

Disability Issues

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Disability Benefits: Path to Prosperity or Poverty

By Ray Glazier



Those of us with significant disabilities deserve the helping hand offered by federal and state benefit programs, just to survive in these tough economic times. Each of us has something to contribute to society at large. Just being out and about, visible in our communities is an important activity. But most of us have some way we can contribute to the economy and to self support. And it's a good thing we do, because disability benefits like Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Food Stamps, and Section 8 Housing Assistance all taken together don't make for economic security or a decent lifestyle.

The basic idea of the original Social Security Act of 1935 was to provide an income floor that would keep persons

Continued on page 5

THE OPINION CORNER

Rethinking Work Opportunities for Women with Disabilities

By Mary G. Mason

"We need to expand our concept of work," says Judith, whose disabilities of chemical sensitivities and Chron's disease have prevented her from having a full time job. "We need a definition of work that takes into consideration a person whose needs and abilities are not standard, but who has assets and talents to offer."

Many of the 30 women I interviewed for a book on the work lives of women with disabilities would agree with Judith. Most of these women are working or have worked—about half of them part-time—despite many barriers and much discrimination.

Success in the work world for women with disabilities cannot always be measured by the number of hours worked or by earning power. Of the women I interviewed, some are self-supporting; others receive disability insurance and live in subsidized housing. All achieve some measure of self-sufficiency and self-determination. They have claimed their disability as part of themselves, just as race or gender or class, and they have confronted the challenge of living in a non-disabled world. They see disability as a socially constructed category subject to cultural norms that place them outside the norm, often creating public discrimination and personal dismissal. But these women do not see themselves as victims. Adrienne, who is blind and a professor, called her disability an "inconvenience" and something she just has to factor in her life "the way that someone with a two hour commute to work does." Debbie, despite severe physical impairments from cerebral palsy, insisted disability is not "who I am. It's something I happen to have."



It is clear that education for disabled women improves the chance of employment. Many of those who work full time have higher degrees and have professional careers as lawyers, academics and social workers. On the other hand, Kristen, who had polio at age one, found being in a wheelchair drastically lessened employment opportunities even with a master's degree. And Robin, who has multiple sclerosis, notes that even a Ph.D. and a successful career did

Continued on page 8

Inside This Issue

The Opinion Corner: Rethinking Work Opportunities for Women with Disabilities.....	1	From the Editor	3
Disability Benefits: Path to Prosperity or Poverty	1	The Advocacy Corner: Living with Endometriosis.....	4
The Work Place: Putting Potential to Work.....	2	Information Briefs.....	6-7



THE WORK PLACE

Putting Potential to Work

By Tanya Skypeck

Now in its eighth year, The Massachusetts Commission for the Blind (MCB) Summer Internship Program has been a model of successful placement of youth with disabilities in work experiences that prepare them for professional careers in all sectors of the workforce. The program has enjoyed explosive growth from year to year, beginning with three interns working in the MCB office in 2005, to 18 interns working in the offices of numerous community partners in only the second year of the program. Clearly the MCB was on to something good. The list of MCB community partners also continues to expand; 33 new partners were added between 2009 and 2010. These include large corporations, state government agencies and non-profit organizations. Employers receive informational and technical supports and resources in an ongoing, mutually appreciative relationship with MCB, which keeps them eager to host interns year after year.

opportunity to bring their broad interests and academic talent into a career-oriented focus.

"I always wanted a career helping people," says Ashley Brow, who is just entering her first year of graduate school at Emerson College to study communication sciences and disorders. "I bounced around in everything, from social worker to nurse, to music therapy. Eventually I stumbled upon speech language pathology and decided to make it my major. Now it is my future career." The work experience Ashley enjoyed through the MCB internship program this summer will help shape the next two years of graduate school. "It has also helped me realize what my strengths and weaknesses are or will be once I enter work in the field. Now I know what skills I need to improve upon." Ashley is leaning toward a focus on pediatric practice. When the real job search comes in two years, no doubt Ashley will be an outstanding candidate.

