DisabilityIssues

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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See the From the Editor letter on page 3 for more information.

Buying and Adapting an Old House

By Ray Glazier

My resident landlady decided she didn't want a single wheelchair guy and his PCAs living downstairs, so I needed to move. To avoid future hassles of being a tenant, I wanted to buy a house. Although I had been gainfully employed since the month after I got out of rehab from my injury, it wasn't enough for me to buy a home and make any needed modifications. It was the small cash settlement I received from my injury lawsuit which gave me, for the first time, the means to consider home ownership. The realtor searched in vain for a single story ranch house that could provide wheelchair access. There was nothing of the sort on the market within my price range and within easy commuting range to my workplace. In desperation, he showed me a 1937 vintage two-story colonial that was one mile directly up the street from my office.

When my PCAs and I went to check it out, I realized it had modification potential. The five back steps could be overcome by a ramp; I could sleep in the first floor den; and the large eat-in kitchen could

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A Place Called Home

by Sandy Alissa Novack

ousing is elusive, especially for people with disabilities who may not be able to accept just any roof over their head. What follows, therefore, are some of my experiences and tips from when I hunted for a new apartment last year.

Know what you need for your disabilities and stay firm that you need it.

I met some salespersons and brokers who, despite me telling them what I was looking for, showed me other kinds of apartment units. For example, there was the apartment building that had an accessible entrance, but I noticed the controls for the heating system were well over my head. I asked about this and was told I could just climb a ladder to get to the controls. That is not safe nor accessible for people with mobility issues.

Tip: Be sure to ask about everything you notice, and do not let anyone rush your looking over any apartment.

A salesperson showed me a grab bar in a bathroom that was sadly indicative of not understanding the meaning of a grab bar. I tried to point out to him that grab bars are for accessibility and they have to be installed where someone can reach it. In this bathroom, the grab bar was wedged between the toilet and shower with no way to reach it. I explained where the grab bar should be located. He replied, "Oh no, that is a fake wall. And anyway, the landlord put the grab bar where they did because they wanted it out of the way."

Tip: Ask yourself if a supposedly accessible unit you are being shown is actually accessible for your needs. If not, move on.

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A Place Called Home - Continued from page 1

I once read about a broker in Greater Boston who specialized in finding apartments and houses to match the needs of people with disabilities. I tried to find that broker, but no one seemed to know of a salesperson or broker who specialized in finding housing for people with disabilities. Fortunately, I found one salesperson who took the time to ask questions and was open to hearing what accessibility meant to me. She was a problem solver who put on her thinking cap.

Tip: There are good salespersons and brokers out there, so keep looking until you find such a person.

Do not take everything salespersons and brokers tell you at face value.

I asked a salesperson what percentage of his clients had accessibility needs and he said probably 5%. I told him I found that interesting because many people have disabilities and require housing with accessible features. He shared his philosophy on this and told me he compares accessibility to having a pet dog. He explained that when a client has a dog it considerably whittles down the apartments he can show them because many places won't accept dogs. When an apartment opens up that accepts dogs, even if it's not ideal, he tells clients to grab it. Similarly, he thinks if a person needs accessibility, they should accept whatever is available.

Though I did understand his point that both accessible housing and apartments who accept dogs are hard to come by, I do not agree that choosing to bring a pet into an apartment is the same as a person with disability needing accessibility. This salesperson, along with multiple others, seemed to have no knowledge of what accessibility entailed and did not understand that each person has unique accessibility needs.

Tip: Do not to hand over control of finding the type of unit you need to anyone; you must have an active role in finding a place that meets your unique needs.

Gather information, and apply, apply, apply.

Make no mistake about it, finding accessible housing that works for you is W-O-R-K! For example, one building I looked at offered a semi-accessible substitute entrance but the only way to get to the laundry room was to use an old elevator that was not disability-friendly. It was one more building I crossed off my list as a possibility.

Tip: Visit each building to see what the equipment is like.

