

[View this email in your browser](#)

DisABILITYissues

Providing people with disabilities, their families, friends, and advocates with relevant information that enables individuals to improve the quality of their life, health and employability options.

Vol 39 • No. 4

Fall 2019

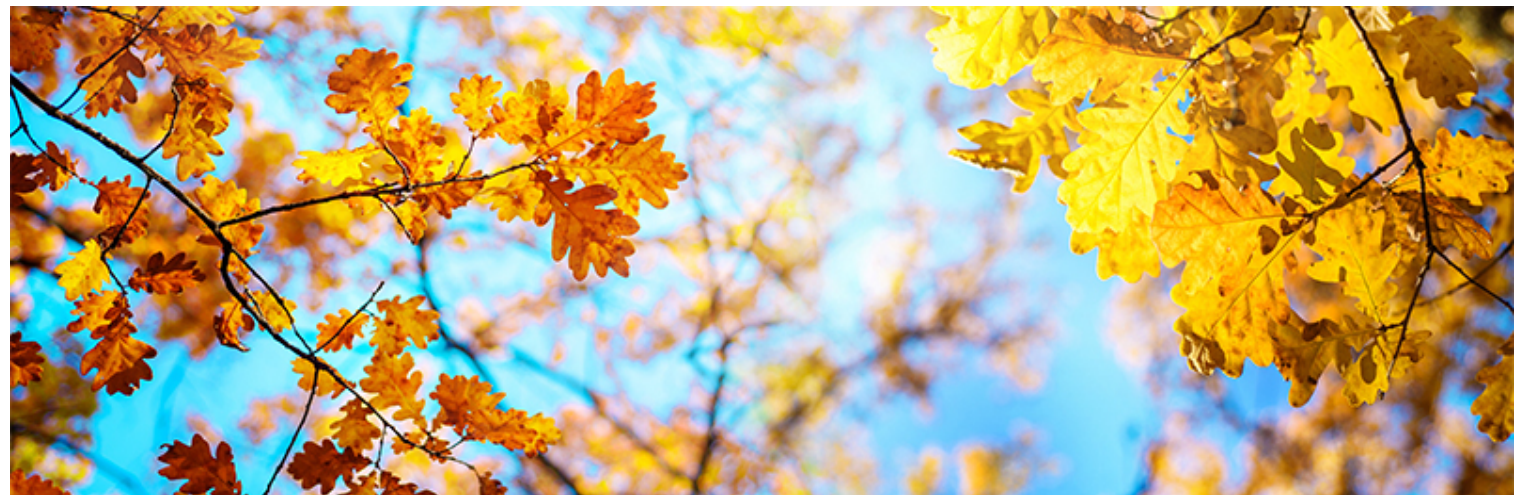


TABLE OF CONTENTS

From the Editor... | Marianne DiBlasi

A Disabled Mother's Dialogue... | Mary Grimley-Mason

Have I Told You Today That I Love You? | Ms. Love

The PCA Corner: *PCAs Make the Movies* | Raymond E. Glazier

Walter's Place: *Disability, Hospitals and Lift Transfers* | Joan Burrows

Circadian Rhythm & Blues: *Shirley's Story* | Ticket to Work Story

Information Briefs:

- Artificial Intelligence in the Workplace and Beyond
- 2019 Disability Summit

- Assistive Technology and Community Living
- Families Creating Together Awards Dinner



From the Editor....

Dear Readers,

In this issue, we bring you stories about the joy and the complexity of relationships between people who are disabled and those who are temporarily able-bodied – PCA’s and clients, spouses, medical staff and patients, and yes, parents and their children. In our lead article, Mary Grimley-Mason, a mom with a physical disability, writes about the relationship with her able-bodied daughter and shares excerpts from their very personal conversations. They both write from a heart-centered and emotional place that openly expresses the complexity that disability plays in their mother-daughter relationship. And, speaking of mother-daughter relationships, Ms. Love shares a poignant story of how she declared her love for her mother and the beautiful power of asking the simple question, “Have I told you today that I love you?”

As a disabled daughter of an able-bodied mother, these two stories touched my heart. My mother and I rarely had conversations about how having a daughter who was born with a physical disability, Spina Bifida, impacted her. I was always curious how my mother *really* felt, but we didn’t talk about it. In turn, I didn’t tell my mother how I *really* felt either. I suspect we were both trying to protect each other’s feelings. In our attempt to not hurt each other, we unintentionally created an invisible space between us that prevented us from being emotionally close.

