

Disability Issues

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Coping with an Acquired Visual Disability and Aging

By Mary Grimley-Mason

Shirley, who is legally blind with macular degeneration, is a very active member of the retirement community where she lives. We had lunch together while she reflected on her experience of coping with the changes in her disability, which began in midlife. She grew up, she says, slightly short sighted but that did not prevent her from going to college, getting a PhD in biology at Cornell, marrying and having three children while she helped support her husband as he went through medical school.

When her daughters went to school, Shirley became involved in educational matters and also in her own personal interest in textiles and beadwork. Her interests led her to the Peabody Museum at Harvard where she worked and volunteered for twenty years pursuing textile analysis and bead conservation as well as her own art work in weaving, embroidery, jewelry construction and beadwork. When Shirley found that she was having difficulty in doing close work with objects, she had a cataract operation and discovered that she had signs of macular degeneration. She says, "I have had to accept the degeneration of my hand skills and be satisfied with 'good enough.'"

After thirty-six years of marriage, Shirley was divorced from her doctor husband and moved to a condo and eventually began to research retirement communities, feeling she would need a more supportive environment.

continued on page 5

Aging with Polio and a Can-Do Attitude

By Sandy Alissa Novack, MBA, MSW

People with some disabilities are now living to an older age. If you are a young person reading this, you may wonder what your future holds for you as you age with your current disability. It is hard to generalize, as disabilities vary as well as individual circumstances. What follows is a condensed and edited version of a recent interview with Mary Grimley-Mason, a member of Disability Issues' Editorial Board. Mary, now 85 years old, looks back on her life and its challenges.



At the age of four, Mary was diagnosed with Polio Infantile Paralysis, an acute, viral, communicable illness sometimes resulting in paralysis, with the site of paralysis depending upon where in the body nerve cell destruction occurred. For Mary, polio meant she now walked using crutches and braces. Her family generally treated her just like her three siblings, but to help treat her polio, they sent her to Warm Springs, GA (known for its warm, mineral spring water, and where Franklin Delano Roosevelt went after he contracted polio in 1921), and

where she always had a physical therapist.

While her older sisters were very supportive of her, they were "Glamour Girls" in the 1940s, glamorous and popular; this wasn't easy for Mary. Mostly Mary feels her challenges were the same as anyone else her age, her thoughts included, "I can't do that" when it came to being a Glamour Girl. She attended an all girls' middle school where students wore uniforms, which helped because all the students dressed the same. For high school, Mary attended a Quaker Friends small, private high school, which also helped because the Quakers had a value system that made things easier. They allowed "nothing glittery" so there was no vying for high fashion and everybody was treated the same.

The issue of mobility prompted Mary to attend a college with a small campus so it would be easier to get around. But in the post-WWII years when no one had cars, she felt restricted. Two professors advised her to transfer to another college where she would be more intellectually challenged. She transferred to Harvard just as cars were becoming more prevalent, and she states that Harvard was good at letting her park wherever she needed. Reflecting on this point in her life, Mary would advise others with disabilities not to undersell their capabilities intellectually or otherwise. Mary knew she needed to transfer from a small college and get a car for her mobility. "There is a lot you have to do practically-speaking to self-advocate, to be proactive." You also either have to have, or develop, a can-do attitude, "You have to do what you have to do, so just do it, and move forward."

Because of the polio, Mary had fewer social experiences than others; going to all-

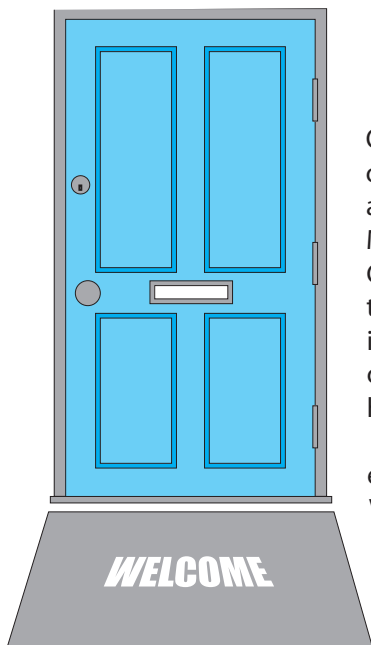
continued on page 8

Inside This Issue

Coping with an Acquired Visual Disability and Aging	1	The 50+ Job Search	4
Aging with Polio and a Can-Do Attitude	1	Your Assets and MassHealth	6
Support for Community Living	2	Information Briefs	7
From the Editor	3		