It takes considerable time to find housing, especially if you also need affordable housing in an expensive area like Boston. The Boston Center for Independent Living (BCIL) offers two housing workshops on affordable housing. The people leading the workshops have disabilities themselves and share practical information. One housing workshop leader explained that many people with disabilities want to live in Boston because of accessible transportation and well-respected medical facilities. Frustratingly, people can be on waitlists for affordable housing for many years. BCIL staff encourage people

who need subsidized housing to be flexible about where they live and to apply to every housing authority in the state because the length of some affordable housing waitlists are shorter than others. BCIL peer counselors are available to work one-on-one with people. Contact BCIL at 617-338-6665 for more information or visit www.bostoncil.org.

Tip: Utilize disability-related expertise and resources.

Do not place all your hopes in new construction.

I was oh-so-excited to learn about a new building that had accessible units was starting to rent apartments. How guickly my hopes were dashed. First, I was told all the accessible units were taken already. The salesperson told me she could put me on a waitlist for such a unit to turn over and invited me to come by to see the building. A current trend in new construction is to offer in-unit laundry. This laundry system had a dryer attached above a top-loading washer and the washer cover could only open part-way. I asked how people are supposed to get laundry in and out of the washer. The salesperson suggested I twist my body so I can pretend to reach into the washer. I told her I could not twist myself, nor did I want to. I asked if the accessible units had the same kind of laundry set-up, and she said they did. Where is the universal access? Many in the general population have back problems and would not be able to twist their bodies to wash clothes in such machines.

Tip: Pretend like you live there; try using the equipment, opening doors, and anything else you'll need to do if you move in.

In another city, I noticed two recently constructed buildings, both claiming to have accessible units. When I asked a realty office about the buildings, I was told the accessible units were not available. When I persisted, I was told that when no applicants with disabilities can be found, they are rented to able-bodied tenants. This took me aback! Given the number of people with disabilities there are, how hard could they have looked? I was later comforted to read multiple scathing online reviews by already former tenants. I did not miss out on a good opportunity, rather I avoided a big mistake.

Tip: Sometimes not getting an apartment turns out to be a blessing.

You will have ups and downs in your search for an apartment.
Count on it, but keep going.
Home is really a special place. It is not just a roof over your head, but it is a sense of peace and tranquility. I hope you find, if not

your "forever apartment," your "where-you-need-to-be-right-now-home."

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From the Editor

Dear Readers,

As you may have noticed on the front page of this newsletter, effective as of the next issue, *Disability Issues* will only be available as an online publication. To continue receiving the newsletter, please send your email address to cmmoran@partners.org and your subscription will be changed from receiving a hard copy to receiving the online version of *Disability Issues*.

This change of becoming an online publication is due to the loss of a funding source, which makes printing and mailing the newsletter no longer financially possible. If you or your organization is interested in becoming a financial sponsor so we can continue providing hard copies of this newsletter, please contact cmmoran@partners.org or 617-952-6927. We would be delighted to talk with you!

I am aware that some of our loyal subscribers do not have a computer, so this change will impact you most significantly. People who don't have a personal computer can visit the library and use the public computer to view the newsletter online. Librarians are available to provide assistance if needed. To view future issues online, visit www.disabilityvisibility.com, click on the "Resources" tab at the top of the page and select Disability.lissues newsletter from the drop down menu.

Perhaps *Disability Issues* moving to an online publication is motivation for you to become more computer savvy. In addition to reading the newsletter, you can also chat with family and friends who are online, search for information on any topic, and browse websites. To help you learn how to use a computer, your local library may offer computer training classes or they can help you find a class in the area. Easter Seals also offers an "Assistive Technology at Home" program that provides equipment and training for people who meet their eligibility requirements. For more information, contact Easter Seals at 800-244-2756 or info@eastersealsma.org.

On behalf of myself and the editorial board, we appreciate all our subscribers. As our publication changes to be available only online, we hope you will change with us. We look forward to continuing to bring you innovative and relevant stories that enhance the lives of individuals with disabilities.