I wonder what would have happened if one of us had taken the risk to share how we *really* felt? My guess is our hearts would have felt like they were being pierced by an arrow. It would have been painful; but I imagine the piercing of the arrow would also have released a deep river of love and empathy that would have dissolved the invisible space between us. I’ll never know what would have happened because neither of us dared to speak fully and honestly with each other before my mom died.

Ms. Love’s story makes me wonder if there could have been another way to release a deep river of love and empathy with my mom. What if one of us had dared to continually declare our love for the other with no attachment to how, or if, the other would respond? What if each declaration was like releasing a drop of love that hit the same spot on our hearts over and over again until it finally pierced its way through to

the river of love inside? Would that have dissolved the invisible space between us?

What I know now is, relationships with those you love, or those you want to love more, are precious. Time passes swiftly and opportunities are lost. I can't do anything to change the relationship with my mother, but I can change other relationships going forward by daring to take the risk of speaking from my heart; of daring to be present with another when they speak from their heart; of daring to declare my love often and ask the simple, powerful question, "Have I told you today that I love you?"

Marianne DiBlasi, Editor



Marianne DiBlasi has been the editor of *Disability Issues* since 2011. Her background is in sales & marketing and disability inclusion training. Currently, she is attending Meadville-Lombard Theological School and is working towards a Master of Divinity degree.



A Disabled Mother's Dialogue with her Daughter

When I asked my children to respond to what it was like to grow up with a mother with a disability as a polio survivor, they could not come up with much. Eventually, Sally, my youngest child, wrote on her website a piece about her reaction to living in a family with a disabled parent. She described struggling, as a child, between guilt at being able-bodied with a disabled mother “so brave” and resentment at having to take care of someone else’s needs. Her essay began a dialogue between us and invoked memories for me about being a disabled mother.

Having grown up in the forties with two glamorous older sisters, I bought into the model for girls: grow up to be a good housewife and mother. And although I broke the mold by going to graduate school and by having a career, I did not lose my sense that only marriage could make me acceptable as a woman. At my wedding my sister, Joyce, helped me put on my dress. As she arranged my short veil, she spoke to me softly, “You won’t want to have children, will you dear? It would be too hard for you.” It was the voice of the world speaking to me telling me *You shouldn’t have children. You won’t be able to care for them.* I wasn’t sure how I felt about my sister’s words. I remained silent. I went on to have three children: Kathryn, Matt and Sally. When Kathryn was born in 1960, my mother – and my sisters too – were thrilled. My mother came for several weeks to help me when each of my children were born. I was well supported as a mother by my family, but my sister’s cautionary words about becoming a mother stayed with me. I felt that I had to prove that I could be a good mother.

Sally was born after a short labor and everything seemed fine in the hospital. When I got home, I was very tired and went upstairs to rest and sit beside the bassinette. Suddenly I was seized with riveting pain which took my breath away. I called for help and found that I could neither sit up or lie down. My husband called the doctor and insisted he come to the house. He came and administered a strong painkiller and diagnosed a complete muscle collapse, not unknown after a third delivery though I was particularly vulnerable. I was told not to try to hold Sally in my arms for two weeks. We hired a student nurse to help me take care of her. She would place Sally beside me on the bed and we gazed at one another. I put my finger in her tiny fist as she began to grasp for things.

Perhaps as Sally grew up, I told her about this scene. I remembered a sentence in her blog years later, when she wrote, “I learned from infancy to feel as though I was much too much for her to hold.” During those two weeks, Kathryn and Matt held her as much as they were allowed to. The two of them loved taking care of her as she grew up. As my children grew

up, I didn't worry much about how they felt about my disability. They were helpful about doing chores. I worked full time as a college professor and hired household help so I would not burden the family with too many tasks.

Our family was in crisis in the early eighties when my husband left and we were divorced. Kathryn and Matt were both away at college and Sally, at thirteen, was the only child left at home. Suddenly she was alone, and she was in the most volatile stage of a young girl's development. She recalled it and wrote in her blog: "Middle school was a nightmare. Everything was changing rapidly. I had emotions I'd never known before, body parts I'd never seen before. I just wanted someone to help me figure it all out. My father wasn't around, my older sister and brother were away, and I was left alone with my handicapped mother." I remember that difficult time in our lives. At night I would go upstairs and find Sally lying in bed with her favorite Siamese cat wrapped in her arms. I would lie down beside her and stroke her head and rub her back until she got drowsy and fell asleep.

