

Disability Issues

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Wheeling With Power

By Kate Ryan

Michael Muehe has been using a manual wheelchair since 1977, and, as he puts it, "Our bodies simply aren't designed to use shoulders this way." He didn't want or need a power chair because he likes the exercise wheeling gives him, but it was getting to the point where he was in so much pain, that he would drive rather than walk a couple of blocks.

Enter his new chair, a **Quickie Xtender** that Michael describes as a "real shoulder saver" although, unless you look closely, you would never see how it is any different from a 'regular' manual chair. What is Michael's not-so-secret secret? The Quickie Xtender is a power assist wheelchair. A power assist wheelchair is a manual wheelchair with wheels that have tiny computers in the hubs. The hubs have sensors inside that detect the movement of the handrails and automatically compensate, giving the user more or less power as needed. "It feels like I am always on a level surface. The effort is the same if I'm going uphill or downhill," Michael states. Instead of the chair speeding up going downhill or the user having to give extra effort going uphill, rides are much more even. There is automatic braking on the



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The Art of Networking The Hidden Job Market

By Bill Allen



Your next job believe it or not may be closer to you than you may think. Most job seekers are not aware of how they can create their own opportunity with employers through what is known as the "hidden job market." Business experts from JobStar Central to Forbes know that 80% of all jobs are not advertised. So you may be thinking where is the hidden job market and how do I find it?

The hidden job market is found through "networking" which is something we all do everyday with all areas of our life. A friend tells you about a great restaurant or the deal they just got on their automobile or an incredible sale on a new suit you may need for your next job interview. It begins as a casual conversation and more often than not eliminates the fear of the formal job search for both the job seeker and employers. Employers would highly prefer to interview people from referrals they respect and trust. In addition it saves money on advertising and recruitment costs. Networking clearly serves all stakeholders in the job search process extremely well.

The Networking Plan:

- 1) Ensure that you have identified the right vocational goals that are matched to your skills set and talents.
- 2) Your resume and cover letter should match the job you are seeking. You

may need several resumes if you have credible transferrable skills (be open minded and flexible).

- 3) Keep your motivation level high during your job search—this can be difficult and frustrating, but enlist your greatest supporters such as family, friends to keep you moving forward...we are your biggest cheerleaders.
- 4) Develop your network list to include: family, relatives, friends, neighbors, community groups, your place of worship, all social media outlets such as LinkedIn, FaceBook etc., local Career Centers, previous employers, your local grocer and pharmacy—these networks can be extremely powerful and are very under utilized.
- 5) Get organized with your lists and contacts. Keep copious notes, as each contact listed above will probably provide several names that could be the decision maker that could result in your next job.
- 6) Develop a pre-planned script known as your elevator speech or your very own 60-second commercial.
- 7) Practice your script with a trusted friend and or family member. You may even want to be video taped. This approach is highly effective and

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Defend Yourself!

By Kate Ryan

The statistics are sobering. Study after study confirms that people with disabilities are more than twice as likely as people without disabilities to be the victims of violent crime. They are also more likely to know the perpetrator, who sees them as an easy mark. At home, in the park, and on the internet, people lurk who want to hurt people like us.

Erik Kondo, 48, who has been disabled for almost thirty years, is out to change those statistics. His non-profit company, **Not-Me!**, was founded with the express purpose of helping vulnerable populations, such as those with disabilities, from becoming victims of crime. He is waging war in person and on the internet, and he takes a firm stance that anybody, regardless of their disability, can take responsible actions and make plans to ensure their own safety.

This is quite impressive for a man who started out with just a real estate business. In fact, he still makes his primary income from his real estate related businesses. Another business he owns is **Together in Motion**, in Arlington, a kids and adults event space that has also proven to be an ideal space for him to teach self-defense since he started Not-Me! in 2007. Although he was somewhat involved in martial arts growing up, as an adult he became interested in self-defense. But he soon found that most martial arts were not compatible with a spinal cord injury such as his. He managed to achieve a 3rd degree black belt in small circle jujitsu despite this, and saw that there was a real need to bring his skills to the disability community. He read all the sobering statistics and decided that he would do something about it.