Marianne DiBlasi, Editor

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Love and Intimacy Corner



To Be, or Not to Be a Roommate: That Is the Question

by Ms. Love

After not sharing a room with anyone for years, my introduction to college life many years ago involved listing dormitory and roommate preferences. I chose to live in a more quiet dorm, and hoped for a roommate who was studious. The college matched me up with a woman from another part of the country who wrote to me about how she wanted to major in biology and was very studious. She asked how we could decorate our dorm room, told me what she was planning to bring, and asked what I could contribute.

On campus move-in day, my parents and I lugged a footlocker full of clothes, bed linens, books, and everything else a freshman needs upstairs to my room. We looked up when someone – my roommate – walked into the dorm room and started talking a blue streak while unpacking the suitcases she had flown into town with. Within a couple of weeks, my roommate was rarely around because she was busy dating and partying. She would try to enter our dorm room without putting on the lights in the wee hours of the morning, including on school nights, which of course led to her frequently crashing into furniture and waking me up. I started getting long distance phone bills for calls I never made, and as other issues between us kept popping up. This wasn't working for me.

I asked my new college friends for ideas on how to find someone who, like me, wanted a new roommate. This time, I wanted to choose a roommate instead of letting the college match me with someone. I soon met Lynn. We spent time talking and getting to know each other. We shared why our assigned roommates weren't working out and what we hoped to find in each other. Happily, my assigned roommate moved out at the end of the first semester and Lynn moved in.

By the spring semester, Lynn and I were pretty inseparable. We often ate meals and studied together; she introduced me to watching Saturday Night Live; we talked about our families and our hopes for future careers. We never had time to look back at our original roommates because we were creating a new life together that we liked. When I became disabled with pain at the end of the semester, Lynn was by my side. We remained roommates in our sophomore year and took some classes together.

Decades later, Lynn and I remain friends even though she lives on the other coast and only get to share with each other a brief outline of our lives. If I had to pick my favorite roommate out of the many roommates I've had during my life, without hesitation, it would be Lynn. We had sincere respect for each other, similar values, looked out for each other, had fun, and weathered hard times together. We were friends.

Do you have to be friends to be good roommates? No. You could have a roommate because as a convenience or because of circumstances. Once I had a roommate who was not a bad sort, but we had absolutely nothing in common. We never did anything together because we had very different kinds of interests and friends. Yet, we managed okay as roommates.

The issue of having a disability should be addressed. Recently, when I was conducting an apartment search, a friend told me she was also looking for an apartment. We were commiserating with each other on everything from how hard it is to find accessible housing to how expensive housing can be. At the same time, I was talking with a male friend about the possibility of looking for an apartment together so we could support each other around our physical disabilities. My friend did not feel a need to move at the time, nor did he feel like he needed more support with his disabilities right now. Another male friend said he was interested in seeing some of the apartments I was looking at. We went to look at a large unit that would allow each of us to have our own room while also sharing the cooking and other household duties. Becoming roommates was an appealing prospect so I began looking for an apartment for two.

I suggested to my female friend that perhaps having a roommate would work for her, too. She brightened at the prospect of sharing expenses with a roommate, and thought a larger unit for two could give her more space to maneuver in her wheelchair. On the other hand, she wondered how a roommate might feel about the service providers that regularly came into the apartment. Disability needs and concerns should be discussed with potential roommates so you both understand the living situation if you pursued a lease together.

Dear readers, there are pros and cons to having a roommate. You could be making a friend for a lifetime, like my one-time roommate Lynn. You could also decide to share space to save money or to alleviate loneliness; an important issue for many with and without disabilities. Yet, be prepared to live alone if that is a better option than feeling lonely due to being in a bad living situation. Of course, you may simply prefer to live on your own. There may not be a right answer to whether you should or should not have a roommate, but Ms. Love encourages you to be open to all opportunities.

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.

