating to the community?

BZ: I am hoping that people realize we are in this position due to our passion for advocating. We are trying to educate people in the community that we are NOT a pageant, we are a competition. The word “pageant” has a lot of negative stigmas surrounding it. We care more about the person and their message than their appearance or outfits. We would like the disability community to know that and to nominate any woman wheelchair user at least 21 years of age they think would benefit from our program.

SN: For people reading this who are interested in applying to become Ms. Wheelchair, or if they know someone who might be interested, can you please comment on the benefits of being Ms. Wheelchair.

BZ: The benefits of being Ms. Wheelchair-Pennsylvania are never ending! Some life experiences I’ve acquired since my spinal cord injury and becoming Ms. Wheelchair-Pennsylvania include:

- Working with my borough manager to get an accessible parking sign installed at the local police department.
- Earning the People's Choice Award at the recent Ms. Wheelchair America 2019 competition.
- Teaching a class of physical and occupational therapy students at St. Francis College in Loretto, PA about how to treat their patients who may have a new spinal cord injury.
- Being the head judge at the Ms. Wheelchair-New Jersey competition this past November
- Being the keynote commencement speaker at the Commonwealth Technical Institute at the Hiram G. Andrews Center in Johnstown, PA.

The best way to see all the opportunities I have had throughout my reign is to check out my Ms. Wheelchair-Pennsylvania 2018-Barb Zabloutney (@mwcpa2018) Facebook page.

I went into the competition not knowing much about advocating and didn't really talk to many other wheelchair users. Having this title gave me the tools and platform I needed to advocate properly. Each reign is what Ms. Wheelchair makes of it. I chose to do it full time and give 100% so I would not look back with regret. For years after my injury I would

break down crying and ask for my life back. Sure, it wasn't what I originally thought I wanted back then, but it has given me my life back. I call this Ms. Wheelchair reign my third chance at life. The most valuable thing I gained throughout my reign are the women I competed against at Nationals. They are my sisters and that means everything!

SN: Is there an equivalent competition for men with disabilities? Is there a Mr. Wheelchair?

BZ: I don't believe there is...but there should be. We did joke at the National competition about Lindsey Becker, Ms. Wheelchair-Tennessee 2018, and her husband, Wes. We called Wes "Mr. Wheelchair-Tennessee" because he is also a wheelchair user who helped out a lot with different things at Nationals.

SN: Decades from now, how do you think you will look back at your reign as Ms. Wheelchair?

BZ: The number one moment during my reign – what has meant the most to me – was finding, nominating, and finally crowning the very first Junior Miss Wheelchair-Pennsylvania. Her name is Ev McConnell, and she is 17 years old and a senior at Altoona High School in Altoona, PA. She is our future and being able to mentor her to be the best advocate she can be is an amazing honor.



Left to Right: Evelyn "Ev" McConnell, Junior Miss Wheelchair Pennsylvania 2018 and Barb Zablotney, Ms. Wheelchair - Pennsylvania 2018, speaking on a panel of people with several different types of disability for a diversity day event.





Barb worked with city officials of Johnstown, PA to do a “Wheel a Day in My Wheels” event, getting several local officials to use wheelchairs to navigate a city they believed to be accessible. It made it on the news (news stories shown on her YouTube page) and front page of the newspaper.

Participating Johnston, PA City Officials

(not all who participated are present in photo)

From left to right are:

- *Tom Chernisky, Cambria County Commissioner*
- *Shanna Murphy Sosko, Chris Allison, Katie Kinka, Cambria County Planning Commission staff members*
- *Matt McQuay, Laurel Medical Solutions*
- *Ethan Imhoff, Cambria County Planning Commission staff member*
- *Anne Stitch, PennDot employee*
- *Not pictured: Frank Janakovic, Johnstown Mayor Frank*

The number one compliment I received from people in my region is about an event I spent five months planning. I was able to get local city officials to use manual wheelchairs to navigate through a city they thought was accessible. They all learned quickly that it isn't.

SN: Parting thoughts?

BZ: I will look back at my reign and be able to smile because I know it is only the beginning of my future as an advocate. I will always remember all the doors it opened for me. I plan to stay involved with the organization in some way so I am able to give back to the organization that gave me so much.