NOT-ME!

DECIDE DETER DISRUPT DISENGAGE DEBRIEF

Training in Arlington MA)

Erik explains that the most important thing in self-defense is not about knowing how to fight. Instead, it is clear communication and how to set boundaries. By practicing progressive boundary setting, people can observe a stranger or a friend's reaction and then dial up or down their response appropriately. Many people in our society lack respect for people with disabilities, so they feel that it is okay to break the rules of society when it comes to dealing with them. By communicating first visually (with a stern look, for example), then verbally (don't do that) and as a last resort physically (pushing someone away) people can convey a message that they do not want to be messed with, and that there will be consequences

for those who do. Erik's main strategy that he wants people to learn is what he calls the 5 D's of Self-Defense.

You can learn more about Erik's work and life by visiting his website at www.Not-Me.org.

Kate Ryan has a master's degree in interdisciplinary studies with a focus on disability studies. She currently works as a personal care aide while searching for work in the disability field.



The 5 D's of Self-Defense

1. **Decide.** Plan and prepare mentally as well as physically for the need for self-defense.
2. **Deter** the person visually or verbally.
3. **Disrupt** the situation, foil his or her plans.
4. **Disengage** is the ideal outcome. When the perpetrator has stopped his assault or you have gotten away.
5. **Debrief.** Think and talk about what went wrong, why, and how to deal with what happened.



Disability Issues is a publication of Spaulding Rehabilitation Network, a member of Partners HealthCare. The Spaulding Rehabilitation Network includes Spaulding Rehabilitation Hospital. Its main campus located in Boston, as well as Spaulding Rehabilitation Hospital Cape Cod, two long term care facilities Spaulding Hospital Cambridge and Spaulding Hospital North Shore and two skilled nursing facilities, as well as twenty three outpatient sites throughout Eastern Massachusetts. Spaulding is a teaching hospital of Harvard Medical School and the official rehabilitation hospital of the New England Patriots. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by *U.S. News and World Report* in its Best Hospitals survey with a #5 ranking in 2011. For more information, visit www.spauldingnetwork.org.

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From the Editor

Dear Readers,

This October we celebrate **National Disability Employment Awareness Month** with this year's theme, **Because We Are EQUAL to the Task**. The theme reflects the reality that people with disabilities have the education, training, experience and desire to be successful in the workplace. As any Career Counselor will tell you, the key to finding a job is to tap into the hidden job market. We bring you an article with 10 tips on how to uncover the hidden job market by becoming a skilled networker. And, if you think networking is just something for the Job Seeker, it's not. Developing and maintaining a strong professional network is just as important when you are working. Networking is about offering help when you can and asking for help when you need it. Once you build a network, keep in touch with your connections and stay networking strong!

But we can't be all work and no play! If you are like me, you are always looking for fun social activities and ways to be part of a community. We bring you an article about a day program with strong community and suggestions of things to do and ways to meet people with common interests.

If you are a wheelchair user, have you ever dreamed of being able to go up hills with as much ease as being on level ground? I certainly have! In this issue we bring you an article about one person's experience of switching from a manual wheelchair to a power-assist wheelchair. There's nothing better than hearing a personal story from someone with real life experience, instead of solely relying on trying out a demo.

As you are out and about in the world, there are times where you may feel concerned for your safety. Help is on the way with an article on self-defense that starts with prevention - clear communication and setting boundaries.

Ms. Love has gone on the road to bring you her experience of shopping at the "sex positive" store, **Good Vibrations in Brookline**. Sex and disability... those are two words you don't often hear together - that is, until you talk with the sex savvy, professional staff at Good Vibrations. Let's go shopping!

