***Disability Issues***

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*Providing individuals with disabilities, their families, friends, and advocates with relevant information to enhance their quality of life, health, and employability options.*

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**In this issue:**

- From the Editor

- Human-Centric Employment

- Tips for Disabled Veterans to Start Their Own Business

- More Access Means More Jobs

- PCA Corner – Understanding EVV

- Love and Intimacy Corner – You are in Recovery from Trauma: Now What?

- Dreaming of Sunrise

- Information Briefs

**Graphic Design:**

Louise Martling, Eleventh Hour Design

**Printing:**

Jon Rebuck, P + R Publications, Inc.

**Constant Contact Conversion:**

Darron Louie, Spaulding Rehabilitation Network

**Spaulding Rehabilitation Network Liaison:**

Colleen Moran

**From the Editor:**

Dear Readers,

As I write this, we have recently experienced the impact of Hurricane Harvey and Hurricane Irma. While Hurricanes are dangerous for everyone, they are particularly dangerous, and even deadly, for the disabled, chronically ill, and elderly.

When Harvey and Irma hit land, the Category 4 hurricane force winds blew roofs off of buildings, uprooted trees, and opened the skies to a deluge of water that turned roads into rivers. Evacuation became the priority for thousands of stranded residents, most of whom had to swim or walk through flood waters to meet rescue workers. But what of people with physical disabilities — those without the ability to swim, walk, or stand? What about people with visual or hearing loss — those who are not able to receive instructions without the right type of communication? What about people with mental or behavioral disabilities — those who might become confused, angry, or inconsolable in a crisis like this?

The Americans with Disabilities Act doesn’t yet have any specifications regarding natural disasters, though Nancy Lee Jones’ *Congressional Research Service Report for Congress* states that there are nondiscrimination provisions in the Act that “are applicable to emergency preparedness and responses to disasters.” But in execution, this often isn’t true — when evacuation vehicles don’t have wheelchair lifts, or shelters don’t have enough electrical outlets for everyone’s medical equipment, disabled, elderly, and ill people are put into life-threatening situations after they manage to make it out of their homes.

These events of nature often come without much warning, that’s why it’s crucial for people with disabilities to work with their communities to plan in advance for these events. If we include disability concerns in emergency plans now, we can be more prepared to act quickly when the need arises. This will require being in dialogue to understand the unique and diverse needs of people who are disabled and those who have health challenges. Emergency preparedness is an article that is being discussed for the Winter issue of *Disability Issues*, so stay tuned.

Marianne DiBlasi, Editor

**Human-Centric Employment**

**By Bill Allen**

What is human-centric employment?  Let’s explore the juxtaposition of technology, innovation and its impact on employment for individuals with disabilities.  From social media to mobile devices there is glaring evidence that we are hugely connected to the world.  You are able to order products and services with one click of your cell phone.  Voice activated software has allowed individuals with disabilities to live and work independently.   Instant news and security alerts have kept us informed second by second as to what is happening globally.  Drones are utilized to provide surveillance for both military and civilian applications to save lives. Hurricanes Harvey and Irma provide clear and convincing evidence that there is no debate about how well technology has served humankind.    
  
I attempted to use some of our electronic mediums to make inquiry of human-centric employment definition.   Amazon’s Alexa response from my question -- “Alexa, please explain human-centric employment?”  The reply I received was “I am sorry, I don’t know what that means.”  Apple’s Siri actually brought me to a website to answer this question which was quite interesting.  The website provided me with the acronym of BPM.  BPM refers to the business management process approach that focuses attention on the “tasks and activities that are relevant to human skills that are utilized to complete a process".  This information is then analyzed to create other automated functions to support humans in the hopes of more efficiency and productivity.    
  
The vernacular of our digital world has clearly allowed us to improve lives and expedite services in all market sectors.  We have seen life changing innovations for individuals with most significant disabilities.  From mobile apps to assist individuals with mental health concerns to Implantable Cardioverter Defibrillators (ICD) preventing sudden cardiac death.   Even though Alexa may not have known the definition of human-centric employment, her technology is allowing individuals to live independently (check out Alexa from Amazon for details).  So how does this technology and human-centric process play out with employment for individuals with most significant disabilities? The unemployment rate for individuals with disabilities remains shamefully high.  The percentage ranges from 13-15% depending on the reference source and these rates have been constant for decades.  However, there is much hope as we embark on redefining how the human-centric approach will be impacted by technology.    
  