Support for Community Living

By Bill Henning



One of the great services offered to people with disabilities and seniors in Massachusetts is Options Counseling (OC), which aims to keep people independent in the community instead of being stuck in a nursing home.

According to Dan O'Leary, executive director of Mystic Valley Elder Services in Malden, people who have questions about their options for community living supports can

request "a confidential, no cost, conversation in person, at home, in an office, or by phone, with the goal of getting a series of recommendations and options based on their needs and preferences." Consumers, family members, and those in facilities can—and do—speak often with OC staff, who work out of ten independent living centers (ILC) and 27 Aging Services Access Points, better known as the ASAPs or Elder Services Agencies. The ASAPs aren't just for seniors anymore! They provide OC for members of the community of all ages who are disabled.

A significantly positive element of OC is that by being based at ASAPs and ILCs, it means that staff are familiar with independent living and services such as the personal care attendant program, home care, housing search, assistive technology programs, and more, which can, as Dan O'Leary says, "assist people to transition back to a community setting as soon as possible if they're in a nursing home or to stay out of one in the first place."

An especially poignant OC story is told by Adrienne Langlois, who provides OC for the Boston Center for Independent Living. In the past year she began working with a man named Joseph, a 58 year-old veteran. He had endured chronic homelessness for twenty years. Health problems landed him in a nursing home after both hips and a knee were replaced.

Langlois said, "I became pulled by Joseph's optimism and desire to get on the right path. We worked to find housing, and after he weaved through the bureaucracy, he found his own unit. This was great, but what was even better was when he called me on his second day in his apartment. When I asked how he was doing, he said, his voice cracking for the first time since I'd known him, "Never better... I took my daughter out for dinner last night, to my apartment on my very first night here, for her birthday, something I hadn't been able to do for over two decades."

One point that Langlois stresses is that she often sees consumers who feel like they are unable to make a personal decision about long-term care options because of competing opinions from doctors, social service professionals and family.

"So what's key about Options Counseling," Langlois indicates, "is that it provides consumers with an outside, objective source which can inform them and help them make the decisions that are right for them"

Bill Henning is Executive Director of the Boston Center for Independent Living.



BCIL's Options Counseling team brings personal and professional experience to this crucial service for people with disabilities and elders. Left to right: Rob Park, Angel Dailey, Adrienne Langlois and Nassira Nicola.

To locate an agency that can provide Options Counseling in your area:

For the **Aging Services Access Points agency (ASAP)**, also known as an Elder Services Agency, contact:

Massachusetts Executive Office of Elder Affairs AgelInfo line: 1-800-AGE-INFO (1-800-243-4636)

or visit www.800AgelInfo.com.

For the **Independent Living Center**, visit: www.masilc.org

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From the Editor

Dear Readers,

The editorial board of *Disability Issues* is bringing you a wide range of articles on the topic of disability and aging. For the first time in history, many individuals with significant disabilities, like their non-disabled counterparts, are surviving long enough to experience the rewards and challenges of "aging."

I have a fantasy about aging and disability. It's one that I know isn't true, yet is still tempting to believe. My fantasy is, because I live with a disability I have paid my health dues and am immune to getting some of the "regular" illnesses. I know this is magical thinking, but somehow it doesn't seem fair that I should experience both disability *and* illness. Yet, the longer I live, the more likely I am to experience physical disorders and illnesses related to aging.

Even those who have been able-bodied most of their lives begin to experience "age related impairments" - a fancy phrase for disability. The likelihood of having a disability increases significantly with age. According to the U.S. Department of Health and Human Services, 44% of people who are 65 – 69 years old have some form of disability. At age 80 and older, it jumps to 73%.