Marianne DiBlasi, Editor

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The Boston Home and B.Fit! – Why Community Matters

By Sandy Alissa Novack, MBA, LICSW, ACSW, CSW-G

The sky was clear, the heat manageable, and I was sitting in the middle of an award-winning garden with multiple raised garden beds, tomato-laden greenery and enough lettuce and eggplants to make meal-planning easy for a long, long time. But it was the goldfish in the good-sized pond smack in the middle of the garden that had me mesmerized. I just love gardens, especially lush gardens growing produce, and I love sitting and looking at water. Was I on vacation or at a resort? No. I was at **The Boston Home** in Dorchester, a guest of their **B.Fit! Day Program**.

The Boston Home is a not-for-profit residential facility specializing in the care of adults with Multiple Sclerosis (M.S.) and other progressive neurological disorders. Unfortunately, The Boston Home can only accommodate just under 100 residents, and it has a waitlist, so in 2006 The Boston Home and the Greater New England Chapter of the National M.S. Society began the B.Fit! Day Program. B.Fit! extends some of the expertise of The Boston Home to about 35 individuals who live in the community. B.Fit! is able to keep people living in the community rather than be admitted to a long term care facility because it helps people maximize their independence with exercise, educational, and health care management programs.

I don't often get to see such a smiling, peer-supportive group of people as I did the day of my visit, but it points to the fact that peer support and socialization, as well as the ability to work on one's functional abilities, encourages wellness. Anyone with disabilities knows this intuitively, yet finding such programs is not easy.

Participant Galeen Jones tells me that she and participant Arcenia Ruth Allen, Jr. were friends before coming to the program. They were also two of the program's pioneers when B.Fit! started in 2006, and still enjoy coming. "It makes us happy, we know each other well," says Galeen. "We exchange phone numbers with other participants and call when someone does not come...you can make friends here and we are concerned if you do not come," she continues.

Rose Saunders spoke about how important it is to be part of a community. Stephanie Hoffman says "I want to be fit, so I joined B.Fit!" Carolyn Lang adds, "I like that people are going through some of the same things I am going through." Michael Zackman, of West Roxbury, says he likes being around people, and he finds B.Fit! to be a welcoming environment.

With an average age of mid-50s, participants come one or more days per week. Some live nearby, others travel a

distance on the paratransit system known as the RIDE. Glory Wideman-Hughes, a bundle of energy, wisdom, and overflowing laughter, is the Outreach Coordinator. "B.Fit! participants choose the kinds of activities they want to do—from shopping to listening to music." They like going to movies and bowling. While other day programs often provide interesting activities inside their facility, B.Fit!'s employment of Glory, who has a mission to get people out of the wellness program's building and into the larger world, is a most distinguishing attribute.

It has been a full visit with B.Fit!, and it is time to say goodbye to the new friendly faces I have met, program participants and aides, as well as staff. I ask Glory if she has any parting words for Disability Issues readers, and she responds: "You have one life to live, live it. You have to choose what you want to do. You are in charge of your quality of life." With B.Fit! having a waitlist, plus all the people living in the community who have non-neurological disabilities, I wondered if Glory had advice on what options people with various disabilities have to feel part of a community like B.Fit!'s. "Find a support group, check community centers or organizations similar to the M.S. Society. Do not be afraid to start a support group or a friendship club."

Sandy Alissa Novack is on the Editorial Board of Disability Issues, a Geriatric Social Worker, and a consumer advisor on the Beth Israel Deaconess Medical Center's Universal Access Advisory Council.



Community and Social Events

- **Meetup Groups** Find an existing group or start a group to meet people with common interests. Visit www.meetup.com.
- **Free (and almost free) events**, are posted online, visit <http://www.boston.com/thingstodo>
- **YMCAs** are accessible and offer a range of classes. Call your local YMCA to find out what programs are available.
- **Centers for Independent Living** often host events, including social events. For a listing of Independent living centers, visit <http://www.mass.gov> and enter "Independent Living Centers" in the Search box.



Ask Ms. Love

Shopping and Sexuality

By Ms. Love

You probably try to address your medical, emotional, and spiritual needs the best you can. Can you honestly say you do the same for your sexual needs? Sexual wellness is just as important as other components of wellness.