Outwardly Sally's life was full of success. In high school she played the flute in the band, sang in the madrigal singers group, starred in the high school musicals – she played Mary Poppins and many other roles – excelled in aerobics and even taught it to the soccer team, and won a contest in choreography at a New York dance academy. She attended summer programs at Boston University in theater arts.

It was there she later told me that a fellow student told her how to keep thin without giving up eating and she developed bulimia that, despite many different therapists, lasted in her life for many years. Later, Sally wrote in her blog about developing the eating disorder and how her feelings connected with being the only child and living with a disabled mother: "I felt very much alone and unable to express myself. It was easier to be a victim than to deal with the guilt of surpassing my mother physically. I disabled myself. I became bulimic at fifteen and it took years to overcome it." Sally moved to California after going to college and majoring in theater arts and film. When her film script was optioned, she "flew away" as she put it and settled in Santa Monica where she found a therapist who helped her.

Sally would send pieces from her blog from time to time for all of us to read. Some of the pieces were directly relevant to our relationship of daughter and disabled mother: "It wasn't so much that having a disabled parent was difficult. The problem was that I couldn't acknowledge that life was different. I couldn't rebel like a normal teenager. How could I after all my mother had been through!" I could have argued that she had rebelled in many ways, mostly however self-inflicting. But Sally's blog had opened up a dialogue between us, a dialogue about our own conflicting experiences. It included a recognition of conflicting

guilt – my guilt as a disabled mother feeling the need to prove that I could be a good mother and a good caregiver and Sally’s guilt about being able bodied. I realized that my need to be a strong person, “so brave” as Sally put it, made her feel she must live up to that image, making her particularly vulnerable to emotional and physical problems in her early teens. Her need, as she said was to “fly away.”

Sally and I continue our dialogues, mostly by telephone. Periodically she shares a lot about her life and wants to know about mine. In one of her more recent blogs, she wrote to me directly with a touching comment: “I’ve also learned more about being taken care of. When I’m hurt, sick, or depressed, the first person I want to call is my mother. You. You, who kept surviving, enabled me to survive.” Sally recently visited me at the retirement community in Concord where, for the first time, I began using a mobile wheelchair. She arrived with her latest boyfriend, Jake. After lunch we went to the North Bridge. Sally insisted on taking my manual wheelchair. She and Jake – mostly Jake – took turns pushing me up the long bumpy hill to the top and to the museum and Center. I kept insisting that we didn’t have to go to the top, but Sally was adamant that we should go on. I realized as I let Sally “take over” that we were both at ease in our roles. I was comfortable being “taken care of” and Sally was comfortable giving me care.



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



Have I Told You Today

That I Love You?

By Ms. Love

One day, decades ago, I had been talking on the phone with my mother for a good while and right before we hung up, without conscious planning, I told her I wanted her to know I love her. There were a few seconds of awkward silence. I guess I had startled her with such an earnest and direct statement. She recovered and said she loves me too. We said good-bye and hung up.

I found myself continuing to declare my love to my mother in each and every phone call we had thereafter. Sometimes it was the original declarative sentence that I repeated. Other times it was a variation of the original sentence that I was professing. I didn't consciously plan any of it. It just naturally poured out of me because I felt a need to let her to know. It wasn't good enough to sign written letters to her with the closing salutation "Love" followed by my name. It wasn't good enough to visit with her, laugh with her, eat with her, nor discuss the routine things family discusses every day. Yes, those show love, and yes, I loved my mother all my life, loved her dearly. But, for whatever sense of time I felt could be fleeing, I never wanted there to be a question in her mind that I love her very much, and I wanted her to be very sure of, and always snug in, my love.

The second time I ended a phone call saying, "*I want you to know I love you*" she very quickly replied with "*I love you too.*" My mother wrote letters to me all the time. Often, she even included funny faces she drew for me or articles about my disabilities that she came across in the newspaper. These made me feel she was thinking of me and loved me, but this phone call was different for her. I had a sense that after the previous phone call she had thought about my declaration of love and decided that she would be ready if I were to repeat it again. In the ensuing phone calls, I routinely proclaimed my love to my mother, and she came up with her own words of letting me know that she loved me too.

One day, my mother's aide entered her apartment and found my mother had died during the night. In the following days, I ached with grief as I touched her wheelchair, as I touched her comb and brush. There were hours where I just played one song on her Frank Sinatra cassette over and over again, *If You Go Away*. Though it was probably written about a man and a woman once in love and the man trying to bargain with the woman so she won't leave him, at the time, it had meaning for me about the death of my mother – how this most loved person was leaving me. Snippets of the song are:

*If you go away, as I know you must
There will be nothing left in the world to trust
Just an empty room, full of empty space...*

*If you go away, if you go away, if you go away, if you go away.
But if you stay, I'll make you a day,
Like no day has been, or will be again;
We'll sail the sun, we'll ride the rain,
We'll talk to the trees and worship the wind.
Then if you go, I'll understand
Leave me just enough love to fill up my hand...*

*If you go away, if you go away, if you go away, if you go away..
Please don't go away.*

My mother went away, but I am glad I told her many times that I loved her.