With so many people living with a disability, or likely to become disabled, doesn't it make sense that there would be a louder outcry for accessibility, accommodations, and acceptance of differences? Why is it primarily only people with disabilities who are fighting for these rights? Maybe many currently able-bodied people are similar to me and have a fantasy that they are immune to becoming disabled. One day, I believe we will all realize that disability and aging have a lot in common. So, let's start working together now to create a world that accepts and supports everyone – those who are disabled today, and those who will age into disability.

Marianne DiBlasi, Editor

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To view *Disability Issues* on-line go to
www.workwithoutlimits.org/DisabilityIssues

The 50+ Job Search

By Bill Allen

You may wake up in the morning and are reminded that you have become a mature citizen (in my view this is a gift and a coveted accomplishment). You have discovered that your job search has become more ominous and attribute this to your age as well as your disability. Although this may be covertly happening with your interactions with some employers, there are discrete action steps you can deploy to keep your skills, knowledge and your rich life experiences relevant in the workplace. Clearly you are not alone as you have joined the ranks of nearly 2 million older workers seeking employment (Bureau of Labor Statistics, November 2013).

Whatever your composition is or has been, you have acquired significant talents and practical work ethics during your 50 plus years on this earth, but you may not be embracing your contributions that you may have made to family, the workplace, and or to the community at large. Your life skills and accumulated knowledge are highly valued, but you must reinvent your marketing strategy.

Reinventing Your Personal Marketing Strategy:

You should be able to demonstrate your skills and abilities with an employer as a “senior analyst” or “senior contributor” not a “senior citizen.” You can market your skills set in any labor market sector, but we as 50+ workers and job seekers must get educated about the current labor market and blend our talents into the applicant pool.

This strategy is best stated by Dr. Gene Emmer, President of Med Services Europe:

“Every one of us has unique characteristics which though unimportant or disadvantageous to some employers, will be seen as advantageous by other employers. This includes disability. The trick is to determine who may be seeking your unique characteristics and why. Then combine your unique characteristics with the skills or training that make you the ideal candidate for a particular job”

So Where Are The Jobs?

I recently attended a WBZ NewsRadio 1030 Business Breakfast Series “Made In Massachusetts: Creating Jobs In the Bay State” event in Boston. The event hosted by WBZ’s New England Business Editor, Anthony Silva, featured a panel discussion of business leaders and experts from businesses right here in Massachusetts. They articulated that the Commonwealth’s manufacturing sector is “staging an epic turnaround”.

The panel members included representatives from New Balance Athletic Shoes, Inc.; Massachusetts Life Sciences Center; Harpoon Brewery; Dukakis Center for Urban and Regional Policy-School of Public Policy and Urban Affairs at Northeastern University. There were over 300 employers that attended this event. It was amazing to learn that manufacturing businesses are struggling to find workers. One of the

greatest needs identified was STEM (Science, Technology, Engineering, and Math) skills. Most interestingly these skills, although in great shortage, create jobs with ancillary support positions in clerical, manufacturing, distribution, production, and other positions that are generated due to product development. There are potentially hundreds of jobs that would enable mature workers to market their knowledge, skills, and abilities...not to mention their incredible work ethic, which by the way was identified as a major problem with younger workers.

Networking in Action

Post event, I networked with several businesses. In particular, I was able to listen to one packaging manufacturer that was struggling to find a plant manager for one of their facilities in Middlesex County. I explained my role at the Massachusetts Rehabilitation Commission and described how we could be yet one more resource for talent acquisition. As he listened to how we could help him solve his need for a plant manager, I was able secure an interview for an individual who had vast experience in manufacturing. This individual’s experience was in alignment with the company needs. The fact that this person has a disability and is 62 became invisible. We secured an interview and at this writing, this qualified mature worker is now on his second interview.