To get to know Barb, I recommend the following YouTube videos:

1. www.youtube.com/watch?v=uo21VNzreZ8, a half hour video that serves as introduction to Barb's journey—life before her accident and changes in her life after the accident. This is an honest and open telling of her story for others with disabilities (and those without). She speaks to you as if you, the viewer, is her new friend and she wants to be frank with you.
2. https://www.youtube.com/watch?v=TFBpSrR_JnE, a 12-minute video “Two female wheelchairs users transfer into a Subaru Outback independently for the first time.” The title says it all.

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.



The Value of Volunteering

By Leslie Johnson

Do you ever feel like you have too much time on your hands? Are you struggling with your self-esteem? Do you want a job, but your resume is a little limp?

Then you might want to consider volunteering.

Volunteering has so many benefits; it's hard to list them all. A volunteer job can reduce

your isolation, boost yourself-esteem and plump up your job resume. I know. I've personally experienced the benefits. I first started volunteering when I was working my way out of a severe depression. I needed to do something that would get me out of my own head and help me build my self-confidence. Having experience working with special needs adults, I decided to volunteer at a day program that Minuteman Arc runs for adults with developmental disabilities. I remember I was afraid to try something new, but I was also ready for a challenge. Despite my reservations, I took the plunge and committed to spending time every week at the day program reading books aloud to the participants. Each time I did this, I could feel my confidence growing. It felt good to balance working intensely on myself with giving something to my community.

Some years later I learned that my town has a commission made up of volunteers who help Acton to be accessible and inclusive for residents with all types of disabilities. I joined the commission and have served on it for the last four years. I've not only been able to apply my own personal experience with disability to the work of the commission, I've also boosted my social life, making good friends and doing fun social activities with them.

More recently, I learned that a nonprofit organization, the Acton-Boxborough United Way, operates near where I live. I thought it might be fun and rewarding to volunteer there. I met with the director and offered my time. She put me to work immediately. Since then, I've been volunteering about once a week, helping to process mass mailings and updating the donor database.

My volunteer work with the Acton Commission on Disabilities, and the Acton-Boxborough United Way helped me get a part-time paid job with the Bedford Council on Aging, working at their senior center. I included my history of volunteer work in my job resume, and when I interviewed for the job, I talked about my duties and accomplishments that have come out of my volunteer work. I'm certain this contributed to why I was offered the job.

Volunteering is a safe way to take on some work responsibility if you're not psychologically ready to get a paid job. It helps you work your job muscles so that, if someday you want to get a job, you'll be more fit for adding some work responsibility to your life.

And contributing to your community can be a wonderful feeling. We have a lot to offer, partly because we have personal experience with disability, which gives us empathy to apply to others who may need help.

There are so many opportunities to volunteer. If you'd like to volunteer, check out the nonprofit or town-run organizations in your town and surrounding towns. Go to your town's website and familiarize yourself with all the volunteer-led commissions that exist. The possibilities are almost endless.

You have a lot to offer the world. Volunteering just might be the way for you to share

your special gifts and abilities. So, don't be shy. Go for it!

Leslie Johnson lives in Acton. As a survivor of mental illness, she takes great pride in her work serving senior citizens and adults with developmental disabilities.



Come Enjoy Winter Fun in Massachusetts State Parks!

By Marcy Marchello

If you struggle with being stuck indoors or isolated, consider braving the cold and attending an indoor skating or outdoor winter program offered by the Department of Conservation and Recreation (DCR). DCR's Universal Access Program (www.mass.gov/dcr/universal-access) offers adaptive recreation for people with disabilities and their families, friends and caregivers. Many individuals and groups have transformed their lives and increased their abilities through discovering the thrill of gliding on ice or groomed snow.

At our first skating program in November, I witnessed Marlene Galica from the Carson

Center for People with Traumatic Brain Injury skating on the ice with a joyous grin on her face. She said gleefully, *“It took me 2 years to learn to skate without a walker but now I can do it thanks to you! Skating is beneficial for people recovering from brain injuries – it helps with balance and brain stimulation.”* Marlene came to our programs on her own, discovered many therapeutic benefits, and eventually landed a job with the Carson Center which allows her to bring other people with brain injuries on recreation outings.