The Massachusetts Rehabilitation Commission (MRC) has partnered with many employers across the Commonwealth to customize trainings and provide direct placement of qualified individuals with the requisite skills to get the job done.  This approach includes going beyond the technology to screen individuals on a professional level.  We have discovered that these partnerships are yielding great results with job matching and job retention while saving time and money for business.  How is this achieved?  The MRC designs job driven trainings utilizing employer job descriptions, employer training curriculum, while understanding the cultural and environmental demands of each business.  Employers assist the MRC with providing critical feedback on training content areas.  We have identified that the technology and software used to screen potential applicants has, inadvertently, excluded otherwise qualified candidates.  The good news is that MRC’s employer partnerships are enhancing the human-centric approach which is increasing successful employment outcomes with higher retention rates for critical positions.  
  
How can this work for you if you are seeking employment and you happen to have a disability?  The following are tips and guidelines to consider for moving forward with a dedicated focus on securing a potential career path:

**Interest and Skills**

Discover your interests and ensure your skills are up to date and correlate to the open positions within the labor market.  Inventory your skills with a vocational rehabilitation counselor or someone who can help you assess your current abilities.  Read job descriptions and visit employer websites as this will provide you with a multitude of information about the company or organization.  You may compare where you rank in terms of the skills required in the workplace.  MRC counselors are here to serve you by providing informed choices about the reality of work.

**Motivation**

Demonstrate your desire and willingness to learn.  Motivation is a critical element to exhibit with employers.  There are many ways to showcase your motivation and the “soft skills” needed in the workplace.  Employers are extremely open to training individuals if they show their commitment to learn.  Set up some informational interviews with employers and you might even consider talking to employees about their experience with the organization.

**Realistic & Flexibility**

Be realistic and flexible.  Flexibility will go a long way with joining the workforce.  Now more than ever, there are opportunities in many industries due to the “skills gap” that employers are experiencing.  Employment experts are predicting the future of work will be based on the “Gig Economy” which is defined as “contractual” or temporary work.  Companies will be seeking to deploy individuals for specific projects that will last for months or a year or more.  This type of “gig” maybe in alignment with your abilities and you have a huge opportunity to test your work potential by taking one “gig” at time.

**Test Your Skills**

If you are unsure about your skills, you can test them with online courses or with a staffing agency.  These companies are in the business of identifying talent for their client accounts.  We have discovered that these quick work assessments provide instant feedback and can guide you in the direction of what types of jobs are immediately available and potential training that you may need.

**Make a Plan**

Develop your plan for employment.  Again, MRC counselors are experts in the field and will assist you with keeping it all together while staying focused on your goal of employment.

*Bill Allen is Director Statewide Job Placement Services at the Massachusetts Rehabilitation Commission (MRC).*

**Tips for Disabled Veterans to Start Their Own Business**

**By Jennifer McGregor**

For veterans living with a disability, starting a business can be a great life decision. As former US Small Business Administration Admin Karen Mills once said, “when you consider the leadership and management skills our veterans develop while on active and reserve duty, it’s no wonder we see so many of them choose the path of small business ownership." Here are some tips for disabled vets looking to take the dive into small business ownership.

**Research what type of business is right for you**

Many vets gravitate toward businesses that, in some way, relate to their military experience. Many times, this is a smart choice - as you’re good at what you know, and vets often leave the military with impressive skills and levels of expertise in areas that can be great for small business ownership.

But it may behoove some disabled vets to look beyond the realm of military-related businesses. Depending on your disability, it may be smart to seriously consider business opportunities that are low-stress, low-impact, and easy to perform from home.

Another good option for veterans looking to run their own business is taking on a franchise. Not only does it not require you to build an entire business structure from scratch, but it also doesn’t require the same type of initial capital investment.

“Veterans are drawn toward franchising because it mirrors the military structure,”, a U.S. Air Force veteran online small-business lender, Mark Rockefeller, tells NerdWallet in the blogpost, *3 Smart Business Ideas for Veterans*, “There’s a plan and a checklist, and it’s passed down to the veteran for execution.”

**Take advantage of the many resources available**

As a veteran, you have more resources and opportunities than the average person looking to open up a business.