Buying and Adapting an Old House - Continued from page 1

be made smaller to allow converting the adjacent half bath into a full one. My PCAs could live upstairs in relative ease with three bedrooms and a full bath. Despite its age, the asking price for the house was a major stretch for me. But I loved the convenient, quiet suburban location. Considering its potential and despite its shortcomings, I made a half-hearted offer that was only 75 percent of the asking price. To my surprise, the owners accepted it the next day.

Financing was the next hurdle. The local bank balked at giving a mortgage to someone who couldn't get mortgage life insurance because of multiple disabilities. I decided I could plunk down almost all my lawsuit nest egg, given that friends had offered free help making the necessary modifications. "Would 50 percent down change the lender's mind?" I asked. (It did.) Now the saga began, and decades later, it is still a work in progress.

My Dad drove out from Ohio to help my PCAs and friends rip out newly installed plush carpeting on the first floor for better wheelchair navigation, refinish the hardwood floors, and paint ceilings and walls. One friend built a ramp from the sidewalk to the back door using scrap lumber and thick plywood with gritty roofing tar paper as the non-slip surface. Another friend walled off part of the kitchen next to the existing half bath and started the buildout for a tub at one end. But that project stalled out due to plumbing and electrical licensure issues. Luckily Mass. Rehab. stepped in at this juncture, providing (and funding) a trained architect and a fully licensed contractor.

The new design of the galley kitchen called for stove burners with knee space under them and an adjacent wall oven; a lowered double sink with disposal set into a wheelchair height counter; lowered wall cupboards with right-height counters; and the floor-mounted cabinets interrupted by wheelchair width open workspace. With the new side-by-side refrigerator I bought, this design made it possible for me to prepare meals. The MRC architect was paraplegic himself, so he certainly knew what he was doing.

The bathroom had a large new tub at one end with a swiveling hydraulic seat lift to raise me high enough to swing my legs over the side of the tub and lower me into and back out of the water. There was a wall-hung wheelchair sink with lever faucets that took up a fourth of the small bathroom. The toilet at the opposite end was set into such a small space that there was no room for grab bars, but since I needed PCA assistance with toileting anyway, that wasn't a problem. Bathroom space was so tight that there was no room for a standard door, so the large doorway between kitchen and bath was closed off with an accordion door – another compromise dictated by circumstances. I began to realize that adapting an old house is a two-way accommodation process.



Photo: Vincent

Unfortunately, the older lone wolf contractor had a heart attack and couldn't quite finish the project. So Dad returned to build the kitchen cupboards. This project setback was an introduction to the realities of home ownership – the roof springs a leak, the washing machine dies, the sink clogs up – and there is no landlord to call. And then there is the financial tightrope to walk when the quarterly real estate tax bill competes with the monthly mortgage payment.

Even with the constant battle of the budget, home ownership gave life new meaning; I became an integral part of a neighborhood, an involved member of my community, and chair of the town Disability Access Commission. To a lesser degree my PCAs also appreciated these benefits, as well as pride in a mailing address without an apartment number. And rent-free housing became an important draw in recruiting new PCA candidates.

At the same time, I was intent on setting aside the funds to make further access improvements. When the rather makeshift wooden ramp began to fail, fate smiled on me; a family in a nearby town was looking for someone to remove the large steel ramp no longer needed to accommodate a now absent family member's wheelchair. Friends and PCAs took it down, transported it in a rented truck, and reassembled it at my place. A leftover ramp piece overcame, for the first time, the single step down into the basement from the driveway door.

Months before my retirement, I took out a second mortgage in order to afford a major overhaul of this old house: a new roof, new energy efficient windows all round, a new full-scale accessible kitchen, and a more truly accessible first-floor bath with an eagerly anticipated roll-in shower. The separate dining room was sacrificed, the investment was substantial, there was another round of smaller compromises, and the project was fraught with issues related to the young contractor's lack of experience with accessibility renovations. Maybe I can write about those matters in future, once the dust settles here, at least temporarily.

Raymond E. Glazier, Ph.D., now semi-retired, is founder and Principal of disAbility Research Associates; operating from his home, it provides disability-related research consulting and disability awareness services to public and private clients.