To keep your job search relevant and effective, here are some basic tips:

- Learn the current labor market and understand employer expectations.
- Identify your transferable skills.
- Have realistic goals and expectations (check in with colleagues and friends about what this means to you and others).
- Develop a skills based resume and highlight significant accomplishments that would be valued in today’s marketplace.
- Practice Behavioral Interviewing Techniques.
- Develop your social media strategy such as LinkedIn.
- Network! Network! Network! (this is the most effective strategy... meeting people face to face will never be replaced).
- Stay focused and positive.
- Re-adjust to the ever-changing labor market by upgrading your skills set.
- Never give up!

Brenda’s 50+ Job Search Story

Brenda was living the dream of economic self-sufficiency and independence through her work as an accountant for a high-tech company. Brenda, who grew up with Depression and Anxiety was able to manage this diagnosis with natural support through friends and family. She was recognized and rewarded as an individual contributor for a prestigious organization that was well known in the computer software world.

continued on page 5

The 50+ Job Search - continued from page 4

She was breaking the proverbial “glass ceiling” and receiving promotions along the way for her talents and capabilities. As Brenda put it “life was good”.

Unfortunately, Brenda was involved in an automobile accident, which resulted in a severe back injury at age 50. She had to leave work and went on disability. As you can imagine, Brenda was devastated as she was at the height of her career. For the next three years Brenda was in and out of physical therapy. She also was in severe pain and was struggling to stabilize her medical condition. As Brenda’s physical restoration continued she became severely depressed and was heavily medicated to control her pain. Family, friends, and Brenda despaired about her future.

Brenda was referred to the Massachusetts Rehabilitation Commission for vocational services at age 54. As Brenda continued with both physical therapy and management of her Depression, she began to discuss her journey back to work. She met with her vocational counselor on a monthly basis at MRC to develop her plan to return to work. As she met with her counselor, Brenda realized that she always found the manufacturing sector to be high on her interest scale. After completing computer courses in accounting to upgrade her skills, Brenda met with the MRC Job Placement Specialist (JPS) to begin her job search. The JPS and Brenda identified an open position with a manufacturing company and as luck would have it MRC had a strong relationship with this

employer. The position of production expediter required 3-5 years of experience that Brenda did not have.

The JPS contacted the manufacturing firm and the department manager was leery as Brenda was lacking the requisite experience. Brenda researched the position extensively and she began to develop a strategy to demonstrate to the employer how her experience, skills, abilities and strong desire to learn would benefit the company. She practiced behavioral interviewing skills and she “mock” interviewed for the position with MRC business liaisons. A formal interview was arranged with the production manager and Brenda did extremely well. However, the manager still had some concerns with the lack of experience as the position required precision math skills. The job entailed working with measuring plastic resins that were worth hundreds of thousands of dollars. There were complex calculations that were essential to comprehend to the production process. After the third interview, Brenda was hired into the production expediter position with MRC underwriting an MRC On-The Job Training Agreement for a short period of time.

Brenda thrived on the job and FOUR YEARS LATER... Brenda was promoted to Production Supervisor!

See page 7 for websites related to [The 50+ Job Search](#)

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

Coping with an Acquired Visual Disability and Aging - continued from page 1

She reflected on the social consequences of her personal upheaval but also on her increasing disability. She says that not only did she lose many of the academic and social connections at the museum, but she began to lose some of her social skills as well, such as the ability to see facial expressions which give us a lot of social cues we depend on. “I am nearly face blind,” she says, and have to develop other ways of identifying people through shape, walk, and voice, for instance.” The most difficult consequence of the diminishment of her sight was when she had to give up driving. She says, “I became particularly conscious of how my physical, intellectual and social world had shrunk.”

Shirley has made adjustments. She chose a retirement community where she has become actively involved in social and community activities, including participation in committees, events, and trips to concerts and museums. She says, “I guess I have become more social though I am basically an introvert.” Shirley is appreciated for her outspoken involvement in discussions and concerns of the community. She started a garden here but lately, she’s had some difficulty distinguishing weeds from plants and she says “I am uncomfortable outdoors in strong sunlight and although I was trained as a naturalist I have had to give up most outdoor explorations.”