Candice Jewell likewise found the MCB internship to be a valuable opportunity to get a taste for how her long-time personal and academic curiosities could be applied in a career field. "For as long as I can remember, I have always liked to analyze people, and I always have found people's behaviors very fascinating," says Candice, who will be graduating from Suffolk University this coming spring with a degree in psychology and wants to pursue a Master's Degree after that. Even though Human Resources isn't necessarily the career field Candice will eventually pursue, an internship in the HR Department at Spaulding gave her an intimate view of a concrete context for the aspects of psychology that she enjoys so much. "I was able to see very constructive dialogue, and see how that makes all the difference in creating open communication amongst the department. I was able to see them work as a unit to solve problems, which is refreshing." Candice was accepted, accommodated, and challenged in her internship, and she knows even better now that a disability need not necessarily be an obstacle to employment. Down the line, Candice muses, "who knows? If I am lucky enough, I will be able to go back to Spaulding one day and work with some of the most accepting people I could have the pleasure of working with."

These days, 70 students are accepted each summer for the eight-week internship program, which provides each student with a small stipend and a work opportunity at a site well matched to their employment interests. In many cases, otherwise untapped potential is blossoming into fruitfulness given this unique opportunity.

Candice Jewell and Ashley Brow are two of these students. Candice spent her summer as a Human Resources Department intern at Spaulding Rehabilitation Hospital in Boston, and Ashley was a Speech Language Pathology intern at Spaulding of Cape Cod Rehabilitation Hospital. Both of them already excelled academically, so the internship was an

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WorkWithoutLimits
Putting abilities to work in Massachusetts.

SPAULDING
REHABILITATION NETWORK

From the Editor

Dear Readers,

In the midst of enjoying the lazy, hazy days of summer, Americans watched anxiously as Democrats and Republicans debated on raising the debt ceiling, which they finally voted to do on August 2nd. The ripples of this long and heated deliberation created upheaval in our financial market and there are still looming unknowns. How will the federal budget cut \$2.5 trillion over the next decade? What impact will there be on the poor, elderly and people with disabilities?

With all this uncertainty, what do we do to keep ourselves moving forward? My response is, I tap more boldly into my inner resources of creativity, adaptability and resilience. These are skills that I, and every person with a disability, uses to navigate through our world and daily activities. In uncertain times, employers value individuals who bring these deeply honed skills to their organization.

The theme for October's National Disability Employment Month is "Profit by Investing in Workers with Disabilities." The theme communicates to the public that people with disabilities represent a highly skilled talent pool that can help employers compete in today's global economy. We need to do our part by clearly identifying and communicating how our unique skills and abilities add value to the workforce. In this issue of *Disability Issues*, we bring you a rich assortment of employment related articles and resources to help you get your creative, adaptive and resilient energy flowing.

Marianne DiBlasi, Editor

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The Advocacy Corner

Living with Endometriosis: A Hidden and Invisible Disability

By Arielle Denise Dance

I have endometriosis, which is one of those hidden and invisible disabilities. Endometriosis is a chronic disease that causes extreme pain in the pelvic cavity and possible infertility in millions of women worldwide. I was diagnosed with this grown woman's disease when I was 15 years old and have suffered daily the past 7 years. This disease has killed many dreams and has nearly stolen my joy. It has landed me in the ICU, physical therapy, emotional therapy, and on five operating tables. I have had hundreds of needles poked in places I dare not name. It won't go away—ever. But still I wear a smile in public and cry in private. Never truly showing the way the debilitating pain is affecting my body and spirit.

Recently I made the decision to stop weeping at the feet of endometriosis. It was time to take my life back. So, as a graduate student studying women's health, I have dedicated my academics to endometriosis research. I have attended conferences and read an abundance of literature on the topic. It is easy to assume you are an expert in a disease because you have it. But truly becoming an expert requires some additional learning. I believe, even without being a graduate student, I would want to know all there is to know about what's going on in my body and I'd want to share that information with as many people as possible.

After utilizing the services of the Disability Office as an undergraduate student, I realized that many individuals did not consider endometriosis a disability. To many endometriosis is merely "bad cramps" and does not require accommodations. I have had five surgeries for my "bad cramps" and am entitled to receive some accommodations. Between operations, irregular (and extremely painful) periods and

daily pain, nausea and vomiting, attending classes was nearly impossible.

The lack of understanding of Endometriosis motivated me to share my knowledge and experiences with those who may not know about the diseases and conditions that can afflict the bodies of women. In my lowest place, I began video recording myself speaking about endometriosis. I used my pain as a platform to educate and advocate. I began with one video blog on YouTube™ (<http://www.youtube.com/hisprincess9>) and now there are nine videos. By sharing educational information and my experiences with endometriosis, I have created awareness and educated people all over the world.