California has multiple locations of the “sex-positive” retailer **Good Vibrations**. The only store located outside of CA is right in our backyard - in Brookline, MA. **Good Vibrations** is located at **308-A Harvard Street, Brookline, MA** with ample metered parking. Staff is aware that their door threshold could be problematic to people with mobility issues, but they tell me that their window allows them to see customers approaching and they are happy to offer assistance.

Once inside, pathways are wide, and there are some backless and arm-less seating space in the back room so you can sit and look at some of the books they sell. The store is brightly lit, spotlessly clean, and full of vibrant colors. Some educational, explanatory material is posted on walls, but not all at the level of a person in a wheelchair. Kristen Cotter, store manager, says they will be moving things around in the near future, and larger size informative material will be made for walls to partially address this issue, and the print will be larger, too.

Products for sale are very tastefully displayed. Forget what you heard about Red Light districts or Boston’s old Combat Zone. This is not that. Kristen says that the most frequent customer coming to Good Vibrations are often too nervous to shop at other sex shops, and staff are here to help people understand that Good Vibrations is different. “We want people to be comfortable about coming in. We’re not trying to sell, but we do ask questions to get an idea about the customers’ needs,” she says. “Everybody is different, no matter what their age or disability. We want to share our knowledge so that folks can feel empowered to make the best choices for their bodies. A common question we may ask a customer who is sent to us by their doctor is, for example, ‘Do you experience pain upon penetration?’ so that we can begin to understand how to help that particular customer.”

A large sign proclaims that staff people are “committed to offering accurate information about sex, sexuality, and the products they carry. They provide a safe, non-judgmental environment for people to shop.” The best way to shop at Good Vibrations, explains Kristen, is to ignore packaging, ask questions, discuss what is right for you, and allow yourself plenty of time. Whether your definition of sex involves cuddling, kissing, intercourse, masturbation, a host of other possibilities, or no sex at all, there are way to enhance your sexual experience.

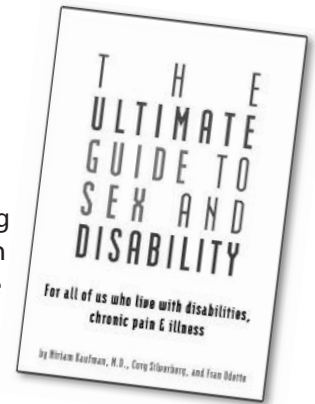
The store offers free one-hour long events each month. For instance, on September 4, the topic was “Love Yourself Literally: Empowerment through Masturbation”, and on September 18 it was “Foreplay is for Lovers”. Two-hour evening workshops for \$20 are offered monthly. In September, workshops included “Understanding Sexual Identities and Attraction”, “How to Please a Man in Bed”, and “How to Please a Woman in Bed”. Every few months they offer a Sex and Disability event, as well as a Male Sexual Dysfunction event. Stop by the store for a schedule, or go online to www.goodvibes.com, and click on the Brookline location to find out what is being offered each month.

Good Vibrations can offer events on special topics if a group wants to learn about something different from their regular offerings. Good Vibrations also has a Sexual Health Outreach Project, where their educators travel outside the region and across the country to lead workshops.

Kristen states, “Unfortunately, not many books are available for people with disabilities that meets Good Vibrations’ sex-positive standards.” One book they carry is, *The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness*, by Miriam Kaufman, M.D., Cory Silverberg, M.Ed and Fran Odette, MSW. Kristen also points out that the Center for Sexual Pleasure and Health in Pawtucket, RI (www.theCSPH.org) is another resource that provides helpful resources. Ms. Love suggests that you also refer to books on your specific disability to see if they have chapters on sexuality.

Ms. Love encourages you to share openly about your disability and how it impacts your sex life. The sex savvy staff can offer creative suggestions and provide an educational, satisfying shopping experience. As Kristen says, “Knowledge and exploration of our bodies is healthy and empowering, regardless of age, disability, orientation, gender, relationship status or anything else that could separate us as human beings. One of Good Vibrations mantras is... ‘Pleasure is your birthright!’ Everyone deserves pleasure and to feel happy and healthy in their own skin. We’re just here to help!”

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 DL.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.