You may want to consider registering your business with the VA as a Veteran-Owned Small Business (VOSB) or Service-Disabled Veteran-Owned Small Business (SDVOSB). If you do this, you’ll receive advantages in contract bidding with federal and state governmental organizations, tax breaks, access to certain business loans, and free business counseling.

Whether it’s training, counseling, mentorship, or help with financing, you should check out the US Small Business Administration’s veteran resources, which are substantial.

Apart from government help, there are many private institutions that provide specific loans to veterans that may come with much better terms than standard small business loans.

**Don’t forget to take care of yourself, first and foremost**

Starting a business is difficult, stressful work. It can be especially strenuous for disabled veterans, who can be at a high risk for a wide range of physical and mental issues like depression, anxiety, substance addiction, or PTSD. The most important thing you can do to maximize your chance for success in the business world is to take care of yourself - both mentally and physically. Don’t buy into the whole “work yourself to death” mentality. It doesn’t work.

Making time to get enough exercise and taking steps to eat a healthy diet are the two most important things you can do. You also need to remember to get enough sleep. There’s always a temptation to squeeze more hours into the day by sacrificing sleep in order to get things done - especially in the nascent stages of a business - but this is unhealthy and beyond counterproductive. For mental wellbeing, make sure you have some sort of stress-relieving activity to fall back on whether it be meditation, yoga, an adaptive sports league, or even something like gardening. Whatever works to help you cope with stress is OK, as long as it’s not unhealthy and habit-forming.

Owning a small business can be one of the most rewarding experiences of your life - especially for veterans with disabilities. But you have to put as much planning, care, and know-how into it as you would any other aspect of your life.

*Jennifer McGregor recognized how difficult it can be to sift through health info on the web, and wanted to make it easier, so she co-created* [*www.publichealthlibrary.org*](http://www.publichealthlibrary.org) *to help spread reputable health information across the web.*

**SIDE BAR**

**Resources for Veteran-Owned Businesses**

*Helping Veterans Start and Grow Small Businesses*

[www.military.com](http://www.military.com/veterans-day/helping-veterans-start-businesses.html) (Enter “Helping Veterans Start and Grow Small Businesses” in the Search field)

*3 Smart Business Idea for Veterans*

[www.nerdwallet.com/blog/small-business/3-smart-business-ideas-veterans/](http://www.nerdwallet.com/blog/small-business/3-smart-business-ideas-veterans/)

*US Small Business Administration’s Veteran-Owned Businesses*

[www.sba.gov/business-guide](http://www.sba.gov/business-guide) (Under “Grow Your Own Business” select “Veteran-Owned Businesses”)

*Registering Your Business with the VA*

[www.vets.gov/employment/job-seekers/start/register/](http://www.vets.gov/employment/job-seekers/start/register/)

*Best Small-Business Loans for Veterans 2017*

[www.nerdwallet.com/blog/small-business/small-business-loans-for-veterans-bad-credit/](http://www.nerdwallet.com/blog/small-business/small-business-loans-for-veterans-bad-credit/)

*Addiction in the Military*

[www.newbeginningsdrugrehab.org/resources/addiction-in-the-military/](http://www.newbeginningsdrugrehab.org/resources/addiction-in-the-military/)

**More Access Means More Jobs**

**By Ray Glazier**

This is the story of a fictional, accomplished New England chef named Dale who just happens to be a wheelchair user as the result of a skiing accident a year ago. Having completed rehab and worked through a lot of personal turmoil, Dale and his Mass. Rehabilitation Commission counselor feel he is ready to re-enter the workforce. The job market is tight, but Dale has been working his contacts; he has heard about Super Chic, a new restaurant set to open in Boston’s Back Bay, situated on Newbury Street in a brownstone townhouse.

The owners of Super Chic were impressed with Dale’s résumé, accomplishments, and references. But their enthusiasm cools dramatically when Dale rolls, not strolls, into the room for his interview. (Sound familiar?) While their architect’s plans envision an accessible main floor dining room, the kitchen is to be on the floor above, with no wheelchair access. How can this be?

The disability access section of the MA State Building Code 521 CMR) is among the most stringent and comprehensive in the nation except, that is, for a loophole large enough to drive a lumber truck through — employee-only areas, the places where we’d like to work, are totally exempt from these regulations by statutory limitation. For example, in a new or substantially renovated restaurant like Super Chic, the dining area must meet accessibility regulations, but not the kitchen or serving areas. Most chefs, cooks, or servers with disabilities can’t work there. We can be patrons, but not employees. And some business interests in the state want to keep it that way.