Comments from other program skaters include:

“Meaghan did not want to come today. Now she is out on the ice having a blast – I can’t get her to come off. It is so great that Ken tried ice skating, even just for a little bit. That is such a huge accomplishment! You have no idea how important this is for building confidence.” - Adriana Goicuria, Triangle, Inc.

“I love this program. It’s great exercise and I have so much fun! I’m coming back next month!” – Chris Hueshe

“This program is AWESOME! Everyone had a great time! We’ll be back with more people!”
– Christina Estrada, Alternatives

Indoor ice-skating programs take place in the following locations:

**East Boston • Worcester • Brockton
Fall River • Holyoke**

Two outdoor skating programs are scheduled on man-made rinks in Wendell and Gardner. For further information, visit www.mass.gov/dcr/universal-access or contact Laila Soleimani at Laila.solemani@mass.gov.

The adaptive skating program was inspired by the director of the Universal Access Program, Tom McCarthy, who spins around in his power wheelchair on ice. It often serves over 100 individuals during a 2-hour session. The ice is ramped and wheelchair users may freely enter and try their wheels on slick and rough surfaces. Metal skate walkers allow those who are ambulatory to try ice skates or ice grippers with a balance aid. Helmets are available for everyone to use. Ice sleds offer anyone the chance to skate in a different way – seated on blades – and propel themselves with short hockey sticks or be pushed by another skater.

Games and activities are provided and often people with and without disabilities find themselves caught up in gentle games of hockey. Others enjoy music while they skate and refresh in the cool air. Some relish speed, others follow the outer wall silently or in conversation. Staff and volunteers assist with transfers, help fit helmets, skates and ice grippers called “Yak Trax” for those who don’t use ice skates.



You can also cross-country ski at the Leo J. Memorial Ski Track in Weston using standing or seated skis on the 2-kilometer groomed track of man-made snow. When natural snow covers the ground, even more ski track is available. Charles River Recreation runs a ski concession on site and can serve individuals and groups most days of the week. For further information call the Ski Track at **617-965-5110**. If you'd like to attend the DCR Universal Access Program in Weston, contact **413-259-0009**. The following quotes from participants express the value of these opportunities:

“This was so special for my two sons to ski together and for us to ski as a family. What a great program. Thank you.” – Sui Wong

“Megan would not miss this not matter how cold it is. We love the program and so glad you are here year after year.” – Ruth-Ann Rasbold, Megan’s mom

“Nikki had so much fun and great to have a ski walker and such skillful staff. This made her experience so successful.” – Beth Humphrey, Nikki’s mom

For those in the greater Boston Area, consider learning to downhill ski or play sled hockey with Spaulding Adaptive Sports Centers, call **877-976-7272** or visit <https://sasc.spauldingrehab.org>. Waypoint Adventure offers winter hiking and other activities, call **781-325-7980** or visit <http://www.waypointadventure.org>.

*Marcy Marchello has been coordinating adaptive recreation with DCR since 1995 and welcomes your inquiries and sense of adventure. She can be reached at **413-545-5758** or marcy.marchello@mass.gov*





Communicating Effectively with Your Doctor

By Ailene Gerhardt

Navigating today's healthcare system can be complicated and challenging. To achieve the most effective outcome it is critical that healthcare consumers are engaged so that they receive quality care and treatment that aligns with their values and goals.

Being a "patient" is not a passive experience. Receiving effective care requires patients to partner with their health practitioners in shared medical decisions. Patients should navigate their own healthcare with the knowledge that s/he is the most important member of her/his healthcare team.

To be able to advocate effectively for your care needs, it is useful to take inventory of your skills. Are you:

- Open to new information and perspectives?
- Comfortable setting the agenda during your appointment and being proactive, organized, inquisitive, persistent, and direct?
- Able to communicate clearly and listen fully?

Knowing what skills you bring to navigating your healthcare will give insight into what can be handled on your own and when you might need additional support and resources.

Being prepared maximizes your time during an appointment. Scheduling an interpreter, expressing needs regarding physical accommodations, or requesting a longer appointment should all be done in advance. Knowing how your insurance plans work, what is covered, and what things will cost assists you in reducing the likelihood of experiencing unexpected medical costs.

It is essential to know who is treating you and what your options and rights are as a patient. It is critical to know about your medical history, your medications, your condition, chronic illness or disability.

