

JR News

Fall/Winter 2020

WORK, HOME AND PLAY

Life is precious... Remember to make the most of each day

Home/Health:

COVID has changed life significantly, for us and for many. I first encountered the new “normal” by learning that some of my Personal Care Assistants (PCAs) could not return to Tallahassee after Spring Break. As most of you know, I use college students as my PCAs- it’s a great way for them to give back and to get a leg-up for their next stage of life. Thankfully, some of the PCAs did not go anywhere because Tallahassee is their home. Therefore, we were able to *change up* the schedule but only because they were compassionate, and committed to my well-being. Others throughout the disability community were not so lucky.

We also experienced the COVID effect through my medical equipment provider. Apparently, under some of the state and federal emergency plans, they can “commandeer” medical equipment for other high risk needs. They do this to ensure that hospitals and assistant living facilities have their needed supplies. It was a little shocking to learn that my vital equipment could be taken from me and be given to others without notice. I don’t mind using less but going without is untenable. My team cannot provide their services without their Personal Protection Equipment (PPE). I am extremely grateful to my friends located across

the country who were able to source non-sterile gloves, hand sanitizer, and face masks for me. Without their help, we would have had to use the *old-fashioned kitchen-sink rubber gloves*...this approach would have been a little rough on the mind, body, and soul.

COVID is also creating a hardship with recruiting and retaining PCAs. The students are all living and learning from home. This has caused a bit of a challenge, because a few of the students have been exposed to COVID, or had it, and had to be replaced on the work schedule for 14 to 21 days. My PCAs can pick up a few extra shifts here and there, but their full-time job is being a student, not working in a traditional sense for a living. This created some scheduling challenges, but the team stepped up. I have a team for Spring 2021, but just enough PCAs to get by (any COVID hardships will be more challenging to accommodate). We are hopeful that we do not have a terrible resurfacing of COVID during the winter and I will continue to recruit.

Erika and I have been most fortunate and have not had any health issues. I think part of the success is that we have PPE equipment for the students and they are very good about using it. We also keep the doors open through the house allowing for fresh air to flow but it hurts the electric bill.

The elections had a direct effect on team JR. Here in Florida, the \$15 an hour living wage was on the ballot. It passed overwhelmingly. I do not disagree with the premise and would like to pay my PCAs more than \$15 an hour but where does the extra money come from? I can't build another widget or go to FSU and say "I need more money". In short, my personnel costs for getting out of bed every day will slowly raise to an extra \$9,600 per year. I currently pay about 20-30%

above our minimum wage, depending on years of service. I don't know the answer to this emerging challenge, but many people with disabilities might not be able to afford to work in the future. I may never get to retire.

Work:

I feel so lucky to be working during this pandemic. To be busy with not one job, but three different jobs is fantastic. Who could've imagined, 30 years ago, that I would have answered the call of duty within the disability space and found such exciting things to do? Teaching, advocacy/public policy, and community service keeps me more busy than Erika would like, but she knows that this is who I am and her support makes it possible.

The fall semester is going much better than I had anticipated. All 3 of my classes are remote (2 of 3 are asynchronous and 1 is synchronous). A big part of the joy of teaching for me comes from the personal interaction with the students. For me, this is the life-blood of the classroom. I get to feed off of their curiosity, be challenged by their questions, and connect with them on a personal and professional level. Switching to the online format is really different. The material is the same, but learning how to deliver it online, and create that "sense of community" is the challenging part. The asynchronous classes are very strange because you never actually see or hear some students. They simply interact with the artificial intelligence called Canvas. This is an electronic platform that has the syllabus, assignments, discussion boards, lectures, and much more built into it. Success or failure for the course is predicated on how well the teacher pre-programs the platform with content and direction. Online teaching pushes the

instructor to write “idiot proof” directions. If not, the number of emails can simply be overwhelming. Learning how to talk to the computer with enthusiasm, emotion, and passion makes a difference, and it takes time to develop that skill. It is an art. I am glad we had the online trial period last Spring to help us prepare for the fall. About 20% of my students do engage me by zoom, email, or phone on a regular basis, but of course these are my A students.

I am prepping a new course that will be taught in the spring of 2021. The topic is leadership. I have the freedom to tweak it any way I want to, so I will be adding some material from Joseph Campbell and his *Monomyth, The Hero's Journey*. Campbell's work had a profound effect on me and maybe the next generation will answer the call to duty, find mentors, develop teams, and master the skills to find their own internal/external dragons. Of course, I am having to master some new details and create engaging online activities. I am working harder than ever, but I am lucky to have so many jobs that I love.