Many years after my mother died, I was with a longtime friend of mine when something interesting happened. Spontaneously, as it had happened with my mother, I began saying from time to time when we were in each other's presence or on the phone, "*Have I told you today that I love you?*" "No" he would say, and I would reply that I love him so very much that I can't quantify it because no one can count so high. Other times we were laughing together over something, and I would say, "*Have I told you yet today how much I love you?*" And he would say with anticipation, "*No, not yet!*" And I would respond, "*Well, I better hurry up and tell you before the day goes any further.*" I proceeded to tell him that I love him more than all the Hostess Twinkies in the world. He would laugh and laugh.

Tell people now, dear readers, that you love them. Current events these days are filled with fires, floods, shootings, and more. They remind us how fragile life can be sometimes. Don't think that you have forever to tell someone you love them. Tell them now – not once, but often.

***“You are loved, you are
loved, you are loved by me.”
Proclaim it out loud with
feeling and say it often.***



You can't always plan ahead when and how to profess your love for someone – a spouse, a parent, a child, a friend. Sometimes it does indeed pour out of you spontaneously. But when the recipient of your love begins looking forward to hearing these words, by all means repeat them, or variations of them, regularly.

You don't need a store-bought card, you don't need a birthday or holiday, just pipe up and let the person know they are very loved by you, in whatever wording comes out of your mouth. In my opinion, the only “wrong” thing you can do is to let time continue to pass by and never express how you feel. “*You are loved, you are loved, you are loved by me.*” Proclaim it out loud with feeling and say it often.

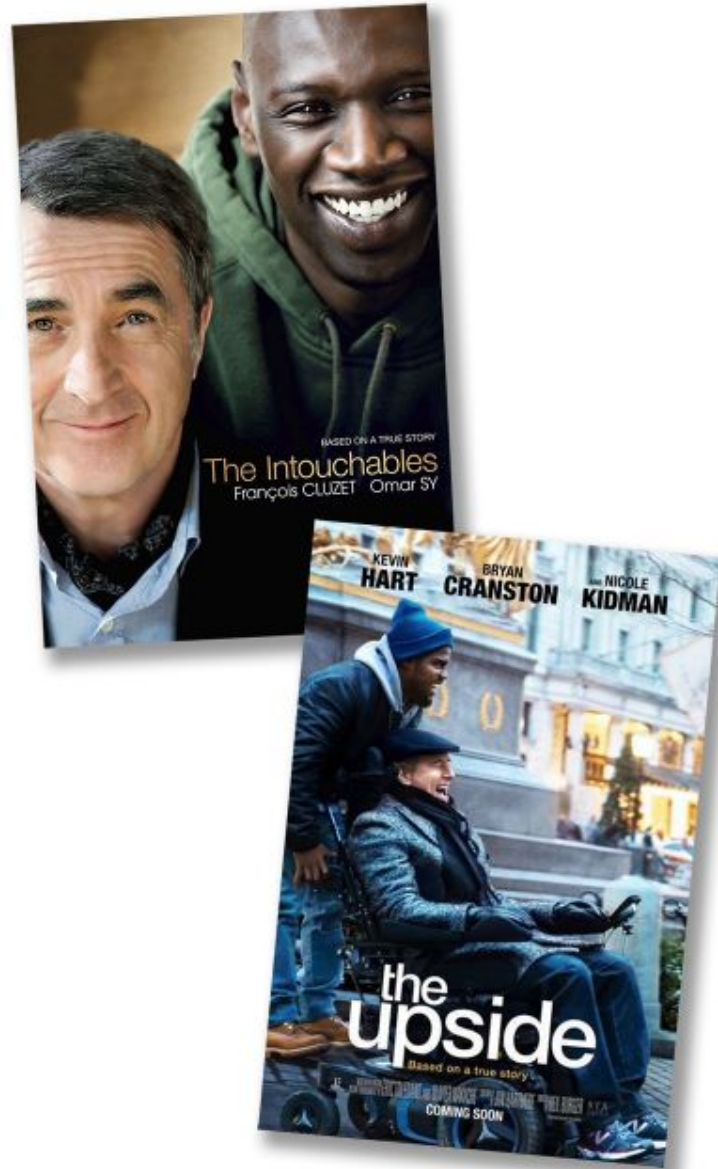
The Love and Intimacy Corner welcomes questions and requests for topic areas from readers. Please send all comments, questions and suggestions to Ms. Love at DI.LoveandIntimacy@gmail.com Questions chosen to be featured in the Ms. Love column will appear under a pseudonym to protect privacy, and may be edited.