When I asked Shirley what has been the most helpful to



her in meeting these physical changes in her life, she particularly mentions the new devices of technology. “I always liked gadgets and machines so computers and tablets, a desk magnifier, and audiobooks have been lifesavers.” She also

advises others to find the best retina specialist—there are some miraculous injections, she says—and stay in touch with your doctor but don’t expect help for your adaptations or for “life issues.” Do, however, register at the Mass Commission for the Blind for services, including a large collection of book readers and contacts.

In concluding about what is needed to help those who are visually impaired, Shirley says, “More research from science and, from society, more awareness and consideration of our difficulties.” She adds, “Growing older, while also losing vision is challenging. Aging adds a new set of difficulties and limitations to deal with.”

Mary G. 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*.

Your Assets and MassHealth

By Ray Glazier

Remember that the basic premise of Medicaid, MassHealth to us, is the provision of health insurance coverage to persons living at or near the poverty level, most of whom would have already cashed out any assets to cover expenses. About one in every six MA residents is insured by MassHealth, so the program's asset considerations matter to millions of people here. Two special cases are elderly persons quickly impoverished by nursing home costs and working persons with disabilities who are without employer health insurance or need PCA services that no private health insurance covers. Nursing home residents usually transition to MassHealth Standard when their money runs out, while working PCA users, who are not veterans eligible for VA home care, can qualify for MassHealth CommonHealth individual coverage, paying a sliding scale monthly premium based on household income and family size. Persons who fit into either of these MassHealth/Medicaid special case scenarios may have assets they wish to pass on to others. Preserving that option requires careful advance planning and expert legal advice.

Generally speaking, the MassHealth 'countable' asset limit for individuals is \$2,000 and for couples living at home \$3,000; these limits are dictated by federal Medicaid rules. "Countable assets include the value of bank accounts, certificates of deposit, mutual funds, stocks and bonds, as well as the value of real property other than your home. Non-countable assets include the home you live in if it is located in Massachusetts, one vehicle per household, and an irrevocable burial trust or prepaid burial contract... (MassHealth information). "You can't reduce your assets by giving them away, for example to family members, or sell them at less than fair market value within 36 months prior to applying for MassHealth; in some cases, for example, need for Medicaid-funded nursing home

benefits, this asset liquidation or asset transfer 'look-back' period is 5 years.

Even if you satisfy these requirements, Medicaid Estate Recovery, another feature of the federal Medicaid law, can dip into your estate when your will goes through probate to take back the total dollar costs of MassHealth benefits paid out in your lifetime. This can be troubling if you had hoped to pass on the family home or other assets with a cash value to the next generation of your family. It is sometimes possible to shift assets to the non-countable category and/or to protect assets from the Estate Recovery process by placing them in trust. But such a move requires specialized legal advice from an attorney well versed in such matters, who is probably not just your family lawyer. In fact, not even all practitioners of 'elder law' are fully competent in this highly specialized area of the law. If you ask the right questions, an attorney should let you know whether she or he is up to the task.

Please do not consider this brief article by a non-attorney as all you need to know on this topic. Check out the accompanying links, plan ahead, and get expert legal counsel, if you are currently, or might become, a MassHealth member and have assets to protect. Providing for the future needs of a child with disabilities involves even more specialized asset considerations and very involved estate provisions.

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

Assets and MassHealth: Useful Links

MassHealth Information

<http://www.mass.gov/eohhs/consumer/insurance/masshealth-apply/>

A policy paper on Medicaid liens and Estate Recovery in Massachusetts at this U.S. Department of Health and Human Services webpage: <http://aspe.hhs.gov/daltcp/reports/maliens.htm>

Find a MA Elder Law specialist by your zip code at the website of the Mass. chapter of the National Academy of Elder Law Attorneys at their website: https://www.massnaela.com/find_an_attorney

Find a Health Care/Medicaid Lawyer by city and state:
<http://lawyers.findlaw.com/lawyer/practice/Health-&Health-Care-Law>