Photo: Arielle Denise Dance

I have always been determined to stay on track academically and excel in all that I do. The worse I feel, the better I do in school. My pain makes me more determined and perhaps that has a lot to do with my area of interest. I am driven to find a cure or some answers. And I am anticipating the day when women will no longer suffer in silence.

As a student, I am able to make my own schedule for the most part. I choose what time to take classes, when to go out or

stay in and which organizations to become involved in. Academically, on painful days I can do my schoolwork from the comfort of my bed. However, with my part-time job on campus, I have to sit at an uncomfortable desk for hours and walk the inclined streets of Boston. I often worry that my disease will keep me from obtaining and maintaining a stable career in the future. I believe I may have to choose a career that is flexible and within my control because it is unlikely that all my managers will be as warm and understanding as the supervisors I've had. So many women with endometriosis suffer from having managers who do not understand and an inability to acquire accommodations or disability benefits during surgical recovery.

Having an incurable disease that affects my everyday life has truly opened my mind and heart to the hardships of others with chronic illnesses and disabilities. I commend everyone who manages their disease especially in freezing uphill cities like Boston. Cold weather is my worst enemy and so are the inclined streets. The next time you see someone on the street struggling up the hill, don't assume they're just lazy. Consider the inner battles they may be facing. Some disabilities are invisible to the human eye but that doesn't make them less legitimate. Endometriosis is one of those hidden and excruciating disabilities.

Arielle Denise Dance is a graduate student in the Master of Arts in Women's Health program at Suffolk University, Boston, MA. A graduate of Spelman College, Atlanta, GA, Arielle has dedicated her academics to Women's Health advocacy. Focusing her research on endometriosis and chronic illnesses, Arielle looks forward to continuing her education in the field of medical sociology.

Disability Benefits - continued from pg 1

with disabilities who have little or no income and assets out of poverty. SSI was introduced in 1972 as a federal benefit program administered by the Social Security Administration, with states having the option to supplement, as MA does, the basic monthly rate.

More than 188 thousand Massachusetts residents of all ages receive SSI benefits. A non-blind, non-elderly person with a disability living alone in MA in 2011 receives a monthly SSI benefit of \$788.39, or \$9,460.68 for the year; this income level is less than the federal poverty guideline of \$10,890.00 for a single person. In-kind benefits like Food Stamps and Section 8 Housing Assistance do help many SSI recipients, and recipients' automatic eligibility for MassHealth is a plus. But living on cash and in-kind benefits alone is a challenge, to put it mildly.

And yet that monthly SSI check can seem like a boon to teenagers with disabilities and maybe to their parents as well. Young people in special education programs who qualify for SSI benefits and are living at home may not feel motivated to plan ahead for self sufficiency by acquiring job skills and entering the labor market. Of the 6.5 million residents of Massachusetts, more than one million persons over age 5 have disabilities, according to the Census Bureau. About 37 percent of working age MA residents with disabilities are working at least part-time; the employment rate is highest for persons with sensory disabilities like deafness or blindness (49%) and lowest for persons with self-care limitations (21%) and difficulty going outside the home (19%).

Becoming one of those working persons, even part-time, may be the best move that a Massachusetts citizen with a disability can make, if it is at all possible. Use the sidebar resources to explore your options.

Raymond E. Glazier, Ph.D. is Director of the Abt Associates Center for the Advancement of Rehabilitation & Disability Services in Cambridge; he is a former SSDI beneficiary who returned to full-time employment in order to support himself and his family; his current work involves managing communications with the one million SSDI beneficiaries and SSI recipients touched by the Social Security Administration's Benefit Offset National Demonstration program.