PCAs Make the Movies

By Raymond E. Glazier

Two recent movies that my PCAs and I have enjoyed watching together are the oddly titled French film *The Intouchables* (2011), based on a true story, and the American remake *The Upside* (2017), starring comedian Kevin Hart as the unlikely PCA. Both films follow the same basic plot, with minor deviations: Philippe / Philip, a rich, depressed and cantankerous quadriplegic billionaire hires a streetwise Black man who is out on parole from prison as a PCA: Driss in the French flick and Dell in the American version. After 'borrowing' a valuable item (a gold Faberge egg that Driss gives to his foster mother and a rare book that Dell gives to his estranged young son) and then regaining his employer's trust, the two become great friends, and the PCA teaches him the meaning of life and how to enjoy it. The trajectory of the PCA's life is also dramatically altered through their relationship.



The opening scene in each film is identical, the PCA speeding at night through the streets of Paris / Manhattan in his employer's fancy car with his boss as passenger. A cop pulls them over and the driver fabricates a story that they are on the way to the hospital. The employer feigns a seizure and they get a police escort instead of a ticket, laughing together all the way. Both films then flash back several months to when the parolee arrives only wanting a signature on a form to show that he is at least going through the motions of looking for a job. Much to his amazement and that of others, he is ultimately chosen as caregiver over several other highly qualified job candidates. (Only in the movies!) Neither movie uses the term PCA or the more PC 'personal assistant.' But we liked *The Upside* job title 'life auxiliary.'

Neither new caregiver quite comprehends the nature of spinal cord injury paralysis with loss of sensation, so tests it out by pouring scalding hot coffee on the quadriplegic's leg. (Note to PCA readers: Do not try this at home!) This almost gets each novice PCA canned by the employer's protective assistant. For Driss this is a lovely redhead he is very attracted to; in Dell's case he senses the assistant (Nicole Kidman) has feelings for their mutual employer. One scene from *The Upside* that had us laughing was the PCA (Kevin Hart) doing a standing transfer of Philip (Ryan Cranston). Only through movie magic was this possible; Kevin Hart's standup comedy routines often joke about his very apparent small stature.



In each movie the PCA helps his employer find love, and each caregiver finds unimagined success, though the plots diverge in how these outcomes happen. And the final scene of each circles back to the opening car chase. The French film closes with a still photo of the real Driss and Philippe, who remain close friends. We found both movies entertaining, with a slight preference for *The Intouchables*, perhaps because we saw it first (multiple times). But if subtitles aren't your thing, you might find *The Upside* more accessible. Both PCAs and consumers alike may enjoy sharing this movie with family members or clueless acquaintances.



While some critics have been lukewarm to this predictable and clichéd buddy comedy-drama, it has been a worldwide crowd pleaser, *The Intouchables* grossing a total of nearly \$445 million. As of this writing, *The Intouchables* was available on Netflix in DVD and on Amazon Prime with English subtitles and likely as a DVD on loan from your local public library. *The Upside*, having recently completed its run in theaters, was available for private viewing on Amazon Prime, on Netflix, and in Redbox in DVD release. There is also an Argentinian Spanish language remake entitled, *Inseparables* (2016) that Spanish-speaking PCAs and consumers might prefer, as well as an Indian remake named *Oopiri* ('Breath') released in Telugu and as *Thozha* in Tamil, both also released in 2016; there is also a Bollywood production in Hindi.



Raymond E. Glazier, Ph.D. has decades of professional experience studying PCA issues, as well as decades of personal experience as a consumer in the MassHealth PCA Program. He is a principal of disAbility Research Associates LLC and welcomes comments or questions at ray_glazier@post.harvard.edu



An ongoing series of articles about Walter Kiver who lived with Muscular Dystrophy (MD); as did his son, daughter, and grandson. Articles are written by Joan Burrows, Walter's wife, in memory of her beloved husband who passed away in 2001, to honor his legacy of living life fully and helping others while facing his own challenges.