Fortunately, there is pending legislation that will require employee-only spaces to be compliant with ADA standards. Read on for more information about the ADA and how to support this legislation.

The ADA of 1990 has always covered employment discrimination, and the ADA Standards for Accessible Design apply equally to businesses’ public areas and staff-only areas. But there are no ‘ADA Police.’ ADA enforcement is only by consumer complaint and litigation; this is often a costly, cumbersome, and lengthy process in federal courts that could end up being appealed all the way to the historically not consumer-friendly Supreme Court.

In the Commonwealth, the all-volunteer Mass. Access Architectural Board (MAAB) enforces 521 CMR, holding biweekly all-day hearings in the McCormack State Office Building to adjudicate consumer complaints, as well as applications by architects, builders, and owners for variances (essentially ‘free passes’) from particular code requirements. Complaints that are upheld by the Board or applications for variances that are denied and not remedied can result in fines of up to $1,000 per day per violation seven days a week.

The dated nature of most of the Commonwealth’s infrastructure means that often a renovation cannot meet new construction code requirements due to: 1) technological infeasibility or 2) truly excessive costs without substantial benefit to persons with disabilities; these are the two grounds for seeking a variance from the code. Applicants for variances must prove to the Board that one of these two circumstances exist.

With regard to variance requirements in the case of Super Chic restaurant mentioned above, for example, it is to be located on the ground floor of an historic Back Bay brownstone townhouse with a front entrance 6 steps down from the sidewalk and no room for the 46-foot ramp to overcome that elevation change. Although access to that entrance could be considered technologically infeasible, in fact there is a level rear entrance on the alley in back, and they can install a wheelchair lift to bring patrons to the restaurant’s main floor. There is clearly a substantial benefit to patrons with disabilities having access to the restaurant, and the costs involved are not truly excessive. The ADA requirement of **an** accessible entrance can be satisfied by this, but MA code requires **all** public entrances to be accessible.

So, the restaurant’s architect and its owners need to seek a variance for this Section 25.1 (Entrances) requirement of 521 CMR from the MA Architectural Access Board. The MAAB may grant a variance in such a specific tricky situation, probably with a set of conditions, like the alley entrance must be made safe and appealing — a level path to the door, appropriate signage, a protective awning, adequate lighting, a buzzer for assistance, no adjacent dumpster, etc.

However, although they may be required to seek a variance for the entrance for members of the public and create an accessible entrance, the Super Chic restaurant kitchen on the floor above need not be reached by the wheelchair lift required for members of the public, because by statutory limitation, the MAAB has no authority over employee areas. Therefore, even if Super Chic is required to have a wheelchair lift by the MAAB, that lift would not help Dale to get to the kitchen. Yet extending the lift up one floor is no big deal. Dale will remain unemployed and possibly unemployable. In theory, the ADA Standards do require that the employee entrance also be accessible, but only a successful Dept. of Justice complaint or ultimately a lawsuit could enforce compliance.

So, Dale, our wheelchair-user chef is probably just out of luck for now. There are currently no grounds for him to file a consumer complaint with the MAAB. However, pending legislation in the MA Great and General Court would merge the accessibility section of the State Building code (521 CMR) with the ADA Standards in order to streamline the work of architects and builders as well as the work of the all-volunteer MAAB by creating a single set of regulations to be followed. Senate Bill 1379 / House Bill 2498 will thereby cover employee-only spaces like the Super Chic kitchen and help Dale (maybe you too) get a job. Contact your State legislators in support of this opportunity-creating legislation.