Easter Seals Assistive Technology Center

Boston Workshops Winter / Spring 2014

Asperger's Independence Apps

Wednesday • February 19, 2014 • 5:30-7:30pm
Presenter: Katrina Caracol-Parker, BS

Getting off the Ground with Proloquo2Go

Tuesday • February 25, 2014 • 9:30am - 12:30pm
Presenter: Kristi Peak-Oliveira, MS, CCC,
Speech Language Pathologist/AAC Specialist

Accessibility and Apple i-Devices

Tuesday • March 11, 2014 • 5:30- 8:30pm
Presenter: Kevin Berner, MS OTR/L, ATP



Assistive Technology Workshop Registration

Location:
Easter Seals Massachusetts office
89 South Street, Boston MA, 02111
Fee: \$80 per workshop

For questions or to obtain a registration form
please call Kim Livingston at 508-751-6328
or klivingston@eastersealsma.org

Visit our web site at www.eastersealsma.org
for more information and biographies of our presenters.

Organizations that are dedicated to the 50+ Job Seeker:

www.workforce50.com

www.operationable.net

www.seniorjobbank.org

www.job-hunt.org (Select "Boomer Job Search")

Save The Date



"Focus" on Vision Impairment & Blindness Conference Meeting the Needs of Individuals with Intellectual Disability & Vision Loss

Wednesday, March 12, 2014 • 8:00 am - 3:30 pm
Four Points by Sheraton, Norwood, MA

We are so pleased to welcome **Jim Elliott, Award-Winning Humanitarian and Founder/President of Diveheart** as our **keynote speaker**. Diveheart's mission is to help build confidence, self-esteem and independence in children, adults and veterans with disabilities through the sport of scuba diving. Founded in 2001 in Illinois, Diveheart is now making an impact in Massachusetts. Join us to meet Jim and be inspired!

Registration Information:

** Early Registration Fee postmarked by
January 31, 2014: \$50.00

Registration Fee postmarked after
January 31, 2014: \$60.00

Registration needed by
February 27, 2014 to attend conference.

Registration brochure and form, including CEU information, can be downloaded from the "Training and Events" section of the DDS website: www.mass.gov/dds/visionloss and from the "Perkins Training Center Schedule" on the Perkins website: www.perkins.org/professional/ptc

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

Aging with Polio - continued from page 1

women schools at a younger age, she was a little shy about dating in college. On the other hand, without the social emphasis, Mary was pushed more into developing her intellectual and academic strengths. "You accommodate and adapt to see where you fit in."

Mary did get married and had three children. She and her husband travelled and lived in other countries. At age 39, she began to have more physical and personal challenges. A hair-line fracture of a hip required her to temporarily use a wheelchair, something she had not had much experience with before. Her marriage also ended when her husband chose to focus on himself and left. In her typical style, Mary "just went on with life."

Now 85 years old, she describes her challenges as mostly physical, "just wearing out." Mary addressed the issue of independence and thought about whether she could continue to take care of herself in the home she'd been living in for 20 years. She recognized that she needed more help and moved into an apartment in a retirement community where assistance is available when needed. After the move, Mary transitioned from walking with crutches and braces to using a power wheelchair most of the time. Using a wheelchair was a necessary, but difficult, decision to make after being accustomed to walking most of her life. Once again, Mary's practical approach to accepting challenges helped

her to adjust to a new mobility device and living in a community setting.

Upon life review, Mary states she developed a kind of independence by attending women's schools. The sense of self-assurance she developed helped her "find her voice." She went on to get her PhD in English, teach, and publish six books, including three since she retired. Mary offers additional advice for readers:

1. If you have a disability, you have to be persistent.
2. Don't feel you can always do things on your own; recognize what you need and seek help.
3. She wishes she had gotten more involved in the disability movement earlier on, and made some contacts. She advises those with disabilities to reach out to people in the disability community for friendship and support.

For more about Mary, read her memoir, *Life Prints: A Memoir of Healing and Discovery* by Mary Grimley-Mason, Feminist Press, 2000.

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