My advocacy and community service is running full-tilt. This being an election year and the 30th Anniversary of the American's with Disabilities Act means there has been a lot of opportunity for education and empowerment. [Here is a podcast](#) hosted by the Tallahassee Chamber about the 30th Anniversary of the ADA. Our local newspaper was kind enough to print my [editorial piece](#). It highlighted where we have come from and where we are still going. Part of telling our story was captured on another podcast called [“Meredith For Real.”](#) For those unfamiliar with Meredith, she has a great following in the Pensacola area and it turned out we had some mutual friends. A few extra likes from you guys and maybe I will get invited to come back.

Because COVID will be with us for a while, one of my non-for-profits (Evergreen Life Services) created a social enterprise initiative called HeavenDropt. It celebrates the service of veterans and the skills of persons with disabilities. One of the products they make is a mask made with recycled military parachutes. Here is a great [little news clip](#) if you should need any masks for your family/businesses. Let us help you while we all stay safe.

The 21st Annual Family Café invited me to read a portion of my book “Now What?”, which some of you have been kind enough to view already. It can be found [here](#). It is always empowering to share and read a part of my story.



Years ago, I served as the Chairman of the Florida Commission for the Transportation Disadvantaged (CTD). As a result, I was asked to give a few thoughts on our current and present transportation needs. I tried to practice brevity which can be hard for me. [Here is the four minute clip](#). Reviewing grants is a great way to stay informed on innovative community projects. I had the privilege of bringing my 38 years of lived spinal cord experience to the annual Congressionally Directed Medical Research Program ([CDMRP](#)). It was really cool to make a modest contribution to the advancement of spinal cord research and the \$40 million they are applying to solving our issues.

I was humbly surprised by a note from the Viscardi Center to be included in this year’s class of PWD leaders across the country and globe. It is a privilege to be

included in such a distinguished group of PWD leaders. Each of them are outstanding. Not certain I am worthy, but I will endeavor to live up to the standard of leading by example. For those interested, the link to this year's recipients can be found [here](#).

Before we depart the work update section, I must ask... have any of you experienced a "Zoom Bomber"? To be honest, I thought it was one of those fable stories until my University of Choice group got bombed during the middle of our annual Disability Awareness event. About 5 minutes into our statewide event, loud music and someone's unmasked back-side was on our screens bouncing to the rhythm of the beat. To be honest, it was just simply shocking at first, then horrible. Getting the bomber out of our feed was cyber-security at it's best. I was very fortunate that I had a young person near me, and she was able to combat this invader with lethal skill. We were able to recover and have a successful event. But everyone was temporarily scarred. Looking back, I recommend everyone experience it once, but not twice. I promise you it will make for great cocktail talk. The lesson from this story is that I highly recommend passwords for important zoom activities. Otherwise, the zoom bomber will come uninvited.

PLAY

With COVID, “play time” has been limited. Most of my activities include bowling with team JR, movies, and reading a book outdoors. We did have some high drama



with the King snake that appeared in the kitchen sink. At first, we were not certain if it was its nasty cousin the coral snake (both of which are found in Florida).

The Wheelchair Highwaymen (a group of three friends with different spinal cord injuries) have been having a lot of fun with our drone artwork. We had a showing at the Tallahassee Musuem and the FSU Fine



Arts. Speaking of FSU, some how we got on the “list” of possible filming locations. We don’t know why, but a film student brought their love story to our humble little home and our front yard, fireplace, and backyard were ideal shots. At one point, we had



almost 20 students here (lights, sound, actors, make-up, wardrobe, etc.) The rule was don’t break anything. Yes, that means they broke something. I must say, we handled it very professionally and the students were probably shocked by how calm we were... in truth we were trying to remind them that “stuff” is only “stuff”



and it can be replaced. Finally, Erika treated me to a wonderful day on the water for my birthday. While the weather was not perfect, it still was a perfect day. There is something about being on the water.

As we conclude this addition of the JR News, I would like to highlight the visit of my good friend Mike Blum. It had been nearly 3 years since we took in a game at Doak Campbell Stadium. The weekend was made even more joyful because he brought his adult son, Joey, with him. He happens to live with Autism and has found meaningful and competitive work as a tour guide for a local zoo. It's been incredible to work with his dad, and others, to ensure that Joey received the proper accommodations throughout K-12, and look where he is today. While we did not win the football game, it was fabulous to celebrate our blessings and once again create memories together.



I would like to give a big thank you to FSU and The Annual [Big Event](#) Team for their community leadership. These students make a differences. I hope everyone has a safe and wonderful holiday season! I look forward to speaking with you in 2021.

JR