October is National Disability Employment Awareness Month



Because We Are EQUAL to the Task is the theme of this year's National Disability Employment Awareness Month. Chosen by the U.S. Department of Labor's Office of Disability Employment Policy, the theme reflects the reality that people with disabilities have the education, training, experience and desire to be successful in the workplace.

"When I was growing up, many people doubted what I could do just because I was blind. But because I had people in my life who instilled in me an expectation of work and showed me opportunities to be successful, I completed college and became known for what I can do," said Kathy Martinez, assistant secretary of labor for disability employment policy. "I urge all employers to benefit from the skills of workers with disabilities by giving them, including our returning veterans, a chance to show that they, too, are equal to the task."

This year's theme echoes the message of ODEP's ongoing Campaign for Disability Employment to promote positive employment outcomes for people with disabilities and expand ideas about what youths with disabilities can do when they receive encouragement and support for their ambitions. Conducted in collaboration with business and disability organizations, the campaign emphasizes that, at work, it is what people can do that matters. More information about the Campaign for Disability Employment is available at <http://www.whatcanyoudocampaign.org>.



Going to College: A Resource for Teens with Disabilities

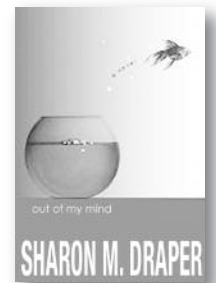
This website contains information about living college life with a disability. It's designed for high school students and provides video clips, activities and additional resources that can help you get a head start in planning for college.

Through several interviews, college students with disabilities from across Virginia provided key information for the site.

Understanding Our Differences Second Annual Family Book Event

Join **Understanding Our Differences** for our second annual family book event on Monday evening, October 28th at 7 p.m. We are bringing Sharon Draper, author of the *NYTimes* bestselling children's book, *Out of My Mind*, to Newton South High School for a special conversation and book signing. Our event moderator is Brian O'Donovan, WGBH producer and host. Please scroll down for online registration.

About *Out of My Mind*: Eleven-year-old Melody is the smartest kid in her whole school, but no one knows it. If only she could tell people what she thinks and knows...but she can't, because Melody can't talk. She can't walk. She can't write. Being stuck inside her head is making Melody go out of her mind – that is, until she discovers assistive technology that will allow her to speak for the first time. At last Melody has a voice, but not everyone around her is ready to hear it.



Sharon Draper

About Sharon Draper: Sharon M. Draper is a two-time Coretta Scott King Award-winning author, most recently for *Copper Sun*, and previously for *Forged by Fire*. A prolific author and sought-after conference speaker, she lives in Cincinnati, Ohio, where she taught high school English for 25 years.

Out of My Mind
 with author Sharon Draper
 Monday, October 28, 2013
 7:00 pm - 9:00 pm
 Newton South High School

Information Briefs



BEWITCHED - Songs of Enchantment

"Bewitched" is the theme of the concert to be presented by Special Needs Arts Programs, Inc. (SNAP) on Sunday, October 27 at 3:00 PM at First Parish Church, 7 Harrington Road. The Halloween-inspired program will feature songs of enchantment from opera to Broadway and will include selections from the hit musical, "Wicked". They will be performed by guest artists, soprano Sonja Tengblad and mezzo soprano Megan Roth with pianist Andrew Altenbach. There will also be a special cameo performance by SNAP's own Sing Along choruses led by Music Director Marsha Martin. A reception and raffle will follow the performance.

For 32 years, Special Needs Arts Programs, a nonprofit organization, has been providing music and, more recently, art programs for people with disabilities. Proceeds from the concert will help support these programs. For more information about Special Needs Arts Programs and its programs, visit www.snapsing.org.

"Bewitched – Songs of Enchantment" Sunday, October 27 • 3:00 PM

First Parish Church • 7 Harrington Road • Lexington, MA
For reservations, email info@snapsing.org
or phone 781-460-3599.

The Art of Networking The Hidden Job Market - Continued from page 1

will build confidence as you progress through your job search.