Disability Benefit & Employment Resources

Gateway to Massachusetts Disability Services:

<http://www.mass.gov>
(Search for Disability Services)

Employment Services from the Massachusetts Rehabilitation Commission:

<http://www.mass.gov>
(Search for Vocational Rehabilitation Services)

Massachusetts Work Incentive and Benefits Counseling Services:

Toll Free: 1-877-YES-WORK (937-9675)

GettingHired.com:

www.gettinghired.com

Career Opportunities for Students with Disabilities

<http://www.cosdonline.org>

AbilityLinks.org:

<http://www.abilitylinks.org>

AbilityJobs:

<http://www.jobaccess.org>

Social Security Benefits for People with Disabilities:

<http://www.socialsecurity.gov/disability/>

Toll Free: 1-800-772-1213

TTY: 1-800-325-0778

Social Security Work Incentives and Other Employment Supports:

<http://www.ssa.gov/work/>

SSDI and SSI applications must be made to the Social Security Administration, either at an area SSA field office, or on-line at: <http://www.socialsecurity.gov/disabilityonline>

U.S. Department of Health and Human Services (HHS) Poverty Guidelines:

<http://aspe.hhs.gov/poverty>
(Select HHS Poverty Guidelines for 2011)

Information Briefs

Harvest Co-op Market Welcomes Shoppers with Disabilities

Harvest Co-op Market (www.harvest.coop) is a community-owned cooperative market with over 3,500 members in the Boston and Cambridge area. We have two full-service



markets open to the public from 7 am to 9 pm daily. Our stores are at 581 Massachusetts Ave. in Central Square, Cambridge and at 57 South St. in Jamaica Plain. Harvest features organic and commercial produce, groceries, deli, cheese, and local craft breads, meat, seafood, an expanded bulk food departments, as well as beer and wine.

Harvest warmly welcomes shoppers with disabilities.

- Non-members with disabilities receive a 5% disability discount card.
- Management and staff are educated on customers who are affected by scent and chemical sensitivities. The stores strive to use unscented products, including low- or no VOC paint.
- Lightweight doors with easier-to-grip handles have been installed at the entryway to the Jamaica Plain store.
- Disability parking spots are available in the Cambridge store parking lot and in front of the Jamaica Plain store.
- The co-op member-owner brochure is available in Braille. To obtain a copy, contact Chris Durkin at 617-661-1580 x 132, or cdurkin@harvest.coop.

Autism Walk to raise vital funding that will provide free services for families!

On Saturday, September 24, 2011 **The Hearts and Hands Walk for Autism and Family Fun Day** will be held from 9:30 -1:30 at Bristol Community College, Fall River, MA.

Today, 1 in 110 school age children have a diagnosis on the Autism Spectrum. The Walk will support Community Autism Resources, a nonprofit Autism Resource and Support Center. Community Autism Resources mission is to provide, at no charge, the vital services and programs that are absolutely necessary for children, teens and adults on the Autism Spectrum and their families!

There are free activities for the whole family including our Bubble Creation Station, Bounce House, Sensory Treasure Hunt, Carnival Style Games, a balloon artist, Face Painting and Temporary Tattoos.

For the adults there will be an Autism Awareness Store with a wide variety of items including: the locally created Glimmers of Hope Autism Awareness Bracelets, Autism Awareness pins, key chains, car magnets, T-shirts and much more! An exciting raffle will be held and there will be free refreshments as well.



For more information about the walk or the free services, resources and trainings go to www.community-autism-resources.org or call Jan Randall at 508-379-0371 ext 16.



October is National Disability Employment Awareness Month

October is **National Disability Employment Awareness Month**. The official theme selected by the US Labor Department's Office of Disability Employment is "Profit by Investing in Workers with Disabilities." The theme honors the contributions of workers with disabilities and serves to inform the public that they represent a highly skilled talent pool that can help employers compete in today's global economy.

"Return on investment means hiring the right talent," said Kathy Martinez, assistant secretary of labor for disability employment policy. "Workers with disabilities represent all skill sets and are ready to get the job done. This year's theme focuses on improving employment opportunities that lead to good jobs and a secure economic future for people with disabilities and the nation as a whole."

Information Briefs

Christine Griffin Appointed as Assistant Secretary for Disability Policy and Programs for Massachusetts



Massachusetts Secretary of Health and Human Services, Dr. JudyAnn Bigby announced the appointment of Christine Griffin as Assistant Secretary for Disability Policies and Programs. Ms. Griffin, a national leader in disability policy, is also a familiar figure in Massachusetts where she served as the Executive Director of the Boston-based

Disability Law Center from 1996 until 2005. Most recently Ms. Griffin served as Deputy Director of the United States Office of Personnel in Washington DC and prior to that as Commissioner on the Federal Equal Opportunity Commission.