PCAs are Special People

By Joan Burrows, Guest Columnist

y husband, Walter, entered a local hospital in August, was transferred to a Boston hospital in September, and finally came home for Thanksgiving. In addition to his Muscular Dystrophy, he was now incubated and on a respirator. There were many challenges ahead. With help, we met them...with help!

A social worker gave me some sound advice shortly before we left the hospital. She asked me if I wanted to be his partner or his caregiver. I told her I had been both. She said things would be different now and if we wanted to keep our relationship, we needed to consider hiring outside people. Neither of us wanted other people doing his care...but...thank you social worker!

We were given information about the Personal Care Attendant (PCA) program, where we could hire and train our own people. I ran an ad. Luckily, Pat, a very special person who lived a few

miles away replied first. She had little experience, but she was a caring person and she and Walter hit it off. How lucky we were! We began our first experience with another person doing his care a few days a week – an adjustment for him and for me.

One day there was a snowstorm. Pat's husband said she should not drive, so Pat walked more than a mile in the snow to get to Walter. When we moved from our apartment to a condo, Pat was there helping with everything. She made great spaghetti sauce too! A few years later, she went with us to Washington DC. She stayed in the extra room at the hotel and helped with Walter's

care during our week's stay. Her start with us made it an easy transition to hire other people (not all as good). If not for her, Walter may not have been able to live at home and he would not have accomplished all he did for other people with disabilities.

It would be hard to list all the PCAs, but the youngest was a senior in high school. Her Mom called to tell me that she should not take the job. She did anyway. She was loving and caring and learned to do everything we needed. She continued while in college, then had a semester abroad and sent us postcards. For many years after she was no longer Walter's PCA, she stopped by to visit. She greeted Walter with a big hug and talked with him by reading his finger writing – his unique way of communicating. If I did not have help for the evening, she helped me get Walter into bed and settled for the night.

She is in California now and has requested references several times. She is still doing home care – over 20 years now!

A woman from Australia came for an interview and we hired her that evening! She had nursing degree from Australia, but could not practice in the U.S. She was an exceptional person and caregiver and became a good friend. We made a trip to upstate NY for my grandson's birthday and she joined us. We planned to get her another room and she insisted, no, and slept on a cot for two nights in our room. She joined in with the family for the birthday celebration. When we went to Cape Cod and needed help, she was right there for us. Many years later, she stopped by with her three year-old daughter before returning to Australia.

Another PCA was a woman who told me that her husband had ALS and needed to live in a facility where she visited him daily.

He had been diagnosed when their children were three and four years-old and was told he only had 2-5 years to live. I asked her why she wanted to be a PCA and she said she wanted to help another family keep a loved one at home. When she worked at night, I always knew Walter was set – the Craftmatic bed at the right height, his buzzer under his hand, the pillows were perfect. She often tried to put Walter's false teeth in upside down – a running joke!

Another PCA came and stayed for many years. She was caring for Walter just before he died. Though he was mostly in a coma and could not respond, she kissed his forehead every

morning, told him her name and that she was there. She works with the visiting nurses now.

Over the twenty years, I can recall only three PCAs who did not work out. Without these super caring people, our lives would have been so much different. We would not have helped all the people with disabilities that we did – raising awareness and increasing accessibility in our town and beyond. We would not have been able to share our love, be with family, or take trips. There are no words I can say that fully express how much I appreciate every one of them.

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.





Renovating and Adapting for Accessibility

By Mary Grimley-Mason

live in a retirement community and recently had the small kitchen renovated to make it more accessible for the times when I use my wheelchair. For now, I still have the option of using the kitchen while standing with the aid of crutches and braces so I'm adapting the kitchen, not renovating it completely.

Adapting is what I do and have done since I contracted polio as a child. In the late 1940's I spent time at Warm Spring's Georgia, at President Roosevelt's Infantile Paralysis Foundation learning how to live in an inaccessible world. The Disability Movement was far from beginning and the able-bodied world did little to accommodate those of us with disabilities.