- 8) Check in with your contacts and exhibit polite persistence.
- 9) Register with a staffing company. Many employers use staffing companies during a sluggish economy. This is a great barometer for growth opportunities in various labor market sectors.
- 10) Be persistent and check your plan often.

Networking In Action:

My very first job and the current position I have were both due to networking. Allow me to share how this happened. The first job resulted with my neighbor. When I was sixteen I just got my drivers license and had the great fortune of finding a deal on a car. It was a 1965 Ford Falcon (a three- speed shift on the column which my parents taught me to drive...thanks Mom and Dad). I now needed a job to pay back my parents and pay for gas and insurance. My neighbor who was fifteen identified an employment opportunity with Bob's Turkey Farm. He was already working there and knew of a potential job opening as the owner asked him –"do you know of anyone else that would like to work on the farm?" Thanksgiving was fast approaching and he needed assistance with preparing and transporting the holiday birds to their final destination. My neighbor also had a vested interest with me getting hired, as he would not have to walk to work. I applied and was interviewed and hired as a turkey transporter. Although I had no knowledge of networking or the hidden job market, it served me extremely well. This first work experience also provided me with the necessary workplace

skills for future jobs.

In my current role as Director of Statewide Job Placement Services for the Massachusetts Rehabilitation Commission, I see how networking the hidden job market has uniquely empowered hundreds of qualified individuals with disabilities to obtain employment and grow their careers in the competitive world of work.

There are many resources that can assist you with understanding the benefits of the hidden job market and below are resources that will serve all job seekers extremely well while reducing stress associated with your job search. Good luck!

Bill Allen is Director of Statewide Employment Services-Job Placement at Massachusetts Rehabilitation Commission

Hidden Job Market Resources

Forbes Magazine Online:

www.forbes.com

- ▲ Enter "6 Ways to Crack the Hidden Job Market" in the Search Box

JobStar Central:

<http://jobstar.org/hidden/index.php>

- ▲ Click on the links:

- What is the Hidden Job Market?
- QUIZ: Is the Hidden Job Market Going to Work for Me?

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Wheeling With Power - Continued from page 1



chair so that it keeps a steady pace at all times.

Michael has had his chair for three months, but he has been hearing about the power assist chairs for years from friends in similar situations to him, who all loved them, and who encouraged Michael to look into one. He made an appointment with physical therapist Michelle Kerr at Spaulding Rehabilitation Hospital's Wheelchair Clinic, and she showed him two options; the Quickie and the eMotion system, which are power assist wheels that can go on almost any manual chair. Although it was a bit hard to schedule try-outs with the durable medical equipment suppliers, Michael is very glad he did because the Quickie was the clear choice for him. He strongly encourages people to try both models and to see what works for them, as they do have differences (for example, the eMotion has different power levels, selectable with a remote control, which the Quickie lacks) and every user is unique.

After he chose it, the chair was customized with his choice of color, seat cushion, and other accessories. It took almost a year and a half for Michael to go from start to finish, but he says it should usually take about two to three months after your appointment at Spaulding. He was lucky enough to

have the entire cost of the chair, nearly \$10,000, covered by his Harvard Pilgrim insurance. However, from websites it appears that the cost can be lower than this, although the batteries are still in the hundreds of dollars to replace.

The chair is only 55 lbs. fully loaded and the battery itself is a lightweight 5 lbs. It is a rigid frame chair, but the wheels come off for travel and can also be easily switched out for regular wheels. A 2-3 hour charge will give you enough power to go four or five miles, which is plenty for the average person to get through their whole day. The chair also turns off automatically when not in use and restarts without having to be reset.

Power assist wheelchairs have actually been available in the US for about 10 years now, but as technology improves, they are becoming easier to use and much more affordable for the average wheelchair user. Michael says that since getting the chair he is much more mobile and gets much more exercise. He highly recommends that people who like the physical activity of wheeling and don't want to give it up completely, to look into this new option.

Kate Ryan has a master's degree in interdisciplinary studies with a focus on disability studies. She currently works as a personal care aide while searching for work in the disability field.