Effectively communicating with your provider involves being prepared to take notes, be a decision maker, and being willing to refocus the conversation to meet your goals. It is helpful to repeat explanations and instructions you've been given back to your provider to confirm you understand the information correctly.

When preparing for a doctor's appointment compile a list of prioritized questions and concerns, notes on symptoms, and new/unexpected medication reactions or side effects. Plan to review the list with your provider, focusing on items that are the most important to you. Always be honest so that you receive the most effective treatment possible.

Compile contact information for all of your current healthcare providers, your medical history, and a comprehensive list of medications as well as over-the-counter supplements, eye drops etc. Make sure you bring assistive devices with you such as glasses, hearing aids, and mobility aids so that you do not encounter unnecessary barriers to good communication.

For quick and complete access to your healthcare information consider compiling all your health information into a "Healthcare Binder." This makes it easier to "grab and go" and take the information with you. While it is useful to have information stored in electronic health record systems, not all systems interact with each other.

Consider bringing someone with you to your appointments. This person - a family member, friend, or professional patient advocate - can be an extra set of eyes and ears, prompt you regarding questions you have, and take notes during your appointment so that you can focus on listening and sharing your priorities and concerns. While having someone with you can be very helpful, it is important to remember s/he is there to support you and should play a supporting role, unless you ask for otherwise.

If you are not able to bring someone with you, ask your provider if you can record parts of your appointment when explanations, options, or instructions are being given. This gives you the option to capture accurate information and review it in the comfort of your own home.

When discussing your condition, disability, or diagnosis, ask effective questions about what is being suggested as well as why it is being suggested. Why something is being suggested helps clarify the diagnosis and suggested treatment options and approach.

Before leaving an appointment, review goals, next steps, follow up actions including tests, specialist visits, new prescriptions, and confirm how to best follow up with your provider with any questions you may have. Make sure your provider knows your communication preferences (email, portal, phone call) and ask for reliable resources for learning more about anything discussed at your appointment.

Make sure to file your notes and test results after your appointment, schedule follow up appointments, and pick up new prescriptions.

To be an effective self-advocate, it is critical to arrive prepared with a prioritized list of concerns, accurate health records, and the intent to take good notes, ask good questions, and push for answers.

It is essential to have a team mindset and approach to your healthcare. You are the main focus and the most important member of your healthcare team. Remember there are two experts in the room when you meet with your provider. The medical professional brings medical knowledge and expertise. You bring the most knowledge about your body and needs. At an appointment, listen to your instincts, use your voice, be persistent and get the answers you need to make informed decisions.

By being engaged in your healthcare, you will feel you have a greater sense of understanding, knowledge, and control which can lead to better outcomes.

Ailene Gerhardt is an Independent Board Certified Patient Advocate and Founder of Beacon Patient Advocates LLC <https://www.beaconpatientadvocates.com>





Building and Opening Doors...

“If opportunity doesn’t knock, build a door” ~ Milton Berle

By Joan Burrows

Four people in one family had Muscular Dystrophy (MD)...Walter, his daughter, son, and grandson. As adults, three used electric chairs for mobility, persevered to have productive lives, and helped others. One did not make it past 27 years old. Their lives show that each person needs a spark of desire and motivation, but also needs help from others to make things happen. No one can do it on their own.

For many years, Walter, a tall, kind, quiet man in his 40’s, stayed in bed in his room because his legs were too weak to support him. His son, Dennis, lived with him and completed all his personal care and meals. No other help was known. Then his daughter, Marcia, left an abusive husband, and moved in with her young son, Justin. Marcia was diagnosed with MD after the birth of her son and was told Justin also had MD.

One day, Walter had a cough. After three doctors told him to call 911, a local doctor made a house call. Help began! This doctor talked to Walter for a long time and asked, “Why are you staying in this room when you have so much to offer others?” After a lot of convincing, arrangements were made for Walter to go to a rehabilitation hospital and get fitted for a wheelchair. There he met a social worker from the Independent Living Center who used a wheelchair. She told him about her job, opportunities, and the availability of personal care attendants. She also connected him with Mass. Rehabilitation where he learned about social day care that would get him out of his house and let him socialize with others. Walter loved to talk!. Mass. Rehab. also widened the door to his bedroom and installed a ramp to get in and out of the house. Now he could leave his room and his

home. A whole new life was to begin! Walter thrived at the social day care center. With help from staff, he continued his education at a Jr. College, something he had longed to do. Walter connected with one special person who helped this happen. Before long they moved in together and bought a modified van.