Photo Courtesy: Disability Images/disabilityimages.com

Because my family "mainstreamed" me and treated me just as they did my brother and sisters, I learned how to adapt to surroundings, which were not always accessible. I lived a full life with a career, marriage, children, and traveling. My skill at adapting, I believe, is part of my determination to keep some independence. I realize I feel a certain freedom when I overcome a hostile physical environment. My "adapting" the kitchen, I acknowledge, is partly my wish to keep control of my life.

When I moved to a retirement community, I became keenly aware of the importance of accessibility for myself and also for the residents who have increasing disabilities. Senior housing institutions are challenged to provide accessible accommodations while still giving residents a sense of freedom and control over their own lives. When I first moved in to my community, I had to join others to lobby for simple changes, such as

automatic doors for public bathrooms and other public places. Things have improved and we are a more inclusive and accessible place now. In the last five years, I have participated in workshops or programs on caregiving, diversity, dementia, LGBT, and others; all designed to recognize not only medical needs, but also the need for autonomy. The policy here for "aging in place" offers the option of staying in your apartment with the assistance of aides instead of moving to the nursing care section. Although this offers a sense of "independence," and normalcy it can become an expensive proposition that few can afford as you need more care.

The concern for changing the culture of elder care and retirement communities started some time ago; specifically during the movement to change the culture of nursing homes. In the 1990s Dr. William Thomas, a geriatric physician, founded the Eden Alternative, a philosophy and program that deinstitutionalized nursing homes in all fifty states over the span of twenty years. This fundamentally changed the relationship between staff and management. Patients are seen as more than just medical cases but rather as individual people. Later Thomas started the Green House Project, a radically new approach to long-term care which replaces nursing homes with small homelike environments where seniors live in private rooms with few scheduled activities. The goal is to create communities that give the residents the chance to feel as independent as possible.

Meanwhile, in my retirement community I am pleased with my new renovation. It was quite a project and required close consultation with the contractor as we figured out how to make a Pullman kitchen wider by using smaller appliances and how to lower counters and the sink to accommodate my small power wheelchair when necessary. It takes a little adapting, but I feel that I can have some control over my environment, which may be what all of us seek as we move through different stages of living with our disabilities.

Mary Grimley-Mason is a PhD Professor of English emerita, Resident Scholar, Brandeis University's Women's Studies Research Center, and author of; "Life Prints: A Memoir of Healing and Discovery, Working Against Odds: Stories of Disabled Women's Work Lives," and "Taking Care: Lessons from Mothers with Disabilities."



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About BSO Resound

BSO Resound is the BSO's disabled-led ensemble, making the BSO the first Orchestra in the world to have a professional ensemble led by disabled musicians as a core part of its activities. BSO is the Bournemouth Symphony Orchestra, located in Poole, England.

Following auditions in November 2017, the BSO welcomed the six founding musicians of its new ensemble, BSO Resound; Siobhan Clough (violin/ viola), Philip Howells (percussion), Roger Preston (cello), Kate Risdon (flute), Matthew Scott (clarinet) and Charlotte Bott (Linnstrument). These musicians will be working alongside the ensemble conductor James Rose as well as Alexander Campkin, the ensemble's Composer-in-Residence, and Lucy Hale, the ensemble's Young Composer-in-Association.

A core part of the BSO Change Makers project is the creation of this professional disabled-led ensemble to be embedded in the Orchestra and take part in a variety of other work, which James will curate and direct. The project began following a funding award from Arts Council England's (ACE) Change Makers Fund. James Rose, BSO Change Maker and disabled conductor, began his 18-month training placement with the Orchestra in June 2017. The Change Makers project is hosted by BSO Participate's strand, Rising Talent, which provides an important pathway for emerging talent in classical music.

To read more about the members of BSO Resound visit www.bsolive.wordpress.com/meet-the-ensemble/

For all of the latest news about BSO Resound, please visit www.BSOlive.com