Disability, Hospitals

and Lift Transfers

By Joan Burrows

Being transferred in a lift is a leap of faith in the lift and in the operators. Walter fell off a new lift because it was defective. The fall caused broken legs – yes, two – and the local hospital could not deal with his situation, so they sent him to the city. It took another day of consulting, while Walter was in pain, to decide there would be no surgery because pins would not hold and he was not going to walk anyway, so casts were put on both legs. We were told it could take eight weeks or longer for Walter to heal. Then there was a ‘fight’ about whether Walter should go to a rehabilitation facility or go home. The staff was quite adamant about going to a rehab. Walter, his daughter, and I were adamant that he should go home. We had a plan – his daughter’s friend and the VNA would help and we had a ceiling lift. We won! That summer we did not have a single rainy day and Walter was able to sit outside in the sunshine, which he loved. We took walks and had friends over to visit. The friend who helped with the transfers to and from bed made a special piece for the wheelchair so his legs could rest comfortably.





We did well for many years with very few problems. Then another major problem – it was becoming difficult for Walter to swallow food because of weakened swallowing muscles. Back to the hospital in the city. This was a really bad time. Because I was the primary person who fed Walter at home, I knew that when the nurses were feeding him, he was not swallowing all the food. The nurses did not listen to me and kept on feeding Walter, even though you could see the food remaining in this mouth. Walter went for a swallowing test and it showed the problem. Meanwhile, he got pneumonia from aspiration because of the continued feeding - the worse kind of pneumonia to treat. He was on an antibiotic but was not responding well. We were told there was only one more antibiotic to try for his pneumonia. If it did not work... a DNR order was in his room as I left that night. Walter made it! The antibiotic worked!

Then, we were told that Walter would need a feeding tube. One kind doctor told us that he could still have a good life; eating was not everything and we could enjoy time together. He told us we could sit outside together, take walks, and do everything else we used to do. This was a hard decision and it was Walter's to make. I wrote him a note telling him how I felt but it was his decision. He decided to take the feeding tube.

Inserting the tube was an easy procedure, but I was not given much training on how to use or manage it. So shortly after we got home, Walter went to another rehab. We had some

good and some bad situations there. The good was, the OT people worked with Walter to help him get back to being able to do transfers so he could regain some independence. The bad was, it was summer and the staff changed often. One evening, a new nurse came on for the evening shift, and when Walter tried to finger-write to her she briskly said that she could not possibly communicate that way! Rather than get too upset with her, I went to the head nurse and said I could not leave until another nurse was given to Walter. She agreed! After a month, we headed home again. The feeding tube issues were resolved, and things went well. We still enjoyed our time together – seeing horse races, taking walks, watching movies, and more. If you think making love stopped...it did not! When I told my primary care doctor that Walter and I made love, he was very surprised and said, he had never known a person on a respirator who could do that! I hope doctors are more aware now.

From Walter's hospitalizations, I learned it is extremely important for a person who is in the hospital to have an advocate. For Walter, it was especially needed because of communication issues. I was his voice. The other important factor is, the staff knows there is someone who cares and is aware of the patient's needs. However, my best advice is to stay out of the hospital if at all possible.

Walter died peacefully at home from kidney failure at age 73. I miss him every day. His love is with me in my heart. He changed my life for the better – much better! He was a kind, caring, generous person who also helped make life better for others with disabilities.



Joan Burrows studied music in NYC and later taught piano. She was a nursery school owner, teacher, and music director. Joan began the Acton Commission on Disability with Walter Kiver. She is a caregiver for people with disabilities and seniors.



Circadian Rhythm & Blues: *Shirley's Story*



Shirley figured being tired all the time came with the territory as a working mom. But when she started to fall asleep at her desk, in the middle of conversations and at the wheel while driving, she knew something was wrong.

A person's circadian rhythm includes physical, mental and behavioral changes that follow a daily cycle. This includes a natural sleep cycle of sleeping at night and being awake during the day. A neurologist diagnosed Shirley with [narcolepsy](#), a chronic disorder related to circadian rhythms that affects the brain's ability to control sleep-wake cycles. Shirley was advised to stop working until they could get her symptoms under control, so in 2009, she began receiving Social Security Disability Insurance (SSDI) and started a 6-year journey to manage the disorder.

"It was distressing to lose that sense of control over my life," she recalls. "...[and] stressful making ends meet on an SSDI check. I began to feel hopeless." [Clinical depression](#) and medications that caused headaches, nausea, and hallucinations made matters worse. "I was suffering more from their side-effects than from the symptoms they were meant to treat," she says.