Commission on Disability to hold third annual Disability Awareness Day

The Fall River Commission on Disabilities will be sponsoring its third annual Disability Awareness Day to be held Thursday, October 6, 2011 at Government Center in Fall River Massachusetts from 10:00 am until 2:00 pm. This year's theme is, "Building a Life of Inclusion in Fall River."

Highlighting the Awareness Day will be the Diman Regional Vocation School demonstrating home modifications for persons with disabilities, along with the Perkins School for the Blind demonstrating how movies can be viewed through Audio Description. There are also going to be short presentations about independent living, technology, and employment. Also, the Fall River Board of Elections will demonstrate the new Automark voting machine for the Blind and visually impaired and will register anyone who wishes to vote in the upcoming November local elections.

This educational event will also have information from agencies and vendors that provide services to people with physical and intellectual disabilities, senior citizens, and veterans with or developing disabling conditions.

For more information, contact Brenda Ritz in the Dept. of Health and Human Services at 508-324-2413.

Five PCAs Receive the Paul Kahn PCA Service Award

The Paul Kahn PCA Service Award was presented on Thursday, September 15, 2011 in a ceremony at the Massachusetts State House. Five PCA's from across the Commonwealth were honored for "the selfless work they perform to enable individuals with disabilities to lead more independent and productive lives."

Congratulations to the 2011 recipients!

- Noah Zazinga - Gr. Boston
- Johanna Montalvo - Central MA
- Luci Johnson - Northeast MA
- Terri Morris - Southeast MA
- Patricia Peles - Western MA



This award is named in honor of Paul Kahn, a long time PCA employer, advocate, and editor of *Disability Issues* who died in January 2010. Having personal care assistants gave Paul the freedom to live on his own terms. It allowed him to pursue his art, writing, teaching and advocacy activities. Without PCAs Paul would have remained institutionalized and not have made his many contributions to the disability and independent living communities. This award, in his name, honors the PCAs who do this important work every day.



Telephone Support Group for People with a Disability or Chronic Illness

The Boston Self Help Center is offering a peer-counseling support group. At these meetings, participants will talk about whatever is most important to the group about living with a disability or chronic illness.

WHEN: Coming soon! Exact start date not yet determined

WHERE: On your telephone

HOW OFTEN: A total of 8 meetings, to be held biweekly

COST: Sliding fee scale; you pay what you can afford

The Boston Self Help Center has been providing peer-counseling support groups in a cross-disability setting for over 30 Years.

For more information, call (617) 277-0080.

Opinion Corner - continued from page 1

not assure her of an academic position as a candidate in a wheelchair. "People look at you funny in a wheelchair," she says. A number of women described doubled or "layered" discrimination in their jobs—as a woman and as disabled.

The women interviewed concur that professional training and awareness, cultural attitudes, and physical accommodations need to change in order to give disabled people, and women in particular, a chance to participate fully in society.

Too often school and rehabilitation counseling is not only sexist but also "ableist." Young women with disabilities are channeled into traditionally female jobs or in jobs related to disability. Counselors need to encourage women to explore options and develop ambitious goals. Alicia, a talented artist, born with cerebral palsy, was guided into a job teaching disabled children and found that this kind of work was not her calling. She changed direction and graduated from the Museum School in Boston, a confident sculptor and painter.

Unlike other civil rights bills, the American with Disabilities Act, 1990, meant to protect disabled people from discrimination in employment, was not followed up with implementation of affirmative action. The high expectations of the disability

community have given way to disillusionment as the U.S. Supreme Court increasingly favors employers in disability lawsuits. The Court has focused on narrowing the definition of disability—excluding more and more people—instead of focusing on the issue of discriminatory practices by employers. The unemployment situation has not changed after more than a decade. The Bureau of Labor Statistics report for June 2009 states that the percentage of women with a disability in the labor force was 33.5 percent compared to 73 percent for women with no disabilities. The percentage for disabled women is only slightly less than disabled men, but women are more likely to work part time and earn less than men.

At a time when many Americans are unemployed, people may question taking up the cause of employment for people with disabilities. But we must also ask ourselves what the consequences will be if we fail to help disabled people, particularly women, to become self-sufficient as part of the work force.

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 and Working Against Odds: Stories of Disabled Women's Work Lives

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