Walter had a major medical set back and needed a respirator, but that did not stop him. He hired personal care attendants to help with his care. He continued in school, earning a degree in social work. He visited elementary schools to help children learn about disabilities. He worked with the Anne Sullivan Center where children watched the lift to his van open. They went inside and had races with Walter in his wheelchair. Then Walter received training from the state and became a Community Access Monitor. He went on to begin a Commission on Disabilities in his town and served as chairman for seven years until his health no longer permitted. Accomplishing all of this required the help of others – individuals, organizations, family, and friends. Moreover, it took perseverance and the desire to help others.

His daughter, Marcia, was petite with long blond hair, smart, and very independent. Even with MD, she was often able to help others in the family. She initially rejected receiving help for herself. Marcia took care of her younger brother when her Mother was not able to, which was often. She also helped her Dad, especially before he began going to the social day care center. One morning, she found Walter sitting in a kitchen chair, unable to walk down the hall, and she helped him to his bedroom. Another time, she came home to find her Dad on the sidewalk in the rain and she helped him get in the house.

After watching how Walter's life changed when he went to the social day care center, she decided to attend the Jr. College where her Dad had graduated. She then went to Wellesley College to earn her Master's in Psychology. She certainly had challenges – transportation (until she bought her own van), access at the college, and social acceptance. While at Wellesley, she got a service dog. In addition to being a huge help, he was also a loving companion and an icebreaker to meet people. The TV show, "48 Hours" did a show about Marcia and her dog. The camera crew followed her at school, shopping, and at home. Just like her Dad, she started a Commission on Disabilities in her town. After graduating Wellesley, she began a job at the Independent Living Center. She worked her way up to become head of the PCA program and worked there until her death.

Walter's son, Dennis, has a tragic story. He was taking a double major in college when his motorcycle fell over one day at his house. Dennis was too weak to pick it up, so a neighbor came over and helped. From that experience, Dennis saw himself living a life like his Dad was before the social day care center – living in his room with someone caring for him; no future. Dennis took his life soon after. If only he had held on a little longer; he would have seen his father get out of his room and become productive and happy! I wonder what Dennis could have accomplished to help others.

Now the grandson, Justin, was tall and thin and quiet like his grandfather. He faced the most difficult challenges. In addition to Muscular Dystrophy, he had hearing loss and low IQ. After rough times at local schools, he attended the Mass. Hospital School where he gained confidence. Justin played his uncle's guitar, created art, and learned to do his art on the computer. When he graduated, Justin moved into his own apartment. He saw what his grandfather and mom had done and wanted to follow in their footsteps.

Justin often ate meals at a local café and chatted with the owner. One day he mentioned that he could do some artwork for the menu. "Great!", the owner said. There was no talk of Justin being paid. The following week, Justin brought in several samples. The owner was very pleased and chose a design for his menus. Then he paid the artist for his work! At first, Justin said, "No, I just did it because I like you and this café." The owner insisted. A first paycheck!

The owner soon asked Justin to make new designs – one each for the breakfast and lunch menus. Another paycheck! Later, Justin designed a poster for a cancer fundraiser. He took voice lessons and wrote music, made some tapes, and was written up in a music magazine. Justin took a wheelchair dance class that was shown on television. Then he decided to try for college even though he was told he would never be able to do it. He was accepted at a Jr. College. Taking the subway in his electric wheelchair brought some challenges, so he spoke to The MBTA staff and modifications were made. Rain or shine, he did not miss a class. Justin graduated with his degree. He wrote a beautiful story about his Uncle Dennis who had committed suicide.

This family was hard working and persevering. Just by being out in the world, they helped people, but even more when they put their skills and caring to work helping others. In doing so, they made their own lives better. The commission Walter started is still going and celebrated thirty years in 2017. This commission has helped many people by increasing accessibility, and just as important, increasing awareness for people with disabilities. Like her father, Marcia also started a commission in her town. Justin created fliers and other artwork for the commissions, which still remains. All three are gone now, but their love and work lives on.