Shirley consulted new doctors who recommended alternative approaches to improving her wellness. Under medical supervision, she stopped taking medications that were causing problems and adapted multiple aspects of her lifestyle. *"I switched to a vegan diet, [exercised](#) 5 days per week, got into bed each night by 9 p.m., and*

[practiced] [meditation](#)," she says. The results were encouraging. "I lost weight and gained peace of mind! Narcolepsy is not something that just goes away. It's a struggle every day. But I've learned to make adjustments in my life to work around the disability."

With her health back on track, Shirley felt ready to try work again. She looked forward to getting out of the house, returning to work and earning income to pay bills and contributing to her family's well-being. But like many people who have been unemployed for years, she had also lost her self-confidence and felt uncertain whether anyone would hire her.

"One day, I received a letter in the mail from an employment agency called [America Works](#)," she recalls, "They invited me to attend a job fair where I would meet people who could help me... transition [to work]." Shirley says it felt good to take this first step. When she met representatives from America Works, they told her about Social Security's [Ticket to Work](#) (Ticket) program.

The Ticket program is a free and voluntary program that supports career development for people with disabilities who are ready for employment. Adults age 18 through 64 who receive Social Security disability benefits (SSI/SSDI) qualify. Through the Ticket program, service providers known as [Employment Networks](#) (ENs) and State Vocational Rehabilitation (VR) agencies offer a range of support services to help people prepare for, find or maintain employment.

Shirley chose America Works as her EN and met with a trained professional (known as a [Benefits Counselor](#)) who educated her about other Social Security [Work Incentives](#). Work Incentives make it easier for adults with disabilities to explore work and still receive Medicare or Medicaid and, in some cases, cash payments from Social Security. Shirley learned that her benefits would not end as soon as she returned to work, and this allowed her to focus on finding and adjusting to a new job.

She had a background in government program administration and decided to pursue opportunities at local government agencies. America Works helped Shirley land a temporary administrative job with the city of Baltimore. She says it felt great to get out of the house again, be productive and interact with coworkers.

By the end of 2015, her anxiety about whether she would have the skills and stamina to work full-time was gone. Shirley moved on to a permanent role and in 2017, landed a new job as the Compliance Officer for Maryland General Services, where she serves many functions and has more responsibility.

"I [make sure] small [minority/woman/veteran-owned] businesses are represented on state contracts," she says. The work has given Shirley a sense of purpose, and she says employment has helped her maintain improvement in her well-being. "I'm grateful for the help I received through Ticket to Work," she says. "It feels wonderful to have my independence back! I feel like I can rely on myself again. I've escaped the black outlook that weighed me down years ago. There are now bright colors on the canvas of my future!"

Ticket to Work and Work Incentives helped Shirley find her path to a better future. Find yours! To learn more, call the Ticket to Work Help Line at 1-866-968-7842 or 1-866-833-2967 (TTY), or visit choosework.ssa.gov

Reprinted with permission from the Social Security Administration's Ticket to Work "Success Stories," <https://choosework.ssa.gov/library/shirley-success-story>.

INFO BRIEFS • INFO BRIEFS • INFO BRIEFS



Artificial Intelligence in the Workplace and Beyond

Artificial Intelligence is a growing resource for people living with disabilities in the workplace and beyond. This article by the Employer Assistance and Resource Network on Disability Inclusion (EARN) discusses AI as a means of supporting employment opportunities for people with disabilities. Read more at [AskEARN](https://askearn.org).



Fifth Annual Disability Summit

2019 Disability Summit

The Massachusetts Office on Disability will hold the annual Disability Summit on September 27 from 8:30AM-12:30PM at the Boston Convention and Exhibition Center, 415 Summer St - Conference Rooms 258A, B, & C, Boston, MA 02210. This event connects leaders from the disability community, advocates, and people with disabilities through a robust series of presentations.

This year's topics include: ADA enforcement, barrier removal for local communities, networking, and more. You can learn more or register for free [here](#).

General inquiries may be emailed to mod-events@mass.gov or MOD's event line at 617-727-7440 extension 27318.



News & Events



Assistive Technology and Community Living

Administration for Community Living (ACL) has released a new [Issue Brief on Assistive Technology](#). Assistive technology (AT) includes software, devices, equipment and products that improve the functioning of individuals of all ages with disabilities. Assistive technology can affect a person's well-being by improving their ability to walk, eat, bathe, communicate, see, speak and live independently. Technologies also can help address social isolation and improve quality of life by assisting people with communication, mobility, and other daily activities.