*Raymond E. Glazier, Ph.D., is a designated member of the Mass. Architectural Access Board and its only wheelchair user. Ray is also founder and Principal of disability Research Associates located in Belmont, MA.*

**SIDE BAR**

**Resources on Architectural Access & Employment**

To view the 521 CMR accessibility section of the State Building Code, perhaps to file a consumer complaint with the MAAB:

[www.mass.gov/courts/case-legal-res/](http://www.mass.gov/courts/case-legal-res/) (enter “521 CMR: Architectural Access Board“ in the Search field)

Know your federally established civil rights to facility accessibility:

[www.ada.gov/2010ADAstandards\_index.htm](http://www.ada.gov/2010ADAstandards_index.htm)

**Contacts for Additional Assistance:**

MA Office on Disability:

[www.mass.gov](http://www.mass.gov) (enter “Massachusetts Office on Disability” in the Search field)

Mass. Rehab Commission (MRC):

[www.mass.gov/eohhs/gov/departments/mrc/](http://www.mass.gov/eohhs/gov/departments/mrc/)

**PCA CORNER**

**Understanding EVV**

**By Ray Glazier**

Earlier this summer, each consumer in the MassHealth PCA Program received a letter about the mandatory introduction of *MyTimesheet*, an Electronic Visit Verification (EVV) system for PCAs. Under this system to be phased in during 2018, PCAs must sign in and sign out via smartphone for each service period. The consumer then electronically verifies the hours and the GPS-tracked service location, which is automatically compared with service locations the consumer has pre-registered with the system.

MassHealth touts *MyTimesheet*’s advantages over paper timesheets and the current web-based electronic timesheet submission process that many consumers find cumbersome. A particular sticking point is the geo-tracking of PCAs and consumers. Many consider this an unnecessary invasion of privacy. There is currently a petition circulating to ask the MA Executive Office of Health and Human Services (EOHHS) to eliminate this aspect of the EVV program. Unfortunately, Section 12006 of the federal ‘21st Century Cures Act’ specifically requires that States implement “*a system under which visits conducted as part of such services are electronically verified with respect to — ‘‘(i) the type of service performed; ‘‘(ii) the individual receiving the service; ‘‘(iii) the date of the service; ‘‘(iv)* ***the location of service delivery****; ‘‘(v) the individual providing the service, and ‘‘(vi) the time the service begins and ends.”* The congressional drafters of this legislation seem to view consumers as stay-at-home couch potatoes and PCAs as potential scammers who need to be monitored and from whom we need protection.

States that disregard this EVV requirement are penalized by a progressively larger percentage reduction of the federal reimbursement share for Medicaid PCA and home health services. The upshot is that we probably need to learn to live with *MyTimesheet.* Consumers were invited to attend one of the Listening Sessions conducted around the state this summer to voice concerns. If you were unable to do that, EOHHS invites email feedback at: [EVVfeedback@State.MA.US](mailto:EVVfeedback@State.MA.US).

For more information, visit [www.mass.gov/eohhs](http://www.mass.gov/eohhs) and search for “*MyTimesheet* Electronic Visit Verification (EVV)” and in particular, the Frequently Asked Questions document.

*Raymond E. Glazier, Ph.D. is a long-term PCA consumer, currently enrolled in the MassHealth PCA Program, who previously self-funded his services. He is principal of disAbility Research Associates LLC of Belmont, MA. Contact him with questions or suggestions for PCA Corner at:* [*ray\_glazier@post.harvard.edu*](mailto:ray_glazier@post.harvard.edu)*.*

**LOVE AND INTIMACY CORNER**

**You Are in Recovery from Trauma: Now What?**

**By Ms. Love**

Sometimes, dear readers, I share what I learn at workshops that are offered by sex-positive retailer *Good Vibrations*. At these workshops, Sales Associates/Sex Educators (SASEs) deliver information on various topics. I recently attended a workshop on the important topic of “Sex after Recovery from Trauma.” The primary focus was on sexual trauma, but many of the concepts apply to other kinds of trauma as well.

The turnout was small enough to allow for questions, but large and varied enough to show that couples, individual men, and individual women were interested in learning more. If some were concerned about feeling safe, SASE and social worker, Becca, helped attendees understand what to do if they or their loved ones’ trauma was triggered during the event. Becca skillfully made feeling safe and comfortable a legitimate topic to discuss. She gave anyone who was in recovery from trauma permission to stay, leave, speak up, or just listen during the workshop.

**Shame-Silence-Trauma**

Becca presented an overview of macro-shame versus micro-shame. Micro-shame is when a person is told not to talk about their trauma. Macro-shame can involve the media and the general public when the message is – we’re not supposed to talk about things like tampons or sexuality. Becca explained that shaming tells us that our bodies are shameful. This affects, for example, masturbation; we are taught it is taboo. Shame comes to equal silence, which in turn comes to equal trauma. “We have to re-center our bodies as important and allowed to take up space.”