Joan Burrows studied music in NYC and later taught piano. She was a nursery school owner, teacher, and music director. Joan began the Acton Commission on Disability with Walter Kiver. She is a caregiver for people with disabilities and seniors.





Accessory Dwelling Units

By Joan Burrows

What is an Accessory Dwelling Unit?

An ADU (Accessory Dwelling Unit) is a really simple and old idea: having a second dwelling right on the same grounds (or attached to) your regular single-family house. Examples are: an apartment over the garage, a tiny house on a foundation in the yard, or a basement apartment. Many times they are built as accessible units for people with disabilities or elders.

Why do we need them?

We need them for a variety of reasons. One is for people with disabilities who want to live more independently. In some cases, building an ADU on the property of a family member provides an ideal balance of independence, privacy, and support in housing that is affordable. The possibility of having adult children living nearby allows family to help out as needed for food, doctor appointments, home repairs, during bad weather, etc.

A second common reason is for people who are aging, who are on a fixed income and living in a home is no longer feasible. In both cases, an ADU allows people to remain in their community where they are members of social organizations and have nearby family and friends who are very important for their mental health.

Remember when children lived above the garage? Another group that would benefit from ADUs are our young people who cannot afford to return to their home town to live after college. An ADU may also offer extra income to homeowners who are struggling financially to remain in their home.

ADU Scenarios

A family who would like to build a small apartment next to their home. They have a lot of land available. Their daughter was born with a disability and died in her twenties several years ago. They have a son who is married now with four children. He and his wife both work and live in a small apartment in a neighboring town. His Mother takes care of the children, especially the youngest who is not in school. She loves to do this. It would make sense and all would be happier if her son and family moved into the house and she and her husband lived in an apartment on the property.

A family with a grown daughter who has a developmental disability, living with her parents,

who needs to be more on her own (and her family needs it too.) She wants to be more independent but does need some help, so having a place of her own on her parents' property would be ideal.

A woman in her 80's who was in good health, driving, shopping, shoveling snow...until she fell, leaving her unable to do those things. She wants to remain independent but needs help. Her family lives an hour away. She has some help from visiting nurses and neighbors, but it would be better for all if she could be closer to a family who lived in the local area who were willing to support her as she ages. In the same town, there is a family who wants to remain in their home in the town where they have lived many years. The only way they can do this is to generate additional income. If they build an apartment or small house on their property, it would give everyone their privacy.

There are many more scenarios similar to these. I see no downside to accessory housing, only mutual good. However, not all towns have approved zoning for ADUs. We need to work on getting approval in every town. For more information about ADUs, visit www.accessorydwellings.org

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**14th Annual
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& Blindness Conference**

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

March 13, 2019 • 8:00am - 3:30pm
Four Points by Sheraton, Norwood, MA

Welcome Remarks:

David D'Arcangelo
Commissioner, Massachusetts Commission for the Blind

Keynote Speaker:

Lotfi Merabet, O.D., Ph.D., MPH
Director, the Laboratory for Visual Neuroplasticity
Massachusetts Eye and Ear Infirmary
Associate Professor of Ophthalmology
Harvard Medical School

**Assessing Functional Vision
Using Virtual Reality in Brain
Compared to Ocular Based Visual Impairment**

Registration Forms available December 2018:

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from: <https://www.focusonvisionandvisionloss.org/focus-blog/registration-now->

[open-14th-annual-focus-conference](https://www.focusonvisionandvisionloss.org/focus-blog/registration-now-open-14th-annual-focus-conference)

and: www.perkinselearning.org/events-monthly

Registration needed by February 22, 2019 to attend.

Registration Information:

** Early Registration Fee postmarked by January 31, 2019: \$55.00

Registration Fee postmarked after January 31, 2019: \$65.00

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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 #2 ranking in 2018-2019. Spaulding was recognized in 2018 by Disability Equality Index® as a company who scored 100% in the category of Best Places to Work™ for Disability Inclusion. For more information, please visit www.spauldingrehab.org

Disability Issues newsletter is published quarterly and shares current information about the world of disability, new initiatives, and other helpful information to the disability community in Massachusetts.

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