This issue brief discusses:

- 1) The important role of assistive technology in helping people of all ages with

disabilities live full and independent lives in their communities; and

2) Certain sources of public funding for the technology, including Medicare, Medicaid, and programs that the Administration for Community Living (ACL) manages.

[View the Assistive Technology Issue Brief](#)



JOIN US!



10th Anniversary Awards Dinner

Celebrating an award-winning, multi-generational, creative arts program serving children of all abilities and their families, led by Founder/Director Edward Pazzanese.



Saturday, November 9, 2019, 6:30–9:00 pm
1st Baptist Church, 633 Centre Street, Jamaica Plain

AN INSPIRATIONAL EVENING CELEBRATING FCT'S 10TH ANNIVERSARY!



SPEAKERS



Jude Goldman
Executive Director,
Lenny Zakim Fund



Reverend June Cooper
Executive Director,
City Mission Society



Susan Perlstein
Founder/Director,
Elders Share the Arts, NYC
and National Center for
Creative Aging,
Washington DC

*Gourmet Dinner
Musical Selection*



TICKETS: \$50

Sponsorships available.

To buy tickets or for more information, please go to
<https://fct10thanniversary.eventbrite.com> or call 617-524-7070.

www.familiescreatingtogether.org

Tickets and all donations are tax-deductible.

Please make checks payable to Community Caring and mail to:
Tree of Life Coalition, 295 Centre St., Jamaica Plain, MA 02130



Program presented in English and American Sign Language
Logo design by Evelyn Berde | Photo by Christle Rawlins-Jackson
FCT is a program of Community Service Care/Tree of Life Coalition



Editorial Board (L-R): Sandy Alissa Novack, Raymond E. Glazier, Joan Burrows, Marianne DiBlasi, Mary Grimley-Mason, missing: Mary Jane Fietze.

Editor: Marianne DiBlasi

Editorial Board:

Joan Burrows • Mary Jane Fietze • Raymond E. Glazier
Mary Grimley-Mason • Sandy Alissa Novack

Advisory Members:

Bill Henning • Ruth Kahn • Oswald Mondejar
J. Archer O'Reilly III

Graphic Design:

Louise Martling, Eleventh Hour Design
www.11th-hour-design.com

Spaulding Rehabilitation Network Liaison:

Colleen Moran
<http://spauldingrehab.org>



Spaulding Rehabilitation Network is pleased to be an underwriter of *Disability Issues*, a free and independent newsletter. The Spaulding Rehabilitation Network is a member of Partners HealthCare and includes Spaulding Rehabilitation Hospital. Spaulding Rehabilitation Network, a member of Partners HealthCare, includes Spaulding Rehabilitation Hospital, its main campus in Charlestown, which is a national model for environmental and inclusive design as well as Spaulding Rehabilitation Hospital Cape Cod, Spaulding Hospital Cambridge and two skilled nursing facilities, as well as twenty-five outpatient sites throughout Eastern Massachusetts.

Spaulding has been awarded a Model Systems designation in three specialty areas - Brain Injury, Burn Injury Rehabilitation, and Spinal Cord Injury - by the National Institute on Disability, Independent Living, and Rehabilitation Research. Spaulding is a teaching hospital of Harvard Medical School as well as the official rehabilitation hospital of the New England Revolution. 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 #2 ranking in 2018-2019. Spaulding was recognized in 2018 by Disability Equality Index® as a company who scored 100% in the category of Best Places to Work™ for Disability Inclusion. For more information, please visit www.spauldingrehab.org

The ***Disability Issues*** newsletter is a free and independent publication. It is published quarterly and shares current information about the world of disability, new initiatives, and other helpful information to the disability community in Massachusetts.

To Subscribe: The ***Disability Issues*** newsletter is available without charge to anyone who finds it useful and interesting. To subscribe, visit [Disability Visibility](#) and enter your information in the Subscribe to Disability Issues form.



Share



Tweet



Forward



Copyright © 2019 Disability Issues, All rights reserved.

Feel free to reprint articles. When doing so, please credit Disability Issues (Vol., No. and Date). For articles that appear under a byline or that will be altered in any way, please obtain permission from the editor. Any inclusion or exclusion of a particular entity, product or service in this newsletter does not constitute endorsement or opposition.

Our mailing address is:

Disability Issues c/o Spaulding Hospital Cambridge, Attn. Human Resources,
1575 Cambridge Street, Cambridge, MA 02139

Want to change how you receive these emails?
You can [update your preferences](#) or [unsubscribe from this list](#).

www.disabilityvisibility.com/resources/disability-issues