**Reclamation of Our Bodies**

The body is a consistent presence during and after trauma. After trauma, we need to reclaim our bodies and learn how to communicate sexual desires and boundaries. “It should be us making decisions about our sexuality and not our trauma making decisions for us,” said Becca. As a resource, she recommends the book *Healing Sex: A Mind-Body Approach to Healing Sexual Trauma* by Stacy Hains.

Sex-positive communities can help you to feel comfortable as you reclaim your body. Groups hosted by *Good Vibrations* or *Pleasure Pie's* monthly discussions can help. Also, being with friends who do not tell you how to feel or seeing a therapist with whom you feel connected are examples of being in a sex-positive community. Becca said she cannot encourage relationship therapy enough; communication with one's partner is important, but can be hard, and therapy can help.

**Masturbation as Exploration**

“Masturbation can be a way of figuring out what feels good, since trauma did not allow that,” stated Becca. Masturbation is a way of allowing our bodies to talk to us: Is our chest tight? Do uncomfortable thoughts come up? In the triangle of Thoughts-Feelings-Behavior, would we masturbate differently if we had different thoughts and feelings?

**Re-Integration and Re-Association**

Becca described disassociation as, “when the body cannot take anymore.” For re-integration and re-association, Becca suggests keeping an ice pack nearby. The temperature, she explains, shocks the body and helps re-ground it. If you find it difficult to speak to your partner about what you need during sex, you can pre-tape a message and play it for your partner in the moment.

**Tips for Setting the Scene for Active Self-Care**

* Keep a journal to become aware of your thoughts: Are you thinking of the trauma when you are having sex? Are you thinking about going to the store or about anything other than sex during sex?
* While masturbating, the trauma survivor can narrate, “I am touching my ‘x’ right now and it feels good.” Saying it out loud can re-ground you and make you feel in control.
* Sometimes we cannot afford to move out of the apartment or house where we were traumatized, but buying a new pillow or blanket may help you reclaim your space.
* If you are the partner of someone who was traumatized, try to masturbate beforehand so you can focus your attention on the trauma survivor during sex.

**Tips for Toys**

* Since trauma is partially about not being in control, Becca encouraged people to get sex toys that let them feel in control. Toys that have the ability to change settings are especially helpful.
* If purple was in the room where you were traumatized, you may not want a purple sex toy. Then again, the opposite may be true; you may want a purple sex toy to reclaim the color purple.
* Softness of toys may be comforting because trauma was harsh.
* The slippery feeling of using lubricant can help the body feel massaged rather than traumatized. If smell is grounding for you, you may want a lubricant that has a strong scent, such as cherry-scented.

This workshop is one of many offered by *Good Vibrations* on Harvard Street in Brookline. To receive an email of monthly events, visit their website at [www.goodvibes.com](http://www.goodvibes.com) and subscribe to the newsletter or stop by the store and pick up a copy of the current schedule.

*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*](mailto: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.*

**Dreaming of Sunrise**

**By Manel Desvallons**

I am my own story

I am my own happening

My heart beats.

My soul feels.

My mind wonders.

I'm not an inspiration to soothe your insecurities

My struggle is universal,

we all face adversities.

I don't have to prove my happiness,

So you can find solace in your small stereotypical brain

Who do you think I am?

What do you really think of me?

When you look at me,

What do you really see?

When you smile at me,

Is it out of pity?

Every time you judge me,

You add to my burden of misconceptions.

Know that a little consideration would change your twisted perceptions,

But you're so wrapped up in my so-called bravery,

You won't even help me fight to make accessibility a common courtesy.

Keep your apologies!

I know who I am

Stop saying you're sorry!

Just don't use me to cover up your misery.

We are all a breath away from befriending disability

I'm just me. There's no one else I'd rather be.

I'm not helpless

I'm not broken

I feel the same warmth of hope

I face the same wrath of obstacle

Just like everyone else!

I am my own story

I am my own happening

My heart beats.

My soul feels.

My mind wonders.

My dreams are alive.

I am dreaming of sunrise.

*Manel Desvallons is the Independent Living Programs & Services Coordinator at Independence Associates, Inc. He has been advocating on all levels; local, state and national for over 7 years, to make sure that people with disabilities have the same access, rights, and opportunities as everyone else. He will continue to fight to help move the Independent Living movement forward, also help pave the way for the ones to follow.*

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